UK
Covid-19
Inquiry

Every Story Matters

Test, Trace and Isolate

March 2025

Some of the stories and themes included in this record include descriptions of death, near death experiences, significant physical and psychological harm and references to experiences of abuse. Some of these descriptions also relate to children's experiences. These stories may be distressing to read. If so, readers are encouraged to seek help from colleagues, friends, family, support groups or healthcare professionals where necessary. A list of supportive services is also provided on the UK Covid-19 Inquiry website.

Foreword

This is the third Every Story Matters record, which has been produced for the Module 7 investigation: Test, Trace and Isolate for the Covid-19 Inquiry. All Every Story Matters records are submitted as evidence to the Chair of the Inquiry, Baroness Hallett, and will form part of the Inquiry's official public record.

Every Story Matters was designed to gather and understand the human experience of the pandemic in the United Kingdom. Many thousands of people have shared their stories with us, and we would like to thank people who have taken the time to do so. Every Story Matters' role as a 'listening exercise' means its value lies in hearing a range of experiences, identifying themes where possible and, crucially, ensuring people's experiences are part of the Inquiry's public record and can be considered when developing recommendations. We must understand the impact of the pandemic to make recommendations which will lessen the harms from a future pandemic.

Module 7 will look at the approach to testing, tracing and isolation during the pandemic adopted by the UK Government and devolved administrations in Northern Ireland, Scotland and Wales. The module will explore policies, strategies and decisions made by key bodies and factors that might have influenced public adherence to official guidelines. Every Story Matters adds a uniquely human perspective, exploring the role of people's behaviour and experiences within the context of this test, trace and isolate system. What was clear was that a lot of people were driven by the desire to protect people around them, including those who were more vulnerable.

We are grateful to the individuals, groups and organisations who have given us feedback, ideas and helped us to hear from a wide range of people. They include: Long Covid Kids, Long Covid Scotland, Long Covid SOS, Long Covid Support, Clinically Vulnerable Families, SignHealth and the Royal National Institute of Blind People. Each of these groups enabled us to speak to their members and ensure that their experiences form part of this record.

It is a privilege to work on this unique aspect of the Covid-19 Inquiry.

The Every Story Matters team

Overview

This short summary provides a high-level overview of the themes from the many stories we heard in relation to testing, contact tracing and self-isolation during the pandemic.

How stories were analysed

Every story shared with the Inquiry is analysed and will contribute to one or more themed documents like this one. People shared their experiences with the Inquiry in different ways. The stories that described experiences of testing, contact tracing and self-isolation during the pandemic have been brought together and analysed to highlight key themes. In summary:

- We analysed 44,775 stories submitted online to the Inquiry at the time of writing this record, using natural language processing (NLP) and researchers reviewing and coding what people have shared.
- Researchers drew together themes from 340 people's stories shared during research interviews and group discussions.
- Researchers also drew themes from Every Story Matters listening events with the public and community groups in towns and cities across England, Scotland, Wales and Northern Ireland. We made a point of speaking to members of key groups from whom the Inquiry legal team were keen to hear from.

More details about who we heard from and how people's stories were brought together and analysed in this record are included in the appendix. This document reflects different experiences without trying to reconcile them; we recognise that everyone's experience is unique.

Throughout the record we have referred to people who shared their stories with Every Story Matters as 'contributors'. This is because they have an important role in adding to the Inquiry's evidence and to the official record of the pandemic. Where appropriate, we have also described more about them (for example, people with different disabilities or health conditions) or the reason they shared their story (for example, as carers or parents). This is to help explain the context of their story.

Some stories are explored in more depth through quotes and case studies. These have been selected to highlight specific experiences and the impact they had on people. The quotes and case studies help ground the record in what people shared with the Inquiry in their own words. Contributions have been anonymised. We have used pseudonyms for case studies drawn from the research interviews. Experiences shared by other methods do not have pseudonyms.

Understanding and awareness of Test, Trace and Isolate

Many of those who shared their stories told us that the guidance was clear in relation to when to test for Covid-19 and when to self-isolate. While some confusion existed about knowing the difference between symptoms of Covid-19 and other similar illnesses, such as colds and the flu, awareness and confidence in being able to identify symptoms grew over the period of the pandemic.

> “As it developed over time, we understood when we needed to test. It was quite clear.”
>
> – Every Story Matters contributor

Few contributors took up twice-weekly rapid testing when it became available to everyone in April 2021 and some struggled with the rationale for testing without symptoms. Testing without symptoms was associated with being required to do so or because of a need or desire to mix with others.

Awareness and understanding of the guidance about contact tracing was far less widespread. We heard that it was harder to understand the purpose of contact tracing and how to follow the guidance correctly.

Awareness of the financial and practical support to help people when self-isolating was also relatively low.

> “Yes, I didn't know how to look for it, or anything. I think that there wasn't very well, wide-spread. The information for that [financial help] wasn't spread widely very well, because I don't recall anything about the £500.”
>
> – Clinically vulnerable person

Changes to official government guidance left people confused about when to test and self-isolate. Uncertainty about the rules in place at any one time meant that, later in the pandemic, some people decided to do what they thought was appropriate regardless of whether or not it aligned with the rules.

> I just felt really quite confused throughout the whole thing as to when we were supposed to be testing, at what stage you were supposed to test […] they kept changing the rules on it.”
>
> – Every Story Matters contributor

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

There were many reasons why people were prepared to test and self-isolate, and many ways of helping and encouraging them to do so.

- **Protecting people they cared about:** For many, the sense of moral duty to protect their loved ones, their communities and those who were vulnerable motivated them to take part in testing, contact tracing and self-isolation.

> It's [self-isolation] one of the few things that made sense, because what you're really doing is you're protecting the people you care about.”
>
> – Carer

- **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:** For some, the support they received – from family and friends, local organisations and community groups – enabled them to engage in testing, contact tracing and to self-isolate.

> Our local shops were amazing at organising food deliveries for us. We are lucky to live in a rural area and could spend time in the garden. But I think it was a more positive experience than we might have expected. My son sometimes says he misses that closeness."
>
> – Every Story Matters contributor

- **Freedom:** As time went by, a desire to attend schools, colleges and universities, to travel and to mix and socialise with others became a reason to test.

> “I'd say that it became so much more important to test, just as a practice. [...] and particularly [...] if people were visiting us or [...] I wanted to [...] see other people, testing for myself and asking everyone to do that as well became really important. Probably more important than seeing them, to be honest.”
>
> – Family member or supporter of someone required to self-isolate

- **Alleviating fear:** People were fearful of catching the virus and becoming seriously ill or passing it on and so tested, engaged in contact tracing and self-isolated.
- **Access and convenience:** Where testing centres were easy to get to, and availability of appointments was good, people found it easy to get tested. 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.

> “The test centres and vaccination centres were really easy to book appointments with and were all within a short travelling distance.”
>
> – Every Story Matters contributor

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

There were many themes which stopped or made it difficult for people to test, engage in contact tracing and to self-isolate when they needed to.

- **Trust:** Scepticism and a lack of trust grew as people experienced problems with testing and contact tracing because they thought they were inaccurate or ineffective.

> “I have never tested positive on a lateral flow test, but I already knew these were no longer fit for purpose, and was instead aware I had Covid due to those around me with the same symptoms testing positive at the time.”
>
> – Every Story Matters contributor

- **Perception of risk:** How much personal risk people were comfortable with influenced their taking part in testing, contact tracing and self-isolation behaviour, and this changed across the pandemic.

> “It got to the point [that] everybody got so fed up, myself included […] that you were just like, 'Oh, life goes on.' It's like, you can't live like this for the rest of your life, […] you just bit by bit started paying attention less and less. Not that I still wouldn't be careful to an extent, but not the same extent as I would've been for the first two years.”
>
> – Every Story Matters contributor

- **Access:** Where people experienced access barriers (for example, booking a PCR test when the system was difficult to navigate or accessing LFTs during a shortage of supply), it was more challenging to test for Covid-19, and caused concern and difficulties.

> “Covid test centres are all well and good if people could easily access them, which I could only do by traveling by at least two forms of public transport while isolating.”
>
> – Every Story Matters contributor

- **Accessibility and inclusion:** Barriers arose where testing centres were not accessible to people, where LFT kit instructions were difficult to understand and use, and where people were excluded from digital forms of contact tracing.

> “There was an awful lot of the community that couldn't read and write, and they depended on family members a lot to do a lot of it for them.”
>
> – Person from a Roma ethnic background

- **Difficulty of use:** We also heard that people experienced barriers using LFTs correctly, interpreting results and switching between the different variations of test kits.
- **Negative impacts:** People told us about negative, or potentially negative, impacts when taking part in testing, contact tracing and self-isolating. These included a loss of personal freedom, impacts on people’s wellbeing - including discomfort and distress from testing - and the challenges of self-isolation.

> “I only did a few Covid tests – if anything I found them more unpleasant than the vaccination.”
>
> – Every Story Matters contributor

- **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 social support and incentive:** Where people didn't have access to social support, they struggled to engage in testing, contact tracing and self-isolation. The fact that reporting test results was unregulated meant some questioned the value of testing in the first place.

> "The uploading of the test results was a farce as well because I could upload my next-door neighbour's test results [chuckles]. There's no guarantee that that was my results. Utter farce."
>
> – Every Story Matters contributor

The experiences of parents, those who supported others and survivors of domestic abuse

We heard from many different people talking about their experiences of testing, contact tracing and self-isolation. In this chapter we focus on the stories of people who found these aspects of the pandemic particularly difficult. This includes parents who had to test young children and survivors of domestic abuse who had to self-isolate with partners who abused them and/or did not adhere to the rules.

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
- More public education on the need for testing, contact tracing and self-isolation
- Improved access to mental health support and financial and practical support for people during periods of self-isolation
- Better use of community leaders in disseminating information to communities
- Alternative options for digitally excluded people and those living in remote or rural areas
- Accessible information available in different languages and formats

Full record

1 Introduction

This document presents the stories shared with Every Story Matters related to Covid-19 testing, contact tracing and self-isolation.

Background and aims

Every Story Matters is an opportunity for people across the UK to share their experience of the pandemic with the UK Covid-19 Inquiry. Every story shared will be analysed and the insights derived turned into themed documents for relevant modules of the Inquiry. These records are submitted to the Inquiry as evidence. In doing so, the Inquiry's findings and recommendations will be informed by the experiences of those impacted by the pandemic.

This document brings together what contributors told us about their experiences 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. While individuals advised to shield were interviewed, the interviews explored their engagement with the Test, Trace and Isolate system, not their experiences related to shielding[1]. This record does not include experiences of being isolated or feelings of isolation as a result of a national lockdown.

The UK Covid-19 Inquiry is considering different aspects of the pandemic and how it impacted people. This means that some topics will be covered in other module records. Therefore, not all experiences shared with Every Story Matters are included in this document. For example, experiences of UK healthcare systems and experiences of vaccines and therapeutics are explored in other modules and included in other Every Story Matters records. You can learn more about Every Story Matters and read previous records at the website: https://covid19.public-inquiry.uk/every-story-matters

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[1] People defined as clinically extremely vulnerable and therefore at very high risk of severe illness from Covid-19 were advised to 'shield' (ie protect themselves by not leaving their homes and minimise all face-to-face contact).

How people shared their experiences

There are several different ways we have collected people's stories for Module 7, these are listed below.

- Members of the public were invited to complete an **online form via the Inquiry's website** (paper forms were also offered to contributors and included in the analysis). This asked them to answer three broad, open-ended questions about their pandemic experience. The form asked other questions to collect background information about them (such as their age, gender and ethnicity). This allowed us to hear from a very large number of people about their pandemic experiences. The responses to the online form were submitted anonymously. For Module 7, we analysed 44,775 stories. This included 36,879 stories from England, 3,665 from Scotland, 3,783 from Wales and 1,973 from Northern Ireland (contributors were able to select more than one UK nation in the online form, so the total will be higher than the number of responses received). The responses were analysed through 'natural language processing' (NLP), which helps organise the data in a meaningful way. Through algorithmic analysis, the information gathered is organised into 'topics' based on terms or phrases. These topics were then reviewed by researchers to explore the stories further. More information on NLP can be found in the appendix.

- At the time of writing this record, the Every Story Matters team has been to **33 towns and cities across England, Wales, Scotland and Northern Ireland** to give people the opportunity to share their pandemic experience in person in their local communities. Virtual listening sessions were also held, if that approach was preferred by participants. The team worked with many charities and grassroots community groups to speak to those impacted by the pandemic in specific ways. For this particular Every Story Matters record, experiences from Deaf[2] people and people who are partially sighted have been included. Short summary reports for each event were written, shared with event participants and used to inform this document. A consortium of social research and community experts were commissioned by Every Story Matters to conduct **in-depth interviews** and **discussion groups** to understand the experiences of different people, based on what the legal team for Module 7 wanted to understand. This included those with particular health conditions which may have impacted their ability to test or self-

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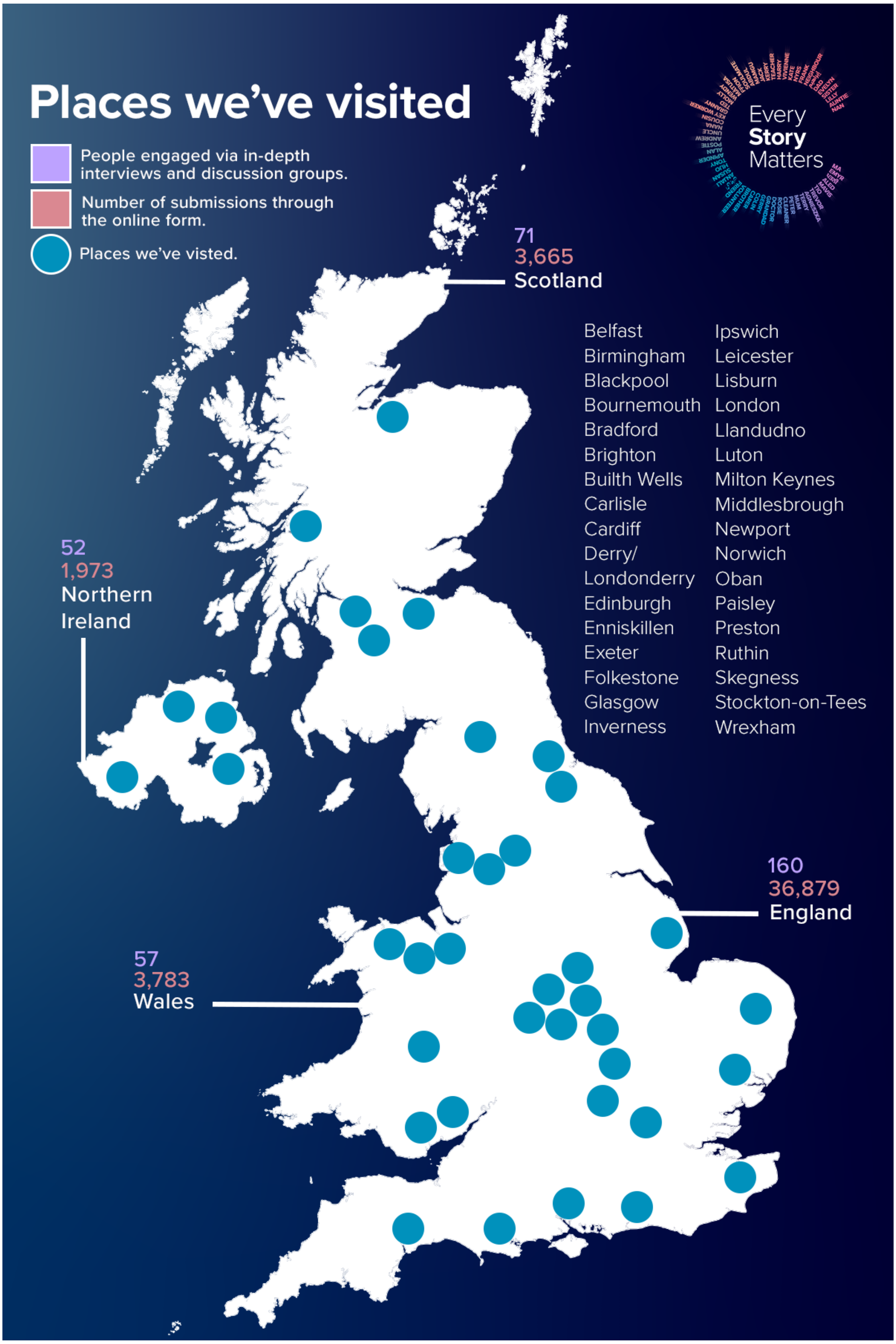
[2] The Inquiry recognises the wider inclusive term of "d/Deaf" although the people spoken to as part of the record identified as "Deaf".

isolate, including physical and mental health conditions and disabilities. This also included family members or individuals supporting those required to self-isolate, particularly those supporting older people, bereaved individuals, or bereaved friends, family and colleagues, those with pre-existing health conditions, or those clinically vulnerable or shielding. Those with caring responsibilities and members of community groups set up to help people to self-isolate are also included. These interviews and discussion groups focused on the Key Lines of Enquiry (KLOEs) for Module 7, information on which can be found here. In total, 340 people across England, Scotland, Wales and Northern Ireland contributed in this way between July and October 2024. All in-depth interviews and discussion groups were recorded, transcribed, coded and analysed to identify key themes relevant to the Module 7 KLOEs.

- The number of people who shared their stories in each UK nation through the online form, listening events and research interviews and discussion groups is shown below:

Figure 1: Every Story Matters engagement across the UK



For further information on how we listened to people and the methods used to analyse stories, please see the appendix.

Notes about the presentation and interpretation of stories

The stories collected through Every Story Matters are not representative of all experiences. The pandemic affected everyone in the UK in different ways, and while general themes and viewpoints emerge from the stories, we recognise the importance of everyone's unique experience of what happened. This record aims to reflect the different experiences shared with us, without attempting to reconcile the differing accounts.

We use the term 'many' to describe where experiences were widespread and a 'few' where these were much less common.

Some stories are brought to life through quotes. These have been selected to highlight the different types of experiences we heard about and the impact these had on people. The quotes help ground the record in what people shared in their own words. Contributions have been anonymised.

Through the record, you will see we refer to people who shared their stories with Every Story Matters as 'contributors' and sometimes we describe more about them (for example, their ethnicity or health status) to help give more context to the quote we have used. For people who contributed to this record through a webform, all their quotes have been labelled "Every Story Matters contributor". Some who told us their stories through focus groups and interviews are also labelled in this way. This was because further detail about their background was less relevant to support the preceding text, but their experiences were still important to include.

Stories were collected and analysed throughout 2023 and 2024, meaning that experiences are being remembered some time after they happened, which influences the details and aspects of experiences recalled.

Structure of the record

This document is structured to allow readers to understand how people experienced Covid-19 testing, contact tracing and self-isolation.

The record starts by exploring people's understanding of test, trace and isolate (Chapter 2) before moving on to discuss factors that encouraged (Chapter 3) and discouraged (Chapter 4) people to participate in testing, contact tracing and self-isolating. The record then focuses on experiences shared with us by contributors in specific circumstances (Chapter 5). Finally, it explores potential improvements around testing, tracing and self-isolation for future pandemics (Chapter 6).

Terminology used in the record

Test refers to people using equipment (described below) to determine if they had Covid-19 or not.

Trace refers to the process used to identify if people have come into contact with a virus, in this case Covid-19, so that viral transmission can be managed and contained as much as possible.

Isolate refers to the period following a positive Covid-19 test, often referred to as 'self-isolation'. This period changed over the course of the pandemic and is different from feelings of isolation that happened as a result of national lockdowns.

We talk about Lateral Flow Tests (LFTs) and Polymerase Chain Reaction (PCR) tests which are two tests used to detect having Covid-19.

Lateral Flow Tests (LFTs)

LFTs are a home test used to detect an active infection. The test works by detecting proteins that are present on a swab taken from the nose and/or throat. The test features a small device with an absorbent pad at one end and a reading window at the other. Inside the device is a strip of test paper that changes colour if Covid-19 proteins are present.

Lateral Flow Tests (LFTs) were made available to everyone in England, Scotland and Wales in April 2021 which enabled free access to rapid testing. Northern Ireland followed in September 2021.

Polymerase Chain Reaction (PCR)

A PCR test works by taking a sample using a swab, usually from the nose and/or throat. The swab is then sent to a lab where the sample is analysed for the genetic material of the SARS-CoV-2 virus (Covid 19).

2 Understanding and awareness of Test, Trace and Isolate

This chapter explores contributors' awareness and understanding of testing, contact tracing and self-isolation and the rules they needed to follow. It describes how some people were confused by the communications, as well as contributors' experiences of the quality of information available.

Understanding and awareness of the guidance

Many contributors described how they understood they had to test if they had symptoms of Covid-19, such as coughing, general flu-type symptoms – for example, a runny nose and sore throat - and loss of taste and smell. Awareness of this guidance came through information from statutory authorities, the NHS, employers and others with medical expertise.

> “They were always explaining that [you should test] any time you felt that you were developing symptoms, or if you came into contact with somebody who had tested positive for Covid, or - you'd have to get tested if you were about to fly as well.”
>
> – Every Story Matters contributor

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.

> My confidence [at identifying the symptoms of Covid-19] grew over time, after I'd heard first hand experiences of people that I'd known that [...had] had it. Because for the first period, it was really what you could see on the news [...], people on ventilators, and it was really, really serious [...I thought] anyone that got Covid would be in that boat. But obviously as the strains changed, but the symptoms stayed really, really similar, we all started learning."
>
> – Every Story Matters contributor

Few people we heard from took up the offer of twice-weekly rapid testing (using LFTs) when it was rolled out to everyone from April 2021 onwards. People told us that when they tested without symptoms it was mostly because of workplace requirements (covered below) or wanting to test before mixing with others (see 'Freedoms' section below). Some contributors struggled with the rationale for testing without symptoms, often feeling perplexed about how the virus could spread between people without causing symptoms.

> My son tested positive, but he had no symptoms whatsoever, so it was so difficult to know what the symptoms were."
>
> – Person working with children

Those who shared their stories understood that having symptoms of Covid-19 meant that they were required to self-isolate. As well, for the most part (and especially at the beginning of the pandemic), people understood that receiving a positive test for Covid-19 meant self-isolation. Some contributors told us how they self-isolated when they thought the results from an LFT were inaccurate because of their symptoms, or when waiting for a PCR test or the result to arrive.

> We'd [self-] isolate if we had symptoms as well, not just on the test, because we were so frightened of giving it to other people because we knew what it was like."
>
> – Domestic abuse survivor

Some contributors described how later on in the pandemic they tested (typically using an LFT) to confirm for certain whether they had contracted Covid-19 before deciding whether or not to self-isolate.

> I think, like the hairdresser, where they pinged me and said, 'You've been exposed, you must [self-] isolate for seven days.' I tested at home, and I didn't have it, and I didn't self-isolate. I think I tested every day, or every other day."
>
> – Disabled person

Many also understood the guidance to self-isolate and to test if they had been in contact with someone who had tested positive for Covid-19 regardless of whether they were experiencing symptoms or not.

> I had three PCR tests [...] very close together [... First] my daughter [...] felt unwell, [... when] somebody at her school had got Covid, so we all went and got tested. And then she actually tested positive at home [...] so we booked a PCR for all of us [the next day]. And then I became positive [a few days later]."
>
> – Person living with Long Covid

> I'm sure we did go back to drama group [when somebody tested] positive for Covid [...] everyone else would just do a test to make sure [they hadn't caught it]."
>
> – Clinically vulnerable person

People told us they better understood the processes around testing and self-isolation compared to those connected to contact tracing. Some contributors described how they had found contact tracing information unclear, that it was hard to understand the purpose of it and to follow the guidance correctly.

> The self-isolation, everyone understands. Testing, everyone understands. The tracing bit, whether it was maybe not explained why it's important or how it works, or how the technology works, or what are the very clear one, two, three steps you need to take. I think that bit for me, there was a confusion."
>
> – Every Story Matters contributor

Not many people we heard from were aware of the financial and practical support to help during self-isolation. While generally being unaware that this type of support was available, some reflected that they would have welcomed it at the time. They explained that it would have relieved some of the financial burden, particularly for those whose income was affected by being unable to work. For others who were employed and working, some mentioned that the thought to apply for financial support did not occur to them.

> I didn't even think of even applying for it, I don't think, because I was still working, so I don't even think I even applied for it."
>
> – Person with a long-term physical health condition

> I had to do a lot of research and also speak to a lot of people to get their own, first-hand experiences of what they've found out was available to them, also from research. I don't think it was readily available [information about support for self-isolation] and I think there was also a lot of misinformation.”
>
> – Every Story Matters contributor

We heard a few examples of contributors hearing about financial support, specifically for self-isolation, through word of mouth or at their work. Some found this helpful while others told us they preferred earning their own money instead of fulfilling the full self-isolation periods.

> I did access them [grants to self-isolate], I just wanted the money. I did access them but then I cut short the period to earn more money. Because everyone likes to earn more money.”
>
> – Every Story Matters contributor

> Yes, the £500 was great, to be honest. That £500 for those affected by Covid was really great. But not everybody received it.”
>
> – Every Story Matters contributor

Sources of information about where to access tests included the internet, the television, social media, pamphlets and word of mouth. Contributors who remembered finding out about tests in these ways felt that information was readily available, clear and easy to follow.

> I remember they'd always tell you on the news on how to access it [testing]. If you went on the NHS website, it'd have clear instructions. Or even if I rang my GP, they'd let me know […] how to access them [… The information] wasn't over-complicated […] just like a few pointers.”
>
> – Carer

We also heard from contributors who 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. Limited access to information meant that some contributors did not know they could access tests for free, for example, until some way into the pandemic. Some were also unsure where to find tests, or what to do when there was a shortage.

Confusion

Some contributors told us how they had felt confused about when and why to test. This was often because it was difficult to differentiate between Covid-19 and other illnesses given the variety and severity of symptoms associated with Covid-19 and other viruses such as colds and the flu. The perceived difficulty made some contributors more likely to test when experiencing possible symptoms.

> Well, I suppose, me personally, I think I understood [when to get tested]. Although I suppose there's some confusion with colds, flu, all of the things that could have had similar symptoms."
>
> – Every Story Matters contributor

Changes to official government guidance left people confused about when to test and how long they needed to self-isolate for after a positive test. This confusion was exacerbated by the different approaches across the different nations of the UK.

> Initially it was really quite clear and everyone was quite on top of it in my [...] hospital, and then [...] I think the rules started changing and it became very unclear [...] I always had to [...] check online or ask work, 'What's the situation now? Do I test or not test?' [...] I think [it] got more confusing as time went on."
>
> – Person working in health and social care

There was also some confusion around how the contact tracing apps were different from other apps that were launched at the time to support with Covid-19 restrictions, for example, an app in Scotland to help with pharmacy requests, and how the different systems worked across borders[3]. Some contributors suggested there could have been one system for the whole of the UK.

> I would just say there seemed to be a lot of apps, all at the one time. And unless you knew what you were doing it was easy to get a little bit lost and to be using the wrong one as I obviously did a few times."
>
> – Person who accessed mental health support

> I had to travel to Scotland for a few days for work (our head office is in Edinburgh) and I found the NHS app/government Covid app QR codes were different up there. I find it wild that there was not a standardised system for the UK."
>
> – Every Story Matters contributor

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[3] The main types of contact tracing used by contributors were the contact tracing apps. Three Covid-19 contact tracing mobile apps were developed for the different regions of the UK: 'NHS COVID-19' for England and Wales, 'StopCOVID NI' for Northern Ireland and 'Protect Scotland' for Scotland.

Some contributors – especially older contributors and/or those who were digitally excluded – reported feeling confused about how to access and use apps, which made them feel anxious. For example, one contributor with a pre-existing health condition (who was also digitally excluded) downloaded a contact tracing app, but was uncertain how it worked. Receiving notifications made them feel alarmed and in some cases very anxious.

> “I had the app on the phone…ping, ping, and I was thinking, 'Why am I being pinged?' And then it would come up…someone had caught [Covid-19] in your area…and I was thinking, 'Oh, blinking hell.'…I turned it down. But I was thinking, 'Oh my God, oh my God, it's getting closer, it's getting closer.'”
>
> – Person who is digitally excluded

More specifically, we heard that people often didn’t know what to do once they received a notification of a contact. This was especially confusing when it was hard to identify when the contact had been made, or when someone was getting multiple notifications.

> I think it said, 'You may have come into contact.' It was so vague…if I knew someone in the office that [for] sure had Covid, then I'm much more inclined [to think], 'Well, maybe I should do a test.'…[but] it didn't seem very scientifically measured.”
>
> – Person working in health and social care

As the pandemic went on, some people felt confused about how long they needed to self-isolate for after they had a contact notification, what the guidance was if they had already had Covid-19 or were vaccinated, and what the penalties would be if they did not follow the guidance.

> I suppose if there are millions of people using it [the contact tracing app], maybe it just didn't have the capacity to, sort of, update it and be more relevant or individualised to the person if they've shown-, like I was fully vaccinated…so it was saying that I still needed to self-isolate, and when I went on the website it said, 'No, you don't need to self-isolate because you're fully vaccinated,'”
>
> – Zero-hours contract worker

We also heard that changing guidelines about self-isolation periods made people more uncertain as the pandemic went on about the rules that were in place at any one time[4]**.**

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[4] Isolation periods changed frequently throughout the pandemic in England, varying from 14 days (March 2020) to 10 days (December 2020), then 7 days (December 2021 – dependent on two negative LFTs) and later reduced to 5 days (January 2022). Different rules applied if you had been in contact with someone who tested positive for Covid-19 (often being required to self-isolate for a specified period from their positive test date). Exemptions were later made if you were vaccinated, or a confirmatory PCR test was negative. Changes to rules happened at different times across the four nations.

For example, some shared how they did not understand why the number of days for self-isolation continued to change, despite it being the same virus. As a result, many contributors said they decided to do what they felt was the “right” thing later in the pandemic, whether this was in line with the self-isolation rules or not. Others decided to end self-isolation periods after testing negative although they were still within the recommended timeframe for self-isolation.

> “Well, the thing that sticks in my mind is, going back to confusion again, why it was 14 days initially, and then obviously it moved down to 5 days, and I remember thinking at the time, 'Either we've massively overdone the self-isolation initially, and we didn't need to do it for 14 days at all, or people are coming out of self-isolation now after 5 days, where they could potentially still have Covid, and pass it on to people.' So, it was just, I didn't feel there was [a] clear explanation as to why that number of days had decreased so dramatically.”
>
> – Person working with children

> “Guidance was sometimes ambiguous and not clear or strict enough - sick people should have been told back in January/February 2020 to self-isolate - and the case made that if they don’t, the country would lock down.”
>
> – Every Story Matters contributor

The ending of mass testing also increased confusion for some[5]. Some contributors felt that the relaxation of testing requirements in different stages of the pandemic seemed inconsistent with previous testing requirements.

> “When infections were still very high, there were […] clear rules, more or less clearly communicated. This became very unclear, when the pandemic was somewhat phasing out […] the recommendation that testing wasn't necessary anymore [even] if you had symptoms was extremely confusing, after we [had been] told for two years that you should test and stay at home.”
>
> – Every Story Matters contributor

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[5] Everyone in England was offered access to twice weekly rapid testing for Covid-19 from 9 April 2021 in an expansion of the government’s mass asymptomatic testing programme. This was known as the universal testing offer (UTO). The period of the UTO lasted until the end of March 2022. Along with several other Covid-19 policies, it stopped as the UK government introduced the ‘Living with COVID-19’ strategy.

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

This chapter details the factors that helped or enabled people to participate in testing, contact tracing and self-isolation. It describes these enablers and gives examples of where and how they influenced behaviours during the pandemic. The chapter finishes with contributors' reflections around the Fixed Penalty Notices that were in place.

Protecting people they cared about

Contributors we heard from referenced a general duty to follow the government guidance to protect both themselves and the wider population, particularly vulnerable people.

This sense of moral obligation or 'conscience' was a strong reason for people to test, engage in contact tracing and/or self-isolate when they felt they needed to, to 'do the right thing' and to ensure they were playing their part in limiting transmission.

> “I'm not [...] a rule-breaker, [...] I abide by all the rules, so I was all for testing, in order to [...] reduce the risk of spreading it.”
>
> – Carer

> “If I have Covid, I don't want to pass it on to other people, so if me saying 'I've been somewhere' is enough to prevent somebody else from catching it, then that's good enough for me.”
>
> – Person with a long-term physical health condition

For some people we heard from, the moral obligation to protect others clashed with their own desire for freedom of movement (more detail on this in the ‘Freedoms’ section below), creating a dilemma.

> “The conscience kicking in. But throughout all of it, I, kind of, didn't want to test, because if I did test positive, then I wouldn't be able to do certain things, you know, this was once we were in less of a lockdown, and you had to [self-] isolate and stuff. And I was in quite a moral conflict of whether do I put myself first and not test, or do I actually put everyone else first and test for their benefit.”
>
> – Zero-hours contract worker

Contributors with caring responsibilities felt stressed during self-isolation. They lived with a deep concern and sense of responsibility about not passing on or otherwise letting their loved ones contract Covid-19. They often described how consistently and strictly they adhered to self-isolation rules to mitigate this risk, but also how the sense of anxiety and guilt about what that meant for their loved one was very difficult to cope with. Contributors living in multigenerational households and with clinically vulnerable relatives were particularly impacted in this way.

> “Mainly, it [adhering to self-isolation guidelines] was because I didn't want to kill them [contributor’s parents]…you just have to be realistic, and you've got to protect people. We were doing what we were told and that was it, you know?”
>
> – Person living in a multi-generational household

In some settled traveller communities, contributors stated that they adhered to strict self-isolation rules on site regardless of if someone in their community had tested positive for the virus or had symptoms. This meant that when someone did contract Covid-19, there were rules and habits already in place which facilitated a high level of self-isolation and protection.

> “… [W]e had no one coming on-site. So then, within each household, everyone kept to their own household. We could stand outside, there's a street just facing the other, you could chat over. You know, don't go out, chat over to one another, let people know how you're feeling over there. But don't come across, don't come out, don't visit. So, when it was times you really had to do that [self-isolate], that was kept within the laws quite well within the community.”
>
> – Person from a Roma ethnic background

Bereavement

For those who lost loved ones during the pandemic and were not able to mourn or grieve with others, the emotional toll was profound. Experiencing bereavement had a significant impact on the extent to which some people felt able to follow self-isolation guidelines. Some shared how their loss meant that they saw following the rules as crucial and often engaged with them strictly.

> “My family had taken it [self-isolation guidelines] extremely seriously, because we had lost somebody very close to us very early in the pandemic, literally that same week that everyone announced to stay at home. So, yes, we took it very seriously from the beginning.”
>
> – Every Story Matters contributor

People also told us how self-isolation guidelines made them reflect on and consider their decision-making when they visited a loved one in hospital who was dying. They feared if a loved one died after a visit and they were told to self-isolate, that they would be unable to be physically present to comfort their family during their grief. They believed that this would have a lasting and traumatic effect on them and their family’s grieving process. Some of those we heard from who had lost loved ones also found themselves confronted with the very difficult dilemma of deciding whether the risk of not following self-isolation guidelines outweighed the potential impacts of following them.

> “We were advised that only one family member could visit the ward [to see her 94-year-old grandmother with dementia, COPD and Leukaemia who was dying] in full personal protective equipment (PPE), and they would have to self-isolate afterwards. My mother and uncle are clinically vulnerable, and my sister was already self-isolating, so that left me with the dilemma of whether to visit, knowing that if she died, I would be unable to hug my 7-year-old daughter for two weeks, while she experienced her first bereavement.”
>
> – Every Story Matters contributor

Ryan's story

Ryan shared with us his experience of self-isolation when his father was receiving end of life care in hospital. Ryan had Covid-19 symptoms at the time and was not allowed to visit him, instead having to communicate by telephone instead.

While he was self-isolating, Ryan's father sadly died and he was left to grieve alone, still feeling unwell. He also needed to make funeral arrangements because his mother was poorly and unable to do so.

> My father dies. I'm alone, ill and unable to see anyone."

He decided to arrange another Covid-19 test via telephone after two weeks of self-isolating. However, his result was a 'false' positive. He felt angry that he had not been informed this was a possibility after taking a test within 90 days after contracting the virus. This meant he was required to self-isolate for further 10 days, although symptom-free. He phoned 119 several times to query his result but was told he still needed to self-isolate[6].

> I call 119. I am basically told it is pointless arguing and that I have to [self-] isolate."

Ryan was impacted emotionally and practically by what he felt was a great lack of understanding for his situation from the people he spoke to at 119, especially during a time of grieving.

> I call again. Am told there is no option but to [self-]isolate. I now have paperwork building up for the funeral and registering dad's death, much of which I cannot complete as I can't go to my parents' house to find the information. I want to go and see dad at the funeral parlour. I am unable. I need to transfer money to pay for the funeral. I am unable. I want to check on my mother's condition as a place has been found in a suitable care home. I am unable."

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[6] The 119 phone service served primarily as a helpline and booking system for Covid-19 related services in the UK, such as vaccinations and testing. It also offered support and guidance regarding self-isolation and financial aid for individuals unable to work due to Covid-19. The service was free and available from landlines and mobile phones. This service closed after 31 January 2025.

Requirements

Contributors working in a range of sectors described how regular testing was part of their workplace rules and requirements during the pandemic, whether people had symptoms or not. This included having to test on a weekly/twice-weekly basis or before every shift. Some contributors described how they felt that testing at work had helped to make it a safer environment.

> My workplace actually had a policy, so we had to test every week."
>
> – Every Story Matters contributor

> Work was a […] key factor for me […] working in A&E, we had to test […] weekly […] with the lateral flows […] it was easy. That was obviously for the patients' safety and my [own], and […] it was important that we kept testing to protect our families as well."
>
> – Every Story Matters contributor

A further reason for testing for some workers in managerial roles was a desire to set an example for other colleagues.

> It [the discomfort] did put me off but at the same time, I knew I had to do it. I had to be an example as well, as the […] manager, […] to my staff, so there was no way that I [would be] preaching, 'Do this, do this,' and […] not doing it [too]."
>
> – Person with literacy difficulties

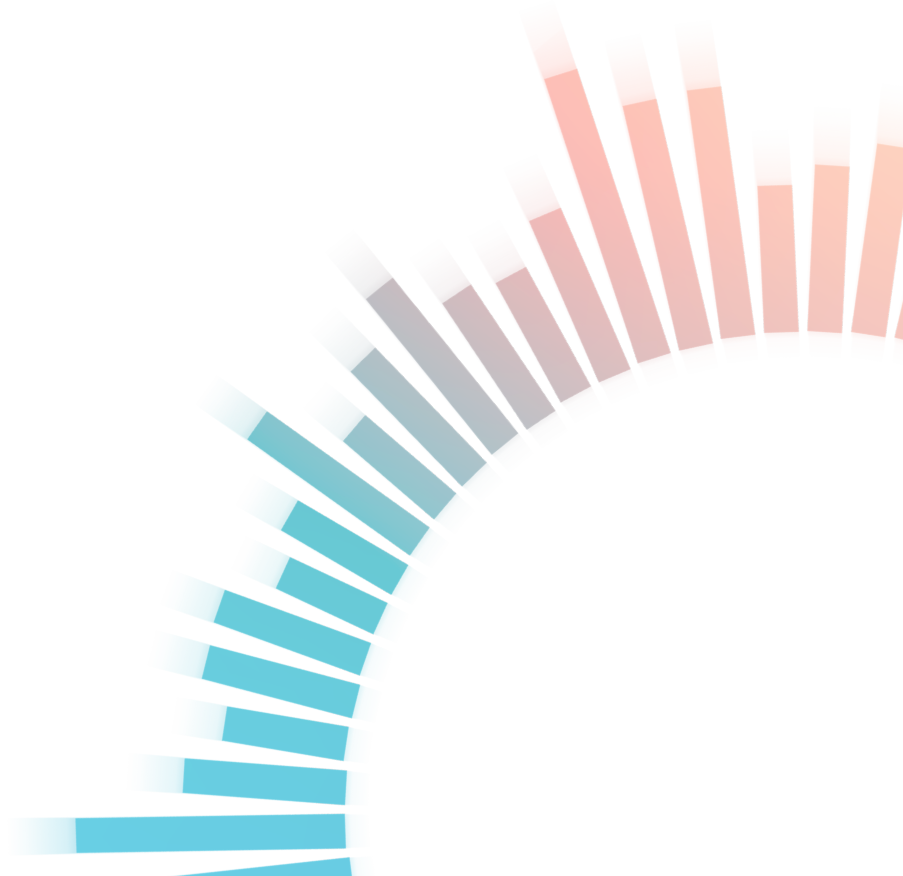
Testing also helped alleviate fears about putting others at risk by passing the virus on to colleagues or family members.

> I was more likely to test because I was […] really scared to get it. […] I was on placement when I found out I had Covid […]. I had a high temperature all day, sweating, sore head […] an hour before my shift was meant to end […] I'd done the test and it was positive, so obviously that also makes people that you're working with panic […] like, 'Well I've spent the whole day with you.' […] you feel a sense of guilt as well […], 'I've put other people at risk'."
>
> – Person working in health and social care

For many contributors who were in face-to-face contact, in either a professional or personal capacity, with people more vulnerable to the effects of the virus, **regular testing was described as a vital part of their personal duty of care**. This was particularly the case for people with caring responsibilities, or who were visiting older or vulnerable relatives. **Health and social care professionals described regular testing as part of their legal duty of care**.

> “I felt like it was my duty of care, to the patients and pharmacy. […] we were there offering the service that we'd always offered, and I felt like it was just my duty […] morally, […] if I had Covid and hadn't been testing, and passed that on to, say, a 90-year-old patient that came in for her medication, I would feel absolutely awful […] it didn't even cross my mind […] not […] to test.' Because I [felt] I should be testing.”
>
> – Person working in health and social care

> “Because I've been a carer my whole life, I've just got accustomed […] like she [my mum] comes first, […] like if something was to happen to my mum because she was always in the home and isolating. I don't know, if I wasn't maybe vigilant enough to recognise that this symptom could be related to Covid and not take the test, and then, as a result of that, not [self-]isolate and then be around her, and she was to get it, yes, I would feel a guilt that I was the one that caused it.”
>
> – Carer



Michael's story

Michael was a student and worked in a supermarket during the pandemic. He was a young person and in his first year of university when the pandemic began. He described how overwhelming the pandemic was for him, because of the effects on his education, work, and family.

The supermarket where he worked had their own internal testing system, which Michael followed. Working in a store where he came into contact with members of the public, Michael believed testing was important to protect others.

> “Work was a large part of that, in terms of going into work, I didn't want to put anyone else at risk, especially the job that I was doing is, well, called a key worker, I never like to say it because in comparison to the NHS, I was just working in a shop.”

Michael also worried for his family members. He had relatives who were hospitalised due to Covid-19 and placed on ventilators, experiencing extreme breathlessness. His mother also had a long-term health condition and became very ill when she contracted Covid-19. Michael worried that if she went to the hospital, her health would be put at risk due to the increased chances of catching an infection. Michael felt that it was important to get tested not only in terms of his own risk for Covid-19, but as a way of mitigating risk for other people. It was important to him to be cautious and test frequently, rather than risk infecting his more vulnerable family members.

> “I had no underlying health conditions at that point, but my mum did and my [relatives] were suffering. Like, it didn't make any sense for me to […] risk it […] it was easier to go with what was advised than to try and be incredibly smart and then potentially run the risk if that makes sense.”

Similarly, some contributors explained how their workplaces supported strict adherence to the set self-isolation periods. People we spoke to described experiencing lower levels of stress when they were able to follow protocols without pressure from their employers, knowing that they were empowered to self-isolate without any negative work-related consequences.

> “Yes I did, because work was quite strict, obviously if you have Covid, don't come in. Because, we need everyone we can. Yes, I stayed at home for, I can't remember how many days they suggested, but I did do the full period. Even when I was feeling better, I waited until I tested negative.”
>
> – Every Story Matters contributor

Access to support

Access to support was key for some people to be able to access PCR testing. Support included help understanding the process, booking appointments or home deliveries, attending appointments or returning tests and receiving results. The degree of support people needed varied: some needed help with one element of the testing process for example, finding and using online booking forms, whereas others were completely reliant on help to book appointments, travel to test centres and access test results.

> “[My relatives] were elderly people and none of them could read or write, they didn’t have phones […] So, I did that: I rang up, made the appointment […] brought them along [for the test…] and made sure they [the staff] had my email and number [for the results].”
>
> – Person from a Roma ethnic background

Community organisations working with Gypsy and Traveller communities, people with low levels of literacy and people whose first language is not English offered 1:1 support to access tests. Some members of the community created and shared videos to explain general test, trace and isolate requirements.

> “Everything was covered around Covid and was shared. Everything that came from the government was shared, so every time there were guide rules put in place, I would do a live video and share it. So, you know, and I knew people who couldn't read or write, and I knew younger kids wouldn't be interested in what I put out there in writing. So, if I'd done a live video and shared it on my WhatsApp and shared it on my Facebook, it could only be a minute.”
>
> – Person from the Traveller community

Similarly, access to support from friends and family members during self-isolation periods was central to allowing people to self-isolate. Informal support networks helped by delivering essentials and providing emotional support to those self-isolating. This type of support was often reciprocal among contributors for whom it would have been very challenging to self-isolate otherwise.

> “I'd text my sister and she would get me what I needed and left it at the front door, and then I would transfer the money into her bank for what she brought me, so that was good. And I'd done the same for her, likewise. For my mum, when I'd be working, I'd pick up messages and drop it at her door for her. So, we helped each other out as a family, especially if you're isolating.”
>
> – Clinically vulnerable person

Often the strength of informal support through friends and family meant that formal support was not needed to self-isolate. This meant that some contributors did not look for formal support services so were not aware of them.

> “I didn't need to use it, but I was aware that [...] ran various schemes over the course of lockdown. Supplying-, taking supplies to families that were isolating and needed to, but as I say, I didn't need to use them myself.”
>
> – Manufacturing worker

Ongoing specialist support at home during the pandemic helped some people with health conditions to self-isolate. These contributors spoke about how this support continuing, often remotely, allowed them to adhere to self-isolation guidelines without their health declining.

> “I think most of the relevant information was coming through [a] consultant at the [hospital]. That and she [his wife with cancer] had a dedicated nurse there. She would phone two or three times a week, just to make sure that [his wife] was fine, and things were okay...we had the backup that we could speak to, and any questions that we had, they had the answers to [...] as I said earlier, that we made sure that we knew the rules that we had to strictly adhere to during that period.”
>
> – Family member or supporter of someone required to self-isolate

We heard from others about being involved with the community providing support during self-isolation periods. This varied between different places depending on existing networks or support set up during the pandemic, with local government sometimes involved. Some recalled using apps and social media to find out who needed essentials during self-isolation so people in the community could help provide them. This was often informal and emerged early in the pandemic for those required to self-isolate.

> “So, we had a Covid group on WhatsApp that was done by our local council, who took every street and set it all up so that everybody who was online obviously had that contact. And, they tried to let people know which homes didn't have the access so that local people could help them if they weren't having any access [to essentials].”
>
> – Clinically vulnerable person

Local community organisations played a pivotal role in providing direct support to some who were self-isolating, which was particularly important for clinically vulnerable households and those living in remote or rural areas. However, this was dependent on the money available, limiting the numbers of people that were able to be supported in this way.

> “My church, [name of church], they were actually supporting a lot of our congregations that maybe their children are sick, and they are not allowed to work or be in a certain space. They were actually delivering food items that they need weekly. So, it was a very good help for some of my church members. Although, if they didn't have enough budget to support a lot of individuals that need that help, they [could] just only do the little that they can.”
>
> – Every Story Matters contributor

> “In March 2020 religious leaders, parish councillors, local GPs and business owners met to discuss how our isolated rural community could support the residents in the village and outlying farms and homes. Over 100 volunteers came forward and each was given 20 homes within a specific postcode to support. They delivered postcards with their names and contact details to each of those 20 homes and delivered medication and shopping, took dogs for walks, chatted from a safe distance and in some cases befriended those living alone who would otherwise have had no contact with anyone for months."
>
> – Every Story Matters contributor

Freedoms

As the pandemic continued, a desire to engage with education and travel became a reason to test for some. People spoke about having to get tested to go to college and testing their children so that they could go to school, as well as legal requirements to supply a negative PCR test to be able to travel abroad.

> “Going on holiday […] you had to do PCR tests when you went and then when you came back, straight away […] when I started going on holiday […] again, [I remember] starting to do more tests just because it was legally required.”
>
> – Every Story Matters contributor

As well, we heard from people who told us that testing played a role in people feeling more able and willing to socialise, and we heard from people who tested throughout the pandemic for this reason. This was because testing was seen as a means of reducing the risk of spreading the virus. A negative LFT provided ‘proof’ that a person was safe to mix with others.

> “That was great because I could prove […] I'm healthy […] so I can go [to…] places [like] nightclubs, […] my college or everywhere.”
>
> – Person whose first language is not English

Engaging in contact tracing was also felt to be an important and necessary step to mixing with others outside of the home, especially as society came out of lockdown and cafes, bars and restaurants opened up again.

> “It was a way for people to be able to go out. It enabled people to go out, you know, 'sign in and you can have food in this restaurant'. It meant that if you did come into contact, you could [self-]isolate, and it almost gave you that urge to go, 'Actually, I should probably do a test'.”
>
> – Person experiencing financial hardship

Alleviating fear

Contributors told us that they participated in testing during the pandemic to alleviate their fear and worry about contracting the virus. This was especially the case at the start of the pandemic as it helped confirm whether their symptoms were due to Covid-19 and reduced fears concerning their own safety and the risk of infection.

> Anytime you sneezed or coughed you were, [...] like, 'Do I need a test? [...] Have I got Covid again?' and testing."
>
> – Person living with Long Covid

> I think panic, you know, if you're getting a text message telling you that you've been around someone that's tested positive, you automatically think, 'Oh my God I'm going to get it.' So yes, you would go out and get tested for it. For me personally, it was panic."
>
> – Person working in health and social care

Worries were more intensely felt by contributors with existing health conditions.

> I was in [a] high-risk group, so I just knew I had to follow the guidelines and get tested. It was a no-brainer for me."
>
> – Community member who supported people to self-isolate

Fear and worry about contracting Covid-19 was linked by some contributors to media coverage and reporting on numbers of deaths. For some, reporting on deaths influenced people to test. Furthermore, personally knowing people who were very ill or who died from the virus meant that some contributors felt even more frightened of Covid-19 which was another reason to test for it.

> I tested all the way through, because [...] my uncle [...] went into hospital with a minor heart condition [and...] caught Covid and [...] he actually died. [...] I've lost a family member to it, [so I know] it is not just media hype [...] it's real. So, I did carry on testing until [...] we were told not to [...] I had the app on my phone, and tested regularly, and gave my results."
>
> – Zero-hours contract worker

Access and convenience

PCR tests

Early in the pandemic, PCR tests were available to book online or by phone and appointments were at testing centres. PCR tests could also be received by post and done at home.

Many contributors we heard from described a straightforward and quick process to booking PCR test appointments online or by phone, enabling them to test when they thought they needed to. It appears that perceived convenience was a key enabler for people deciding to test. After providing their postcode, they were offered a choice of test centres listed by proximity and were able to choose a convenient timeslot.

> “It was very easy to follow […] you literally just put your postcode in, and […] it would say, […] ‘this one's 1.1 miles away, this one's 3.5 miles away…’ […] you'd just pick […] then [select] the time that you could turn up […] put in your details, and that was it.”
>
> – Single parent

> “I booked a Covid test which was really quick and easy. The test centre was about 20 minutes’ drive from me. […] The whole process was really clear and well-planned.”
>
> – Every Story Matters contributor

Some of those who considered themselves less tech-savvy said the online booking process became easier over time, as they gained familiarity and as the system saved and recalled personal details.

> “It was all online, which […] was something that we were not familiar with […] we struggled with it to begin with, but then we got the hang of it.”
>
> – Person living in a multi-generational household

> The more tests you order[ed] the easier it got because it [the booking system] had all your info [stored].”
>
> – Person with literacy difficulties

The option to book by phone helped some people to mitigate literacy barriers.

> We had to phone up and ask for a test [...I booked it by phone] because I'm not very good at reading.”
>
> – Person with literacy difficulties

Many contributors who visited PCR test centres said appointment availability was good. Same or next day appointments were generally provided for those booking in advance, and short wait times facilitated access for those attending drop-in centres. Test centres’ opening hours also enabled people to attend appointments at convenient times.

> The [testing] stations were open for [...] a long time in the day. So, say [...] symptoms [started] in the night, you wouldn't have to necessarily wait long to go and get tested, you could get in at [...] 7 o'clock in the morning if you wanted to.”
>
> – Single parent

While some contributors felt that larger test centres were more accessible due to their capacity, others deliberately sought appointments in smaller test centres and/or during quieter times to minimise the anticipated wait. Having a choice and range of centres facilitated people making decisions that suited them. Other people we heard from did not experience easy access to test centres and these stories can be found in the ‘Barriers’ chapter.

> We made sure that we went at more of an unsociable time, and it wasn't busy at all, there was no queue. We went straight in, very easy.”
>
> – Family member or supporter of someone required to self-isolate

Many test centres were local, some within walking distance, which made them easy and convenient to get to. This was particularly the case for people who had access to a car, or to good public transport links, in both urban and rural/remote areas.

> “I was surprised by how easy it was, I have to admit. The first one I did, I thought it was going to be a lot more hassle, whereas [in fact] there were options around me. I didn't have to go very far […] considering I'm quite rural.”
>
> – Carer

Some contributors said the proximity of test centres increased over time, with centres opening closer to home as the pandemic went on.

> “At the early stages there was only so many big test centres […] by the time it got to me, […] in August the following year, it wasn't that far away where we had to go.”
>
> – Family member or supporter of someone required to self-isolate

We heard from some contributors who found the testing centres easily accessible for Deaf people and people with disabilities, including for those with physical disabilities[7]. This made accessing PCR tests from these test centres easier.

> “I visited the Covid test centre. They had an A4 piece of paper laminated with simple information on it. And then they would sign to me, are you Deaf? And I'd say yes. Then they would give me this piece of laminated paper that was accessible and used simple communication. We have a lot of Deaf people living in this area. This was good practice and should be set up in all centres.”
>
> – Deaf person

> “I am a wheelchair user [and have] a WAV [wheelchair accessible vehicle…] when we've gone to test centres it's all been disabled access, disabled parking. There's been no issue with that at all.”
>
> – Every Story Matters contributor

We also heard from contributors living in rural/remote locations who felt it was reasonable to travel further to reach a testing centre, as driving was the norm for them[8].

Many contributors described clear and well-organised test centre processes. Those who had positive experiences of PCR test centres said signposting to and within the centres was clear. They said pre-booked appointments for specific

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

[8] The Scottish Government Urban Rural Classification uses ‘Remote’ for areas that are more than a 30-minute drive time, or areas that have a drive time between 30 and 60 minutes from a Settlement with a population of 10,000 or more.

timeslots helped to minimise waiting times, and guidance from staff in the test centre also helped make the process simple and straightforward.

> “They were very well set up. It was a very quick, efficient process. […] You [would] drive in and people would indicate, ‘Come here’, ‘Park here’, ‘Window down’. […] It was over in seconds and out you drive the other end […] we never had to wait.”
>
> – Carer

> “They were very, very well-organised. When we went out for the tests, everything was well-signposted, well-directed. We were able to keep our distances; parking was easy. We had our timeslots and they were kept to. It was good.”
>
> – Clinically vulnerable person

Social distancing and infection control measures (including personal protective equipment (PPE) and cleaning regimens) were in place at test centres, which some contributors found reassuring.

> “I was quite happy that they had the [cleaning] wipes there ready to wipe down after each person.”
>
> – Carer

People we heard from also commented on the supportive, friendly, and calm approach of test centre staff, noting that this was facilitated by good staffing levels. Clear instructions from approachable staff were particularly helpful for people who felt less confident, including for example some whose first language was not English.

> “At that time, my English language was very bad. I couldn't follow the rules in the application [contact tracing app], I didn't know anything about it [… at the testing centre] they helped me, really good, so much. It was really helpful for me.”
>
> – Person whose first language is not English

Some contributors who were unable to attend test centres due to a health condition used home kits instead. These were sent through the post or by courier. Contributors appreciated their accessibility and speed of delivery, explaining that the convenience made PCR testing easier for them.

Being able to return tests via post boxes that were close by also worked well for the contributors we heard from who had used these. Those who shared their stories said that their experience was that priority boxes were well-marked and easy to find. Extended collection times offered additional flexibility and convenience. Those who lived further away from the nearest post box, however, said they would have struggled to use them without access to their own transport.

> “It was right at the top of my road, so I didn't have to travel far, and I just thought it was very, very convenient. I think there were actually [...] late collections as well at one point, so you couldn't miss it.”
>
> – Clinically vulnerable person

> “[The] nearest one was four miles from me [...] if I didn't have access to a car, then that would have been a challenge.”
>
> – Family member or supporter of someone required to self-isolate

Other contributors described booking courier collections to return completed tests. This was helpful for those with mobility issues.

LFTs

Lateral Flow Tests (LFTs) were made available to everyone in England, Scotland and Wales in April 2021 which enabled free access to rapid testing. Northern Ireland followed in September 2021.

The speed of accessing LFT results was important to contributors. The instant results of LFTs were more convenient than waiting days for a PCR test result, particularly as this allowed people to make an immediate decision about whether or not they needed to self-isolate.

> “The lateral flow testing was so much easier than the PCR in the sense of not having to wait for the results to be sent away and come back. You knew there and then whether you had to start your [self-] isolation or not [...] if you were to have sent a PCR away, thinking you had Covid, you'd [have] been [self-] isolating for three days [while waiting for the result], and then it [sometimes] turns out you've [self-]isolated for nothing because it's not Covid. So that aspect of it was great, I thought.”
>
> – Carer

Some contributors welcomed the ease and convenience of being able to test for Covid-19 at home without having to book an appointment at a testing centre and appreciated that the tests were free of charge.

> “We used to test more frequently because you didn't have to make a booking or anything like that. Once the tests were in hand, you could test as and when you felt it was required.”
>
> – Person with a long-term physical health condition

> “When we were given the [LFT] boxes [...] it was almost, like, 'Okay, well I've got it [an LFT pack] so I might as well [use it].' It wasn't inconvenient [like when you had] to go and test [...] at a centre [...] I probably was more inclined to do it once we had the facility to do it from home with the lateral flow tests.”
>
> – Person working in health and social care

Free provision enabled some community organisations to distribute tests to people and actively encouraged more widespread testing. One example was at a foodbank, where staff would distribute tests and masks along with food packages.

> “We were able to [...] give them a flow test [as well...] They didn't ask for it; we were [just] like, 'Here's a flow test.' [...] we were also handing out masks. The message was, 'Keep safe.' And I think it took people a while, but they started [using them...].”
>
> – Community member who supported people to self-isolate

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. This included people who were immunosuppressed, clinically vulnerable, or living with Long Covid, as well as people with loved ones with these health conditions.

> “Self-testing [...] meant you had the security of your own home to [...] do these things; you didn't have to go out.”
>
> – Person living with Long Covid

Many contributors told us that LFTs were readily available to them throughout the pandemic, despite awareness of shortages or restrictions. Contributors said they were not personally impacted by shortages and attributed this to priority access for certain groups (such as frontline healthcare staff), the range of places from which test packs could be collected, the ability to order multiple tests when shortages were not an issue and sharing between families or other contacts.

> The lateral flow tests were easy to get. We didn't have any issue [...] There was always enough.”
>
> – Carer

> I [...] put them aside [...] only using them when I had to, because I knew there was a shortage at one time. [...] if I didn't have [any...] and I wanted to use one, I phoned my sister and [...] got one [from] her [...] there was always somebody you could phone and say, 'Do you have a spare testing kit?'”
>
> – Clinically vulnerable person

Ordering tests for home delivery and collecting them locally were both described as relatively quick, easy and convenient. Some contributors reflected that accessibility was the same for those in remote areas as more populated ones.

> Folk on my little island got theirs the same time that folk on [...the] mainland [were] getting theirs. I was well impressed with how quick [...] and how easy it was [...] some got sent in the post, and then it changed to having to pick them up from various centres. It was so, so easy.”
>
> – Person living with Long Covid

Contributors also noted that test packs were readily handed out and available, without people having to proactively look for them. This included in public spaces like supermarkets, libraries, places of worship, foodbanks, in GP surgeries and at Gypsy and Traveller sites.

> I got handed a box of ten outside [a supermarket], so I didn't even have to look for them. They were thrust upon you: 'These are free, take them home. Use them whenever you need them’. So [...] I wouldn't say getting access to them was difficult at all.”
>
> – Carer

> There was a [NHS] van that came out and [...] parked up in the shopping precinct, and it was advertised [online] that it was going to be there [...] at certain times, and there were people there [...] handing out [LFT] boxes [...] and giving you advice if you didn't know how to use them.”
>
> – Clinically vulnerable person

Some contributors also recalled test packs being included in deliveries of prescription medication or dropped off to vulnerable households by healthcare workers. Some contributors who worked in community-facing organisations said tests were sent to them for distribution to community members.

> Because of my asthma […] I could have them dropped to me, or posted to me as well. […] just knowing that was an option, I think that's great."
>
> – Clinically vulnerable person

Contact tracing

Contributors who had one of the contact tracing apps generally thought it was easy to navigate and use. It was quick to download and input information, seemed to run alongside other apps on their smart phones without interference and didn't require much interaction from the user once it was set up.

> It was straightforward. From what I remember it was straightforward putting in your details, personal details, reasons why, that was a very quick and easy format to do."
>
> – Zero-hours contract worker

Confidence

Some contributors placed more trust in PCR tests being conducted by staff at test centres. They felt that, because of their expertise, PCR testing centre staff would be more thorough and accurate than people using nasal or throat swabs themselves.

> I remember when they first came out, the PCRs […] they used to do the test for you […] you would literally pull up like [in] a drive-through, and they would […] put it up your nose for you, and it just felt like because somebody else was doing it for you that it would be more reliable."
>
> – Person experiencing financial hardship

Ease of use

Despite some contributors recalling that they needed to read the instructions each time they used LFTs, contributors who found the tests easy to use shared that the steps were straightforward and self-explanatory. People completing PCR self-tests at home also told us they found instructions for completing and returning the tests clear.

> “Re-reading and following the instructions were important. It wasn't […] instinctual to use them [the tests,] but the instructions were fine and there weren't too many […] processes involved that I couldn't understand.”
>
> – Family member or supporter of someone required to self-isolate

> “Ordering Lateral Flow Test kits was simple online and instructions on [their] use were clear.”
>
> – Every Story Matters contributor

Some contributors said they used diagrams in LFT kits and online videos to help them to understand the steps required for testing. These tutorials were often used in addition to, rather than instead of, reading written instructions.

> “It was one of those things where even if you didn't read or speak English, looking at the pictures you would instantly know what to do. […] there was even […] online videos where you can […] see how people are doing it […] for you to just copy […] it wasn't hard whatsoever: very, very straightforward.”
>
> – Person living in a multi-generational household

The introduction of LFTs that only required nasal swabs made a considerable difference to some contributors’ level of comfort when testing[9]. Some contributors expressed a strong preference for nasal swabs and described being relieved by this change.

> “The latest ones with the shorter bud were the best thing that they've ever done […] that natural hesitance to put a long […] stick up your nose went out the window. I definitely saw more people wanting to use the [lateral] flow test.”
>
> – Community member who supported people to self-isolate

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[9] Nasal (nose only) Swab Lateral Flow Tests, rather than Nasopharyngeal (nose and throat) Lateral Flow Tests, became more widespread in 2021.

Fixed Penalty Notices

While we did not hear from anyone who told us that they had received a Fixed Penalty Notice (FPN), some people discussed the perceptions of FPNs and their impact on behaviour[10].

Contributors spoke to us about how **effective or ineffective they thought the FPNs were as a deterrent to breaking self-isolation rules**, the **variable financial consequences** of the fines, as well as some **wider implications of using FPNs to patrol behaviour**.

For some individuals, the **threat of penalty fines** for breaking self-isolation rules influenced behaviour and **encouraged compliance**. Those influenced by the fines highlighted the **financial burden**, describing the amount as significant even for those with greater financial means.

> “ ... [W]hen I heard you got a fine, I thought, well, yes, [I’m] definitely [self-] isolating. Yes. I think that was a real positive to put a fine in place because I feel that it did make people [self-]isolate more.”
>
> – Carer

> “ If I was to have a fine, it would affect me financially. I wouldn't be able to afford to pay it anyway. I think it's good of them to introduce that, to put people off not [self-] isolating.”
>
> – Person living in crowded or cramped accommodation

Some believed that **harsher financial penalties** would have **increased the effectiveness of the fines**, given the potentially fatal consequences of breaking self-isolation rules.

> “ It's possible more severe penalties could be imposed because we are talking of life - because of your carelessness about 200 people died, doesn't make any sense. So apart from that, talking of a fine of say £500 or whatever, there could be steeper penalties to it. You are talking of life. I wouldn't want to die because of somebody else's carelessness.”
>
> – Carer

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[10] Fixed Penalty Notices (FPNs) related to self-isolation were issued for breaches of the legal requirement, in England and Wales, to self-isolate when required:

1. If you received a positive Covid-19 test result, you were legally required to self-isolate for a specific period.
2. If you were contacted by NHS Test and Trace and identified as a close contact of someone who tested positive, you were also legally required to self-isolate, even if you tested negative yourself.

There was a strong contingent of contributors who thought the penalty fines were **ineffective at driving compliant behaviour.** This was due to **cynicism about how enforcement of self-isolation could be implemented in reality.** Comments from contributors suggested that **the lack of transparency about how enforcement could be policed undermined the threat of FPNs.**

> I heard about them, but I think it wasn't really implemented. Like, some people were being arrogant, and they didn't [self-]isolate, and they were supposed to, but I didn't really see any measure being taken against them."
>
> – Person living with Long Covid

In some cases, contributors' uncertainty about enforcement was increased by a **lack of awareness of anyone being fined.** This made these contributors feel that, regardless of their behaviour, they would not get fined.

> Well, I didn't recall anyone that I knew or I knew of, who got fined. Do you know what I mean? And, I think, because you don't know when it happened, it's not going to happen to me. It's that kind of mentality."
>
> – Community member who supported people to self-isolate

There was the suggestion from a small minority of contributors that the existence of severe enforcement measures may have had the **opposite effect**, causing them to **not follow the self-isolation rules at the time.**

> The more [the] measures were put in place to try to punish people, the more inclined I was to not go along with their instruction."
>
> – Every Story Matters contributor

When discussing FPNs with contributors, many spoke about the **variable financial impact** the fines had on people depending on **personal circumstances.**

The **disparity of the financial impact on people who were not working** during the pandemic, or had been furloughed was spoken about. It was thought to be **unfair to impose penalty fines on people who were potentially out of work** due to the pandemic.

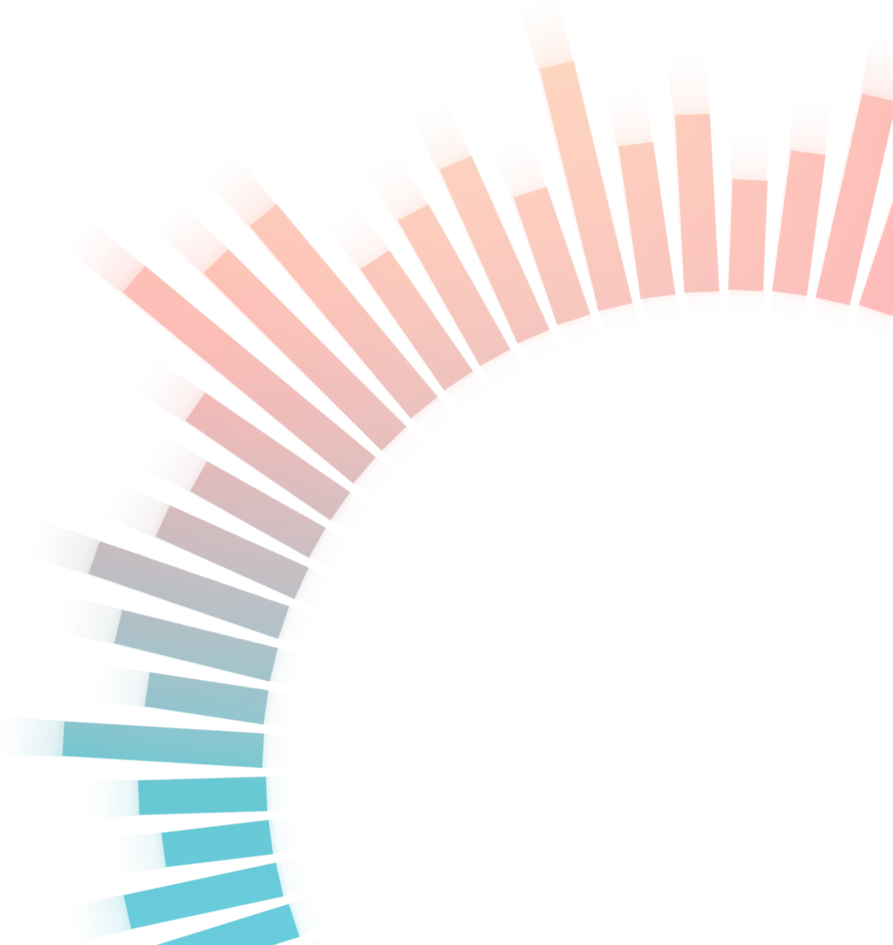
> It was ridiculous because it was like people aren't earning money, people like me that weren't furloughed, and then it's like I'm going to get fined. I didn't have any money to lose at that time."
>
> – Person living in crowded or cramped accommodation

Similarly, people who had no choice but to break self-isolation (for example to earn money, for mental health, or to come to the aid of someone else) and risk getting a fine were also mentioned as a group who would have been disproportionately impacted by penalty fines.

Beyond monetary implications of the penalty fines, contributors who had immigrated to the UK additionally talked about the fear of wider ramifications if caught breaking self-isolation. This led contributors in this situation to overcompensate by being extra cautious about breaking any rules.

> When you are new in another country and you are not fully [aware] about that language and you don't know anyone, you have to just keep [to] the rules because no one is there to support [you] if you make a small, small mistake. So, we were following all of them."
>
> – Person whose first language is not English

> But there was this scare that if you go out, you could be fined. And then I thought, 'Gosh, if I actually - since I'm not a British citizen, if I get fined, if they say, 'You're doing something you shouldn't do', there could be a danger of losing my right to stay in this country."
>
> – Person who is digitally excluded



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

This chapter details contributors' experiences of the barriers to testing, engaging with the contact tracing system and to self-isolating. The chapter describes these barriers and provides examples of where and how they influenced behaviours during the pandemic.

Trust

We heard from contributors who expressed strong scepticism and a general lack of trust in the testing programme. One example was the view that PCR tests were designed to give 'false positive' results.

> False positive[s] were used to create the thousands of so-called 'cases' and produce the associated hysteria. […] I did not have any test (as a matter of principle)."
>
> – Every Story Matters contributor

There was also scepticism among the stories we heard relating to the accuracy of LFTs and effectiveness at detecting the virus. Some contributors, for example, were not convinced that a LFT done at home, which provided a result so quickly, could be accurate when they were accustomed to accurate medical testing being done in a clinical setting.

> […] before the pandemic, if you had to have a test you had to go to the lab or to a surgeon, and now suddenly you can do it at home and […] get the results after two minutes? […] It might be [true…] but I don't think that we'll ever know if they actually worked or not."
>
> – Zero-hours contract worker

Some contributors considered the LFTs to be less accurate than PCR tests, describing PCR tests as more sensitive and better able to pick up asymptomatic cases of Covid-19[11]. People reflected on their direct experiences where they believed LFTs failed to deliver a positive test despite them having symptoms consistent with the virus, or when their symptoms were similar to those around them who had tested positive for the virus.

> “The […] walk-in ones […] were definitely more accurate. There was one time that I was completely asymptomatic and went to a PCR […] walk-in centre, and it ended up that I did have Covid. [… Another] time […] I was convinced [I had it]: I couldn't smell anything […] I had the flu […] and […] three days in a row I did lateral flows […] They were all negative and then only on the fourth day, when I was so ill, would it come up saying that I did have it. […] I'd lost my smell and [… was] already so ill, [it] makes you think that they're not that accurate.”
>
> – Every Story Matters contributor

> “My lateral flow test was showing negative, but my symptoms suggested otherwise, so I lied in order to get a PCR test. The results were positive.”
>
> – Every Story Matters contributor

Contributors were also sceptical about how accurate and effective the contact tracing system was. They described gaps in the system that they thought undermined how useful it was, for example:

- Contact tracing only worked if people tested, and would not include people who had Covid-19 but had not tested yet or were avoiding testing
- The time taken to notify people could be enough time to spread the virus
- It would be impossible to correctly identify all the people who had been in contact with someone with Covid-19
- The definition of a contact was unspecific – and might not be triggered by being close enough to someone to contract the virus

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[11] Published evidence shows LFTs are more likely to miss an active infection (false negative) especially in early stages of infection or asymptomatic cases.

> “I just don't see how they could trace everybody or know people's names with who you've come into contact. Because if the person was carrying the virus but not feeling the symptoms, they go into a shop, but does the shop then work out who was working or who they might have spoken to, so the whole trace thing, I find it a great idea, but I don't think it would actually work.”
>
> – Person living with Long Covid

> “It's a bit difficult to say whether that system was effective or not because depending on how quick the letter got to you or depending on how quick the email got to you, you know, because you could still be infecting people.”
>
> – Person with literacy difficulties

> “You'd get pings at random times, I guess. You always wondered where the exposure was because it would be two or three days after you'd been somewhere, I guess, and somebody had been tested and registered their test.”
>
> – Person with a long-term physical health condition

For some, the fact that contact tracing was in place alongside social distancing and other precautions - such as mask-wearing, protective screens and socialising outdoors - felt irrelevant and counterproductive, adding to a lack of confidence in the system.

> “I found it a wee bit pointless as well, like if you did go in a restaurant and whatever, you had to socially distance, so all the tables and everything were set out really far, compared to normal...But, then you would still get, like, an alert from track and trace.”
>
> – Person working in health and social care

It was also pointed out that app-based contact tracing systems relied on large numbers of people using their contact tracing app, uploading test results and inputting contact information accurately and honestly. However, many contributors assumed that the systems were not being adhered to by everyone, which led to further uncertainty about usefulness and impact. Some contributors pointed out that it was easy to upload inaccurate information onto a contact tracing system, such as using a friend’s test results. Contributors also knew of people not participating in contact tracing, or shared that they did not participate themselves, either at first, or after some time using it. We also heard stories of scepticism around the effectiveness of contact tracing systems that connected and used input from QR check-in systems at venues.

> “It's only as reliable as the inputter, isn't it? You can have 100 people scanning it, but if you've got 200 people, and the other 100 aren't scanning it, then it's worthless.”
>
> – Person with a long-term physical health condition

We heard from contributors who did not like contact tracing because of the personal information it required. For them, this felt uncomfortable and invasive. Additionally, some were uncomfortable providing the contact details of their friends and family members. Concerns related to general mistrust of government use of personal data, fear about cybercrime, unknowns about why and how their information was being used and scepticism about why this information was really needed, and the potential to inconvenience others.

> “It is a worry when you think about putting your information there, and with some of the major hacks that have been happening lately with all our information. I think it could be quite vulnerable to that. That's probably why I deleted it, if I remember rightly. I think I got to the point where I thought, ‘I don't think it is very good having this on my phone’, so I got rid of it.”
>
> – Clinically vulnerable person

> “Like, I do remember going down a real rabbit hole during Covid, so most likely I probably did have a problem with it at that time. I was down the whole conspiracy route and everything. I can't remember exactly, but there's a high chance I probably did have a problem with it.”
>
> – Zero-hours contract worker

Some who shared their stories did not participate at all in contact tracing because of these concerns, or eventually switched off the app because of concerns about data security and privacy.

> “I did question them taking so much information from us. I do remember at the time, my partner, he categorically said, 'I am not giving them anything. If I've got Covid, I will test, I will [self-]isolate, I'll do all that, but I am not giving them any information that they're asking for.'...It definitely did make you question it and feel a little bit uncomfortable at times...it did feel quite invasive really.”
>
> – Every Story Matters contributor

We heard many examples of contact tracing, and the apps in particular, not working well. The more people experienced these issues, the more they lost confidence and trust in the system. The problems experienced ranged from receiving a notification even though the person had not left the house or been in contact with anyone, to testing positive for Covid-19 but not receiving a notification that they had been in contact with anyone who had the virus.

> “I used to get regular alerts saying I'd been in contact with somebody, or possible contact, so I sort of distrusted it on my side because some of the times I hadn't even been out and I was getting pinged and everybody I know who I worked with never got a ping yet I sat with them every day.”
>
> – Every Story Matters contributor

Again, we heard this led some people to turn off the app, Bluetooth or location devices, leave their phones at home, or stop providing accurate contact information.

> “I did sign up to it initially and then, sort of, as perhaps a year went by, it fizzled out because, again, you're relying a lot on compliance with other people, and it just did become a little bit of nonsense.”
>
> – Every Story Matters contributor

> “I remember being, like, left to work all on my own because everybody else on my team was off, and it was just ridiculous. It was like, 'I'm turning this off, this is so stupid.' Like, they didn't even know if they had Covid or not, but regardless they had to stay off work for two weeks. It was just ridiculous.”
>
> – Zero-hours contract worker

> “Yes, there were times when your app would have said that [to self- isolate] to you but I ignored it, really, to tell you the truth because it was giving me all negatives, there was never any positives so I just tried ignoring but that never worked, do you know what I mean? It should have said in the plain that you have been in contact with somebody or something like that.”
>
> – Community member who supported people to self-isolate

We also heard that people’s distrust and scepticism in contract tracing apps meant that they were less likely to follow self-isolation guidance, especially given how inconvenient and potentially stressful self-isolation was for some.

> When I got dinged on the app, I just ignored it, because, again, the number of people who said, again, ‘that was inaccurate and didn't work,' and were getting dinged when they hadn't even been anywhere, it was a case of, 'This is just a load of [obscenity], so, you know, I'll carry on with my life,' because no one had been dinged, so I'll just carry on.”
>
> – Every Story Matters contributor

We heard from a few contributors who had heard about or had been targeted themselves by scam messages posing as part of the official contact tracing system. This reduced confidence and trust in the system for these contributors.

> There was an awful lot of scam texting going around, and it was quite difficult to work out. As soon as you click on it, and then they start asking personal questions, or bank details, then you know that it's a scam.”
>
> – Clinically vulnerable person

> Any other texts that I received were definitely from scam accounts. And that all happened really quickly after the track and trace thing was up and about. And I thought, 'Oh that was quick.' Scammers got onto that really, really quick.”
>
> – Person who accessed mental health support

More generally, some contributors spoke about a broad distrust of the overarching system and information being shared about testing and the virus. They experienced this personally or second hand.

> The initial ones were really uncomfortable [...] the swabs were very long, so that put people off, but I think it was more a total distrust of the system [... and] of the NHS generally, this element of people who just thought, 'No, I don't trust this. I'm not going to [test].' [...] my own partner [...] I had to fight for him to take a test because [...I am] high-risk and I had to say to him, 'I don't want you around me unless you can prove that you haven't got Covid' [...] it took a lot for him to get there.”
>
> – Community member who supported people to self-isolate

News about politicians and government officials not following guidelines was described as a turning point by many contributors in their attitudes to following the rules. This often changed how they applied self-isolation guidelines to their own situation. They shared that they did not understand why they should self-isolate if those in leadership positions were not following the rules. Many contributors told us that because of these events, they decided to use their judgement in how closely they should adhere to self-isolation rules, especially given the stress and anxiety that many referred to if they self-isolated.

> When information came to light about government scandals… and people were getting tired of strict isolation rules, I think that's when it got to a stage where people started rebelling, and people started saying no, enough's enough. I think it got to a stage, I'll be totally honest with you, people were going, 'Do you know what, if I'm going to die, I'm going to die with all my family around me.'"
>
> – Clinically vulnerable person

Contributors also told us how the actions of politicians and government officials changed how they viewed the enforcement of self-isolation guidance. These people told us how they took penalties less seriously as a deterrent to breaking the rules as a result.

> I think the penalties became a bit of a farce in the end because it was like, whenever you see people breaking the rules from the… government, it just became a bit farcical."
>
> – Every Story Matters contributor

Perception of risk

Personal risk assessments fed into the extent to which people participated or not in testing, contact tracing and self-isolation.

We heard from people who doubted the need for testing or participating in contact tracing, especially when they did not have symptoms, or they felt that their lifestyle meant they were at lower risk of contracting Covid-19. Some of these contributors believed that the way they were spending their time, such as being at home with minimal contacts, placed them at minimal risk. We heard stories of people taking their own precautions instead of following the official guidance.

> Sometimes you'd think, ‘I've not really been anywhere recently, so how could I […] get it?’ […] if I've literally been in the house for five days […] and I've got no symptoms, why would I need to test for it? There was no point. So, I just tried to apply a little bit of common sense and logic to it.”
>
> – Single parent

> [explaining why they didn’t participate in contact tracing] The majority of the time, we had been bubbling, so it was very minimal people that we were seeing. We weren't seeing friends, we were only seeing family and even then, we were very careful when we were seeing them, making sure that we were negative and everything else.”
>
> – Clinically vulnerable person

The degree to which households self-isolated separately often depended on perceptions of the risk from Covid-19. We heard from some contributors who told us about how their households did not follow strict self-isolation guidance (i.e. to confine individuals to one room) and instead moved freely around the house and self-isolated as a household. They felt using the entire home versus one bedroom to do this was more practical and comfortable. Having the space to move around during the self-isolation period was also important in their view. Different types of households decided to do this, including those with children and those with numerous housemates.

> In all honesty, like if one of us had Covid at home, we wouldn't self-isolate in a bedroom as we were told to do. That was a bit ridiculous for us, because we're all in a home, sharing things, sharing the environment. Self-isolating, for me, was making sure I was in my home, and not going out into public spaces.”
>
> – Every Story Matters contributor

Some contributors avoided test centres because of the potential risks of either passing on or contracting the virus, where they were likely to encounter other people, including those who may have Covid-19, acting as a barrier to testing.

> I was actually too paranoid to go to one of the test centres because it was more of a fear of, ‘What if I haven't actually got it, and then I turn up there, and [… other people] they're coughing like the clappers, and then I end up getting it because I went to the testing centre?’ So that was always a worry.”
>
> – Every Story Matters contributor

There were also contributors who said their engagement with testing decreased during the pandemic, because they considered the risks associated with contracting the virus to have decreased over time. Reasons people discussed included having contracted the virus previously and therefore thinking they were immune; media coverage including declining number of deaths; and lifting of restrictions.

> “Once we got Covid, after that, just with stuff going round and so much media that your body becomes immune to it, so I started paying just generally less attention to getting tested, it wasn't as frequent.”
>
> – Zero-hours contract worker

> “As it went on [...] and [...] I'd had it a second time [...] I thought, 'Oh, it's not that bad really.' And other people [...] were saying, [...] ‘we've just got to get on with it, haven't we? [....] we don't really care if you've got Covid or not, it doesn't make any difference.' So, [I thought], 'Well, I won't bother to test then.’”
>
> – Every Story Matters contributor

Receipt of one or more doses of the Covid-19 vaccine made some we heard from feel that there was less of a need to test for Covid-19. They said this was because the vaccine offered protection that reduced their likelihood of catching the virus.

> “After the vaccine as well, it kind of felt like I didn't test as much because I could fight against it more, so I had less chance of even getting it.”
>
> – Zero-hours contract worker

Additionally, the end of widespread free testing from April 2022 was, for some contributors, a signal that the pandemic was no longer as serious as it had been and the risk of contracting Covid-19 had reduced. Testing was seen as less necessary, with the onus being more on individual preferences about whether or not to test.

> “When they stopped doing the free testing I started to think, 'Right, it just can't be that serious anymore. If they're not providing this [...] service for people’, it's almost saying [...], ‘It's up to you [...] now it's just a judgment call. You just have to [...] make up your own mind whether you think you're vulnerable or not’.”
>
> – Manufacturing worker

Access

PCR tests

We heard from contributors who told us they found the PCR booking process challenging, creating barriers to testing for themselves or others. Navigating the booking system, including the options it presented, could be confusing and stressful; accessing support and guidance was also time-consuming. Some contributors experienced booking errors where appointments had not been recorded on the system, which could result in them being turned away.

> I had problems with the booking [...] you thought you'd booked the slot [...] and when you got there, they said, 'Well your name's not on [our list]'. [...] I'd waited in a long queue and now you're sending me away."
>
> – Family member or supporter of someone required to self-isolate

> I mistakenly booked the drive-through instead of the [walk-]in centre. [...] When the address came through, it was a drive-through. It wasn't what I was expecting."
>
> – Carer

Some contributors said access to PCR appointments was more difficult at the start of the pandemic and when international travel was permitted with a negative PCR test.

> At first it was quite hard to get a slot; you had to keep checking because it was so busy [...] everyone was doing it all at the same time. [...] there weren't many set ups and [...] a lot more people [seeking tests] than [...] volunteers."
>
> – Person living in a multi-generational household

Another barrier for some was access to test centres close to where they lived, either because these were not provided locally, or because appointments were not available at centres close by. Having to travel longer distances increased costs and worry about getting to test appointments.

> “You always had to travel. […] We are quite semi-rural and there were no facilities at all for anybody […] anywhere near. We have a small hospital in our town but, at that point […] no testing [was] done there […] just done at big centres […] the message was, 'Go and get tested. It's easy, it's straightforward,' but it wasn't.”
>
> – Person living with Long Covid

This was the case for some people living in urban areas, as well as those in more remote/rural locations.

> “We were living in a city centre, which actually made it more difficult to access test centres because they were quite often on the outskirts of the city. [The] financial burden of having to get private transport to those test centres […] it was added stress, it was added planning and logistics.”
>
> – Family member or supporter of someone required to self-isolate

People who were unable to secure private transport were not always able to access testing appointments. Some test centres were drive-through only, while others were distant from public transport routes. Public transport was also sometimes restricted.

> “I had to walk ages because […] I just knew that I had [Covid], so I didn't want anybody to come with me and I can't drive, so I literally had to walk, like, 50 minutes to this testing centre […] on the side of the motorway […] because there wasn't anything closer to me.”
>
> – Every Story Matters contributor

Travelling to test centres was also more difficult for those who were unwell with Covid-19 symptoms.

> “My partner and I had Covid in the early months of the pandemic. My partner was very unwell and came close to being hospitalised, which was very frightening […] when it was difficult to get help. Our nearest testing centre was 40 miles away.”
>
> – Every Story Matters contributor

> “I struggled to get to the testing centre as I was so unwell – [I was] feeling weak, [with an] extreme cough, high temperature and headache.”
>
> –Every Story Matters contributor

LFTs

We heard from contributors who were affected by not being able to easily access LFTs, particularly at the start of the pandemic, when schools reopened and when international travel was permitted. Shortages or rationing of LFTs caused them concern, fear and some panic.

> “At the very beginning, it was such a high demand for testing, some of the pharmacists [...] couldn't get the test kits.”
>
> – Person from a Roma ethnic background

> “When schools reopened, I continued to work as [a] supply and it was terrifying. I was getting Covid alerts on my phone almost every day for contact, but due to the lack of planning there was just no tests available, meaning I had to choose between earning money which I desperately needed, or potentially spreading this deadly disease. That's not something someone earning little more than minimum wage should have on their shoulders.”
>
> – Carer

Later in the pandemic, the number of free tests per person was limited at times. This affected those with larger households, who got through tests more quickly. It also affected people seeking to order tests on behalf of others – for family members who struggled with the ordering process themselves, or for professionals visiting their home to provide services such as domiciliary care.

> “If the [carers] hadn't got Covid tests [and our free ones ran out...] I had to go out and buy loads of them. I did sort of feel I was being penalised...other people didn't have that extra cost.”
>
> –Every Story Matters contributor

Accessibility and inclusion

PCR tests

Some contributors felt that the needs of people who were digitally excluded, or who had lower levels of literacy or English, were not sufficiently supported by the PCR booking systems. This resulted in high levels of dependence on informal support from family or friends.

> “Older people […] really struggled with the technical side of […] booking their PCR test […] we often had older patients phoning in asking us questions about booking […] nobody took that into consideration that a lot of elderly people, they don't have mobile phones.”
>
> – Person working in health and social care

Some who shared their stories described how they did not feel test centres were accessible for people with disabilities, either in terms of physical layout or the protocols in place. For example, long queues and social distancing were difficult for people with some conditions and some test centres were not wheelchair accessible.

> “It was hard for [my sibling with a learning disability] to stand in line and follow [social distancing guidance…] there was no situation where [if] you're vulnerable or you've got a learning disability or autism, [accommodations would be made, recognising,] 'This is difficult, we'll bypass you from this long queue and you can go [straight] in'.”
>
> – Family member or supporter of someone required to self-isolate

> “[The test centre] had loads of stairs and really narrow cubicles. [A wheelchair user] wouldn't even be able to sit in there. And then the next one available to me was up near the airport, and that was a drive-through, but that's an hour-and-a-half journey [away].”
>
> – Every Story Matters contributor

> “The PCR tests were quite involved and for some people, quite arduous to get to, or anxiety-inducing.”
>
> – Every Story Matters contributor

We heard from people with sight loss who were not able to have someone accompany them to a PCR testing centre, and said this made the process difficult.

> I lost my eyesight during Covid, I had to do it [testing] alone because no one was allowed to go with me.”
>
> – Person with sight loss

We also heard from people who had negative interactions and experiences with the staff at PCR test centres, for example staff making people feel under pressure during tests and discomfort around the physical proximity of staff when administering tests.

> They actually had to do it for you, and I found that really challenging, really triggering, really uncomfortable and unnecessary. I felt like, why can't I do it myself? It felt very invasive, especially as somebody who has experienced trauma. It felt like a breach of my personal space.”
>
> – Person with a long-term physical health condition

> The second time we went to a test centre the staff tried to make me, a heavily pregnant woman, climb into the back to test my daughter. I could not physically do it at seven-plus months pregnant. There was a huge empty car park; no one was at risk of me passing [Covid] on to them as there was no one there. We left without testing her.”
>
> – Every Story Matters contributor

Contributors from Gypsy, Roma and Traveller communities in particular reported negative experiences of the professionalism of test centre staff.

> Completely unprofessional [...] We wrote and complained, [including...] an explanation of what had happened [... and that] they didn't answer [our questions] properly [...] when we asked them, 'Are you sure this works?' sometimes they were even laughing, [saying] 'Don't worry, we know what we're doing.' [... Information we wanted] was difficult to get. We decided we were not going to go there anymore.”
>
> – Person from the Traveller community

Some contributors who spoke English as a second language also found it difficult to understand the verbal instructions given by test centre staff making it difficult to access instructions and information. This, in turn, made their experience of PCR tests particularly stressful. Some contributors who were Deaf 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.

> I didn't really have enough English to communicate with [...] the person who was doing the test on me would say something, and I wouldn't understand what they said, which just makes it more stressful for me [...] it just gives me anxiety because I just don't understand what is going on around me."
>
> – Person living in crowded or cramped accommodation

> There was no Deaf or disability awareness given to any staff apart from one, in my local area. There are a lot of Deaf people living here. But that wasn't a government directive."
>
> – Deaf person

LFTs

People with physical disabilities reported more difficulty using LFTs. For example, opening packaging was difficult for people whose disabilities affected their dexterity, and small text was difficult for those with visual impairments to read.

> I found them physically hard to open at times. I have a bit of a tremor, so tipping the tiny little bits of liquid [was difficult], and it was a very intricate process which was quite physically challenging."
>
> – Every Story Matters contributor

> Information [leaflets] in a [...] small print, [meant] the Covid tests were not accessible to partially blind people."
>
> – Person with sight loss

Older people, Deaf people, those with English as a second language, those from the Gypsy, Roma and Traveller communities and people from communities impacted by literacy barriers sometimes had difficulty understanding the written instructions in LFT (and PCR) test kits. Some people required support from friends or family to use tests. For others, these challenges meant they did not use tests at all.

> “I remember talking them [my parents] through it whilst I was outside and they were at their kitchen table [...] with the window open [... guiding] them [as they used the swab], 'Yes, you do this and put it right at the back’. [...] They couldn't have done it if they didn't have me to talk them through it.”
>
> – Family member or supporter of someone required to self-isolate

> “With the travelling culture [...] a lot of my family members can't read [because they left school early], so unless someone is there to show them or to help them, [...] they won't be able to follow [written instructions...]. They need something visual that they can see, or an audio [recording] that can explain to them what to do.”
>
> – Person from a nomadic community

Some contributors, particularly those whose first language was not English (including those who were Deaf), said that LFT instructions in other formats would have been helpful for them. Suggestions included the addition of more diagrams in test pack leaflets, and links to online videos showing the steps involved, using British Sign Language (BSL). Some contributors did not seem to be aware of online videos that were available during the pandemic, suggesting that these could have been more widely publicised. Another suggestion was for volunteers in organisations or the community to give demonstrations.

> “Deaf people were receiving the test kits, and [...] weren't sure how to use them. They just kept contacting me as I work for social care: 'Please, can you explain how to use these kits?' There was nothing [...] in sign language to show people how to use them [...] I had to do sort of facetime [...] tutorials [to help them understand...] really. And I think the NHS should have created videos in sign language to show how to use the test kit.”
>
> – Deaf person

Contact tracing

Some contributors also noted that barriers to using digital technology was a reason for not taking part in app and online forms of contact tracing. This was due to a lack of knowledge about how to download the app or access the webpage or not having a mobile phone that would support the app. Very few older contributors aged 75+ had used contact tracing apps or online forms of contact tracing. Some younger contributors also said their parents were not able to use the app or online versions of contact tracing.

> “[The] test and trace system was not applicable to me as I do not operate a mobile phone.”
>
> – Every Story Matters contributor

> “I was never pinged because I didn't have the app and the main reason I didn't have the app is because I had a very old phone that would not have been supported in that, and I wasn't going to buy a new phone just to get the app.”
>
> – Every Story Matters contributor

Some contributors from communities whose first language is not English also described creating their own approaches to contact tracing, rather than participating in the official system. For example, a contributor from the Bangladeshi community described contact tracing not having a big reach in their community due to low levels of digital literacy and English. Instead, the community played an important role in tracking Covid-19 infections amongst themselves, for example alerting people to infections in their neighbourhood, and making sure affected people got tested and reduced their contact with others.

> “Because…some people can't use the apps anyway, and it's a bit of gaining information [and] then people either read it and they were able to digest the information, and they tried their best. But other than the apps, it was like one-to-one information…say if I know, so pass it [to] someone else, something like that other than using those apps…word of mouth.”
>
> – Person whose first language is not English

Difficulty of use

Contributors told us that it wasn’t always straightforward to work out how to use a test kit.

It could be challenging to interpret how to use the LFTs correctly, and some contributors we heard from described feeling uncertain that they had done tests accurately, which often led to them repeating the process. Reasons included uncertainty about correct testing processes such as how far swabs should be inserted or the length of time they should swab their nose or throat; variability in accuracy between nasal and throat swabs; and faulty tests, for example, where the extraction tube was empty or contained little fluid.

> I'm always thinking, 'Did I go far enough up my nose? [...] Did I do it properly?' Moreso if I was unwell and it was negative, I would think, 'Oh, have I done it properly?' and then [...] do it again and again [because] your mind is saying you might have it."
>
> – Person with literacy difficulties

Some people realised much later on that they had been misreading results for long periods, which could have an enduring impact, for example, by leading families to self-isolate unnecessarily.

> We ended up locking ourselves in the house for about four weeks over Christmas because we were reading the tests wrong! [...] that was our own fault."
>
> – Carer

We also heard from people who found the variations between test kits made them more challenging for some to use. Kits from different brands had different components and instructions, and contributors recalled having to review the instructions each time they used a new test type. Some contributors said that tests became easier to use over time however, both because their familiarity increased and because test kits improved. One example was the inclusion in some test kits of a cardboard stand to hold the extraction tube, which some people described as helpful.

> We got used to doing it one way and then another [different] one arrived [...] you're like, 'Oh God, I've got to tip this in here and not [...] there [now]' [...] it just took some effort to read some [more] instructions, but that's not the end of the world, really, is it? It's like five minutes out of your day."
>
> – Carer

Negative impacts

We heard about a set of barriers to testing, contact tracing and self-isolating which related to negative, or potentially negative, impacts on people in different circumstances. These included loss of freedoms, financial implications, impacts on people's wellbeing such as discomfort and distress from testing, and mental health implications of self-isolation.

Loss of freedoms

We heard from contributors who either avoided or delayed testing, and/or avoided self-isolating when they had symptoms, so that they were not restricted in terms of mixing and socialising with others.

> “I only really tested if someone said, 'You need to do a test.' […] if I had a runny nose or something and someone was like, 'Do you think you've got Covid?' I wouldn't really think about it […] I'd be like, 'Probably just got a cold' […] they'd really have to push me […] Part of me would be, like, 'If it comes back positive then I cannot go out on Saturday, so I'm going to hold off. I don't think I have it, I'll see if I feel better' […] only if people really pushed me would I take a test.”
>
> – Every Story Matters contributor

> “Sometimes it was like, you must now [self-]isolate for ten days, five days, or you could I guess lie and be like, what day you saw the person and put it earlier than it actually was so you'd be out of isolation sooner. I feel like the length of isolation was a bit excessive, and again there was that ripple effect…. We had a Christmas thing at my friend's house and on the day before I had felt a bit rough, but I tested in the morning, I was fine. I went there, so I was there all evening, all the windows, a few of the windows were open… [Then] I remember at the time being like, I don't feel great, but it wasn't typical Covid, I just had shoulder pains and felt quite cold… The next morning, I woke up, absolutely no sense of taste or smell, really ill. I immediately was like, I need to get a test, and then I was like to everyone, 'I'm really sorry, I have got it.”
>
> – Person with a long-term physical health condition

Young people and parents also described finding it difficult to adhere to self-isolation guidelines, particularly later in the pandemic. We heard examples of self-isolation requirements feeling far from their usual routine and the reduction in physical freedom challenging to manage.

> “That two-week one, I thought it was awful. At first it was fun, but I was confined to a room. I wasn't confined to a house, like I am now, if I were to [self-]isolate. I had a double bed and I had a puppy who was teething, and it was just stressful, especially when I got told I couldn't go out. That's what made me want to defy it, actually, was when I've got someone telling me I can't leave my room, I can't walk the dog. That's what made me think, 'No, I'm not doing that.’”
>
> – Every Story Matters contributor

> In terms of everything else, well, we don't tend to go out a lot anyway really, it didn't affect us [parents] greatly. I think it affected my son more because he wasn't able to see his girlfriend and, you know, they were desperately in love and they found it mentally extremely difficult."
>
> – Person living in a multi-generational household

Financial implications

For others we heard from, inability to work and potential loss of income was a barrier to testing. This was because they would be unable to work if they had tested positive. Contributors recalled hearing from others who had not followed the guidance to test as they could not afford to miss work if they tested positive.

> I remember people saying, 'I can't test because, if I test and I'm positive, I can't work and, if I can't work, I can't support my family.' You can understand them making those choices, rightly or wrongly, you can understand they've got to provide for their family."
>
> – Every Story Matters contributor

> I actually never took any test at all whatsoever [...], purely because I didn't want to restrict me or to dictate to me how-, you know, my movements because I was quite busy.[...] because there was a lot of contradictions, you know, when you get tested, how many days you can take off, where you can go [...] I just chose not to use the test at all or use any app [...] and luckily I didn't catch it..."
>
> – Person working in health and social care

This was particularly the case for agency staff or those working zero-hour contracts who shared with us the stress and financial pressures they faced around work and self-isolation. These pressures often led to people avoiding using the contact tracing app, not testing before work and avoiding, or shortening, self-isolation so their income would not be impacted.

> The reason I did not take part in the app was because I went back to work in July 2020, and then my manager said if we got pinged we needed to be off work, and with my job, I don't get paid if I don't work. I'm thinking, 'I will not just take part in it because obviously we need money so I should be working. Besides, I am positive that I will not get the Covid.'"
>
> – Person working in health and social care

> Obviously that [paid sick leave by employers when taken ill with Covid-19], was happening at the start but towards the end, like, work were saying, 'No, we're not paying, we're not doing this, we're not doing that.' At that point everyone was just saying, 'Well, I'm not taking 10 days' unpaid leave, so I'm coming in. I'm doing nothing.'"
>
> – Zero-hours contract worker

There were examples, too, of employers advising or instructing their employees to stop using the contact tracing app and/or telling people not to self-isolate, or shorten the recommended self-isolation period, so that they could continue to work. Some of these contributors described feeling angry and frustrated at this treatment by employers. They told us how they had been attempting to follow self-isolation guidelines but were feeling under pressure not to do so.

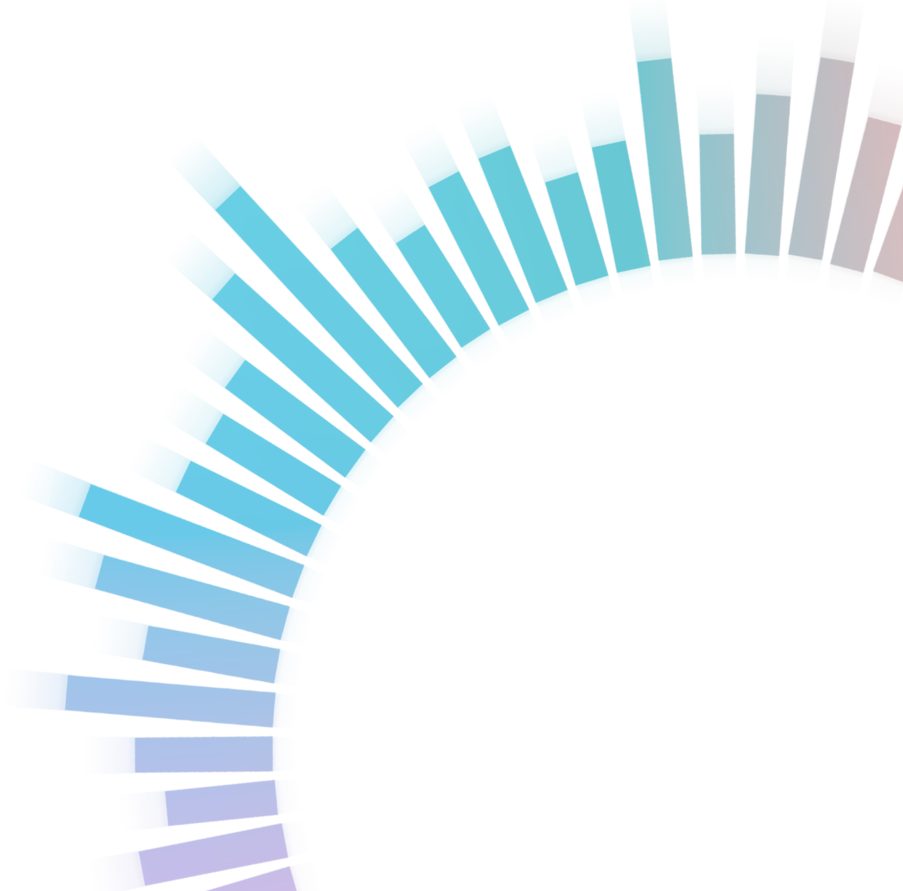
> The advice/instruction from the government at the time was that anyone who had a temperature and/or a new cough should self-isolate, so she when she developed the cough, she called into work and told them that she had a new cough and would need to stay off work and self-isolate in accordance with government guidelines. However, her manager at [supermarket where she worked] told her that she had already taken a night off the week before and there were lots of reasons why she could have a new cough and that if she didn't come to work, disciplinary action would be taken. She needed her job and income, so she went to work, but she and I were and remain horrified and angry about the response from [her employer] to this situation. Covid testing wasn't widely available at the time and we will never know whether my daughter had Covid-19 or some other less harmful virus, but I feel that [daughter's employer] should not have insisted that she disregard government advice at the time and go to work while she had symptoms that could have been Covid-19."
>
> – Every Story Matters contributor

> When I got Covid in early 2021 I was bed-ridden for two weeks. My employer harassed me the entire time, making me take daily tests and calling me at 9am every day to find out the results. They wanted me to come back to work as soon as I got a negative test, whether I was feeling better or not."
>
> – Every Story Matters contributor

Cost of tests

Having to pay for tests became a barrier for some who shared their stories with us. This meant that some who had tested when they needed to (using an LFT) no longer found it as easy to do so. This was seen as unfair for people who were considered vulnerable, given their reliance on tests to stay safe.

> “If I had to pay for them, I would have not tested as much. We did pay for a batch of tests [when] there was another strain and […] I don't think we had […] tests [left] at that point or they were out of date […] I was slightly less willing to pay for them than I was to get hold of them for free. I think it was £8 for four or something like that, so it wasn't particularly cheap.”
>
> – Person with a long-term physical health condition



Patricia’s story

Patricia is a mother and one of her children was classed as clinically vulnerable during the pandemic. She found the pandemic overwhelming and stressful in all aspects of her life. She lived in a rural area, with the closest testing centre a 30-minute drive away from her home.

Patricia tested frequently throughout the pandemic because of her child’s clinical vulnerability. She also had to ensure that carers and workers coming into the home had tested. This was sometimes stressful, especially if people refused to test or did not have access to their own tests. Patricia would sometimes give other people tests, but this could be difficult as her household used a lot of LFTs. Patricia found it difficult to test her children and had to sometimes make multiple attempts using several test kits, if her child struggled with testing.

> “It made it hard for me to do it, so sometimes you'd get through about three swabs trying to get one off the child because... Particularly with the LFTs, I mean, you got through quite a few swabs because she'd spit or cough or yank it out [...] or something.”

As she needed to continue to test regularly even after LFTs stopped being freely available, Patricia felt financially penalised by the extra cost imposed on her family by having to pay for tests.

> “I did sort of feel I was being penalised because I had the child that's vulnerable, whereas other people with children - not that they didn't care, that's completely the wrong word - but there wasn't that issue. They didn't have that extra cost. It was like, again, it's another cost in this world for having an illness.”

Some community organisations were able to continue to supply free tests after mass testing ended, extending the period in which vulnerable people could access tests. Contributors felt this was key to ensuring people on low incomes continued to use tests they would not otherwise be able or willing to access.

Physical discomfort associated with testing

Contributors discussed feelings of physical discomfort associated with using LFTs ranging from mild to significant. Testing made some we heard from feel very unwell and for some the physical discomfort of testing made them test less and less over time.

> “When I [...] put the swab down my throat to test, [...] I couldn't breathe. It was as if there was a clamp on my neck, on my throat. I struggled, really struggled - and it was frightening - to breathe.”
>
> – Carer

> “I didn't really enjoy sticking it up my nose or at the back of my throat! I remember when I actually went into have my C-section to have my wee girl, [doing a Covid-19 test] didn't get mentioned, and I was like, I might just get away with it, [...as] they've not come round and asked. Then [after] five minutes [...], they came and done it. I've just got a really bad gag reflex, to be honest, and it wasn't a nice feeling. So, if I didn't need to test, then I just wouldn't.”
>
> – Carer

The throat swabs caused gagging reactions for some who shared their stories. Nasal swabs were also challenging for some as there was an understanding that the swab had to go quite far up the nose to retrieve a good quality sample. Sometimes this could make people worry that they might injure themselves. We heard examples of nasal swabs that had caused nosebleeds.

> “The first test, you had to do it in the back of your throat and your nose, and then it [the style of test] changed so you just had to do it in your nose [...] I remember thinking, 'Oh, thank god', because it [the first test type] made you retch, [...] when you did it in the back of your throat, and it wasn't so bad sticking [...a swab] up your nose.”
>
> – Clinically vulnerable person

> “The testing kits caused me and others to have sore throats and nosebleeds.”
>
> – Every Story Matters contributor

Neurodivergent people shared that they experienced heightened discomfort and distress due to sensory sensitivities. This meant they spent longer trying to complete tests by themselves, whether PCR home test or LFT, and they also struggled with the process of being tested by someone else.

Chloe’s story

Chloe is an autistic adult who had a job which required her to test frequently during the pandemic. The first few times Chloe was tested was in a hospital setting where she was tested by doctors. Chloe found the experience of being tested by someone else extremely uncomfortable and relayed her experience of being “pinned down” by staff. On these occasions, the doctors were ultimately unable to complete the test.

> “It was distressing. I think because [...] there's a lot of stimulations that I have issues with. So, with people, with noise, smells, and stuff like that. [...] I was at the doctors and they had to do the test, and they spent about an hour trying to force me. And then, they just said, 'You've got to go home because we can't test you. You've got to go home, we can't have you here.”

Chloe later changed jobs and was allowed to complete the tests at home. Though testing herself was still very uncomfortable and took a long time, she found this much easier than having someone else administer the test.

> “I could just do it at home [...] it still took me, like, an hour to do because of [...] the sensations, but it was a lot better because I didn't have [the test] forced upon me, physically being put in my mouth.”

Due to her negative experience, Chloe stopped testing as soon as she was no longer required to. She felt her experience of being tested would have been better if she had more control over the process, such as being able to test herself, or having the tests administered in a quiet place, with only the person doing the test in the room with her.

Some contributors found PCR tests that were administered by professionals less comfortable than LFTs they used themselves. Self-led testing was preferable because they felt in control and could go at their own pace. Some contributors also described experiences where tests administered by professionals seemed less carefully administered, adding to their discomfort.

> “The home testing was better, because sometimes, when you went out and got the test done by people, they were very rough. I had one done [...] in hospital and she made my nose pour with blood.”
>
> – Person from a Roma ethnic background

> “One of the nurses was particularly malicious with the throat swab for the Covid test and kept redoing them, seemingly unnecessarily. I was tested positive on entry by another nurse, and [then] he redid that test three more times in the nine hours that I was there.”
>
> – Every Story Matters contributor

Impact on wellbeing and mental health

We also heard from contributors who spoke of avoiding testing because they were worried about a positive result and the implications of a Covid-19 diagnosis on their mental health.

> “I didn't have those tests [...] because I didn't go anywhere [...] I literally didn't leave my premises because I was too scared I would get sick, so I didn't have [a need for] any of those tests [...] if I found out I had Covid, I would get 10 times worse anxiety, so I never did it. I probably had Covid, because I was sick an awful lot of times with flu-like symptoms, but I just didn't want to face it.”
>
> – Person from a nomadic community

People we spoke to made a connection between a change in testing behaviour throughout the pandemic and the impact it could have on people’s mental health. One example was that frequent testing early in the pandemic was linked to feelings of anxiety, and reducing the amount of testing done over time helped to alleviate this.

> In the beginning [...] I was maybe doing them a bit too much, but [...] when not even the government [...and other] people just generally weren't taking it seriously anymore, I [...] started to give up myself, and started to do less tests. [...] I [had] started to get a bit obsessed [...] with doing the tests because I got so anxious, and that [later shift] was also me [...] forcing myself to do less tests [...] to calm my own anxieties down as well. As I mentioned, I have longstanding mental health issues, my anxiety [and] depression, so it was quite hard to manage in that respect."
>
> – Carer

Receiving a notification of a contact was described as a stressful and unpleasant experience by many contributors. The unpleasant aspects of the experience included the alarm itself (going off on the phone via the app), the stress of not knowing where the contact might have been made, or who with, and the wait to see if they had Covid-19 – via a test or waiting to see if symptoms started.

> I think it was quite scary for people getting a message saying you've been in contact with someone. Depending on how the person is, if it's someone who already had some kind of anxiety, it would have made them feel 100 times worse."
>
> – Every Story Matters contributor

Contributors described a range of impacts on their mental health due to following self-isolation guidelines. These included worry, loneliness, stress and low mood. They felt the requirements of self-isolation were strenuous which sometimes had a lasting negative effect on their mental health.

> [I] couldn't get outside, couldn't go for a walk; it [self-isolation] affected my mental health, my health. I thought things would get better, but it didn't; it took a long time."
>
> – Deaf person

> I self-isolated for myself for 11 days. Isolation is really hard compared to anything, you know. Taking tests is even okay. You know, going to hospital is okay, but isolating yourself away from everybody is not okay. Because, you know, you can't live without talking to, without looking at anybody or without talking."
>
> – Domestic abuse survivor

We also heard experiences from people with pre-existing mental health conditions whose conditions worsened as a result of self-isolation. Some of these contributors described feeling anxious due to long periods of lockdown and that these feelings were exacerbated by self-isolation requirements. Self-isolation in these instances often felt like an intensification of lockdown restrictions for them.

> With my mental health, it, for a while after I remember not wanting to go out and just staying home. Having this social anxiety, which I've always struggled with anxiety, but it [self-isolation] just made it ten times worse.”
>
> – Person living in crowded or cramped accommodation

Several periods of self-isolation, and especially close together, also had a negative impact on some contributors’ mental health. Some told us how staying indoors and away from people repeatedly made them feel increasingly anxious and less inclined to go outside after their self-isolation periods had ended.

> It was hard to stay indoors for that length of time, especially on the site. You had to wait in, because you just couldn't go out. Do you know what I mean? You couldn't go out and mix with people, because you're in that situation where you've been in contact with Covid. I could say, 'Well, no,' and go on, but I found it very hard [mentally] to [self-]isolate, because we had to [self-]isolate a couple of times.”
>
> – Person from a Roma ethnic background

Some contributors found mental health support which helped them to cope with self-isolation. These services had typically existed before the pandemic among the contributors we spoke to.

> But yes, you go through all the feelings of being unwell and it can be a little bit scary, I suppose. Because I was completely on my own. But I think if I wasn't in active therapy at the time I would've really struggled mentally and just keeping myself going every day. So, I was very, very lucky.”
>
> – Person who accessed mental health support

> And on our island, we've got, what's called, a development trust. You didn't even have to ask [for help]. So, we actually have a health and wellbeing coordinator on the island, whose job it is to know who is maybe, you know, not doing so great, or is a bit isolated… And the ethos was very much, 'If anyone is struggling, let us know. There's folk there to help.”
>
> – Person living with Long Covid

Ivanka’s story

Ivanka shared her experience of self-isolating for an extended time due to her and others in her household testing positive for Covid-19, as well as coming into contact with Covid-19 in her workplace.

Ivanka is 27 years old and lived with her partner and a friend during the pandemic. Both her and her partner were care workers and travelled to different care homes as part of their job in an agency.

Over the course of two months, she was told to self-isolate on several occasions due to hers or others’ positive Covid-19 results. She was informed of these results through either her work register or the contact tracing app.

She shared how difficult it was having to stay inside for this extended self-isolation period. During this time, she was not paid and had to use her credit card to afford essentials. She also described how challenging it was to get a delivery regularly since other groups were being prioritised for this service.

> “With no income I had to rely on my credit card and I ended up racking up a bit of a credit card bill after that period of time that I had to work on paying for a couple of years afterwards because obviously with necessities and everything.”

Ivanka found the anxiety and stress due to self-isolation particularly difficult, despite accessing mental health support. She found this herself through a mental health organisation for young people. She explained that having professional help outside her partner and friend was helpful, however she explained that she still lives with anxiety.

> “Not even stepping outside for fresh air for almost two months you almost get-, we got anxious when it came time to leave. I remember on the final day that we were all cleared of things we were, kind of, just sitting in front of the door for half an hour and being like, 'So, do we step out now?' It definitely had a very negative impact on our mental health.

> “I think that was a big thing. We all got a little bit more easily triggered, a lot more anxious and I think the whole situation as a whole, I think us working in a profession where we were met with a lot of exposure to the virus, but also a lot of death that came from the virus, it did leave quite a big trauma.”

Living arrangements

We heard examples of people's living situations which acted as a barrier to following self-isolation rules at all or fully.

Larger families or households described self-isolating as difficult when living in small spaces. We heard examples of partitions to help contributors or those they lived with to self-isolate safely. Where contributors had access to several bedrooms or rooms, they shared that self-isolating was less of a strain. They thought this made it easier to complete full self-isolation periods.

> “I can't [self-]isolate at home anyway because everyone's literally on top of each other. I'm almost like, 'If I'm not going out, why do I need to do this?'… It wasn't practical for everybody. It would depend if you had, we're in a small flat, some people might have a bigger house and, I guess, the guidelines that were given out didn't suit everyone and their situation.”
>
> – Person living in crowded or cramped accommodation

For contributors living in crowded, cramped and shared accommodation it was not always possible to fully self-isolate because of their living conditions. Some spoke of how they had been worried and anxious about living in a small space with other people because of the risk of virus transmission.

> “We all, we could never self-isolate anyway because we were sharing a room. Yes, we all got it, I think all of us did.”
>
> – Person living in crowded or cramped accommodation

> “There were some times when I got Covid-19 and [was] stuck in the house and thinking, ‘That's it, we're going to die, and I'm going to get everyone in the house sick with me.’ Then you would start blaming the thing on yourself for getting the sickness in the house, where I was thinking, ‘I'm going to give him Covid-19, I'm going to give him Covid-19.’”
>
> – Person living in crowded or cramped accommodation

Angus’ story

Angus is a transgender man and a domestic abuse survivor. He was in his early twenties during the pandemic when he became homeless. He shared with us how being homeless during this time affected how he was able to engage with the test, trace and isolate system. Angus explained how testing positive for Covid-19 made him feel very anxious as he had nowhere to self-isolate comfortably.

> “Before I had stable housing, like, to self-isolate meant being very unprepared for having food in or having enough resources for everybody to be comfortable to self-isolate. And then, in later periods…it meant relying on food deliveries or Uber Eats situations and having them left outside the door and things. But it was still impossible to do it, I think, in a fully efficient way where you were fully isolated because of, I guess, my demographic of very low income, regularly unstably-housed friends, it was very impossible for it to be fully isolated.”

At one stage, while he was waiting for housing, he was staying with a partner in a crowded two-bedroom flat when a flatmate tested positive for the virus. This meant everyone in the flat had to self-isolate until they tested negative. However, this was not possible to do safely given the number of people living there.

Angus contracted the virus multiple times over the pandemic. He now lives with Long Covid.

> “It was something that I think people were emotionally adverse to finding out [Covid test results], and when they would find out because they needed to find out, then would have, like, negative consequences instead of just that being at home in a safe environment.”

Lack of social support and incentive

Where contributors told us they did not have friends and family close by, they sometimes struggled with self-isolation. They felt abandoned without these networks and did not always know where to seek support during these times. Contributors also shared that being left alone while ill could be lonely, even when loved ones dropped off essentials.

> “ I have dementia, right? And to me, it was my worst nightmare. It was. And then, because at the time I had Covid myself and there was no one checking on me, and I was really ill. Really, really ill for about two weeks, and in the house myself. You know, on my own, and nobody could come into me.”
>
> – Every Story Matters contributor

Contributors with accessibility needs were especially impacted by the closure or reduced services of community organisations, including those who were digitally excluded and people with learning disabilities or difficulties. They found it challenging to organise online deliveries while self-isolating due to a decrease in staff levels. For example, some contributors had no one to help them organise online food deliveries from supermarkets. This made it more difficult to access the essentials while self-isolating.

> “His [food] box was hit and miss. Sometimes he'd have one a week, and the following week he might not have any, but then the following week he might get two boxes delivered. So, I think he wouldn't have survived, food-wise.”
>
> – Clinically vulnerable person

Though people were encouraged to record Covid-19 home test results via the apps or online, it was unregulated, so people could choose whether or not to report a positive test, which meant they were not held accountable by a formal system to self-isolate. This led some contributors to question the value of testing in the first place.

> “You're only proving it to yourself with the LFTs [whereas with] a PCR, [if] you test positive, [...] people know that you've got Covid and there's almost that pressure to do the right thing [...] because now you've got that [test result] on your NHS records. Whereas an LFT, I could have Covid, like I did, and go to a concert.”
>
> – Every Story Matter contributor

5 The experiences of parents, those who supported others and survivors of domestic abuse

This chapter explores the specific experiences shared by parents, those who supported others and those living in abusive situations around testing and self-isolation.

The experiences of parents with young children

Parents described testing their children as challenging and parents of children with additional needs found it particularly difficult. Some parents we heard from recalled having to physically restrain their children to test them and described the experience as distressing. Difficulties testing sometimes led to concerns about the impact on the child, as well as test results being inaccurate.

> I tried doing my daughter two or three times, and she just couldn't do it. […] She'd gag. And then you'd send that away and it would come back […] clear. But you'd know to look at her, […] she was sick. She'd lost all taste, she'd no smell. She was sick with the flu for weeks […] and you think, 'She has it. But I can't get this test to prove that she just has it'."
>
> – Person from a Roma ethnic background

> For the kids, it was a nightmare! Chasing them round, pinning them down, bribing them. What else can you do, though?"
>
> – Person with a long-term physical health condition

Parents of children with autism, ADHD and other complex needs found it particularly difficult to test their children. This was due to increased sensory sensitivities and, as was the case for children more generally, difficulty explaining why a test was needed and reasoning with the child or young person.

> “Can you imagine encouraging an autistic child to be swabbed for a Covid test? It was the worst time of my life.”
>
> – Every Story Matter contributor

Grace’s story

Grace lives with her husband and son, who was under five years old at the start of the pandemic. Her son has since been diagnosed with autism and is awaiting assessment for ADHD. He struggled with lots of elements of the pandemic, including remote learning, lack of time spent outside and the changes to his normal routine.

Grace was keen for her family to follow government guidance and test regularly as they had formed a bubble with her older mother. However, testing Grace’s son proved very difficult, due to sensory sensitivities associated with his autism. Her son quickly became distressed when she took him to be tested at PCR test centres. Difficulty testing her son contributed to a feeling of immense stress for Grace.

> “Because of his autism-related sensory sensitivities, he found nose swabs very distressing and throat swabs completely unbearable - we had to hold him down screaming in the car at testing stations while he vomited onto the swabs in severe distress.”

Grace and her husband have made adjustments to support their son’s neurodivergence and they now feel they are in “a much better place”.

Parents expressed concerns about the appropriateness of testing very young children due to the distress and discomfort that it caused. Difficulties testing young children meant some parents made the decision to self-isolate rather than continue to test. There was also some confusion about whether testing young children was required after a period of self-isolation.

> “It got to a point where I stopped testing the children because it would just be easier to [self-]isolate, to stay at home and stay away from people for seven days, than [...] to pin my kids down in a headlock and test them.”
>
> – Every Story Matters contributor

> “There was one point where my son went back to school and they were [...] required to [test...] every day. And I did just think, 'I don't know how good I feel about him putting that stuff up his nose every day.' [...] it was just the discomfort [...] combined with I'm not sure how accurate this is... [...] I [...] thought, [...] ‘you're all healthy young kids really, back at school. It's bad enough you wearing masks and all the rest of it’, so I think probably I was a bit more lax over making him do that every day.”
>
> – Single parent

Parents with young children also found self-isolation difficult for practical reasons. These contributors raised concerns about what would have happened to their children if both parents became ill with the virus. Other parents shared that they needed to self-isolate with young children in their bedrooms to keep the rest of the family safe.

> “Yes, obviously the little girl was only about nine, so she couldn't [self-]isolate in her room by herself, that's why her mother volunteered. It wasn't that bad, I don't think. My wife didn't suffer any symptoms, so she didn't get it the second time, she just kept my daughter occupied for the week playing games and watching TV and just keeping an eye on her, so that was just one room isolated.”
>
> – Clinically vulnerable person

Parents with young children spoke about needing to approach self-isolation in a pragmatic way. They told us about managing it carefully while trying to balance the needs of their child as well as the rest of the family. They shared that sometimes following self-isolation guidelines was not possible in order to provide care, and how they used protective measures instead. There were contributors who told us that having no support from family or formal support services increased their likelihood of not following self-isolation rules to care for their children.

> “But the thing is, my children could [self-]isolate and stay in their room and I could take their food up to them, but when it was my turn, you know, the children would insist, but then there's a responsibility on me as the head of the family to make sure everything's working. So, I couldn't [self-]isolate that often.”
>
> – Every Story Matters contributor

There were also emotional reasons behind why parents with young children found self-isolation challenging. Some contributors told us how anxious and helpless they felt during this time, especially when they had no support from another parent or formal services and they fell ill with the virus. This situation was made more difficult when people had multiple children to take care of.

> “I just felt really lonely. I think I cried most of the time when I had to [self-] isolate. You know, because I was unwell and I had to look after seven children because no one could come in to help me… Like I said, I felt very anxious, I felt depressed.”
>
> – Person who accessed mental health support

Other parents with young children told us how they received support from local organisations like churches and charities when they contracted the virus. They shared how these organisations provided food deliveries which enabled them as parents to fully self-isolate. Some explained that without this help, cooking and preparing food for children would not have been possible, otherwise forcing parents to deviate from the guidelines and avoid self-isolating.

> “My church were amazing. They were coming with cooked food, and there were loads of restaurants giving […] cooked food, […] so my church were amazing, because they would just come and drop them off at the door, son would pick them up, so, for that, I was very, very grateful and thankful for them… Even though you would order online, they [groceries] still have to be cooked and you can't be buying takeaway every day. So, without the help of my church and neighbours, no, definitely not [self-isolation wouldn’t have been possible].”
>
> – Person experiencing financial hardship

> “We had a couple of food parcels from a local charity, because I was struggling with cooking for the kids…. So, we got frozen meals that had been personally cooked by somebody locally… That was the most helpful thing that I've ever experienced, because having three small children and being pregnant, I was just like, cooking was hell, it was awful. That made a big difference to our household.
>
> – Person with a long-term physical health condition

The experiences of those who supported others to test

Some contributors described needing to support others to test, either in a professional capacity or to assist family members at home.

Assisting disabled people or neurodivergent people to test

Some family members who supported disabled people and neurodivergent people to test described their relatives not always understanding why they needed to test. In some cases, those being tested would resist testing attempts, making this more difficult. This was distressing for both the person being tested and those trying to administer the test.

> When it came to my brothers with the disabilities, it was like, […] 'Why are you putting this up my nose? I don't want it'. They would not allow me to do it. That was really horrendous, trying to [administer a test…] It was very difficult [… but] they're adults, [so] if they refuse […] I can't push it."
>
> – Family member or supporter of someone required to self-isolate

> My brothers couldn't do it on their own […] they'd just throw […] the test [down, and] then it's dirty, isn't it? So, if I didn't get it correct […] there was a lot of wastage."
>
> – Family member or supporter of someone required to self-isolate

Some contributors felt that testing could exacerbate existing health conditions. One example was where tests appeared to trigger epileptic seizures. To avoid this, those contributors tested the other person less often but increased their own testing to ensure they posed a lower risk of infection.

Assisting older people to test

Contributors 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.

> My mother has got arthritis. Peeling those little things off was really hard, so it would've been good to maybe have some available for people with physical disabilities to be able to actually use.”
>
> – Carer

Family members and healthcare professionals 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.

> I always found it straightforward on myself, but patients could be a bit of an issue, especially elderly patients with dementia [...] They really didn't understand what you were doing and why.”
>
> – Person working in health and social care

The experiences of survivors of domestic abuse

We heard from contributors with experiences of domestic abuse and who were living with an abusive partner during the pandemic. These contributors expressed how they felt pressured by their partner to follow or not follow self-isolation guidelines in the same way their partner was. It was also reported that abusive partners generally did not consider the consequences of not adhering to guidelines (where relevant). This sometimes put children in the household at risk, including those who were also clinically vulnerable, along with others who came into contact with them outside the home.

> For me it was even harder because I was living with an abusive partner that was very selfish and didn't abide by the rules, didn't think they applied to him. And so, I was trying to keep my son safe, trying to battle with him, it was just a really hard time.”
>
> – Domestic abuse survivor

Millie’s story

Millie shared with us her experiences of conflict with her abusive partner when trying to adhere to self-isolation guidelines. She found it challenging to follow the rules when she felt she was constantly arguing with her partner on whether they should adhere to them or the extent they should. She believed the “right thing to do” was to follow them while he did not think this was always the case.

> “It was frustrating because it [debating self-isolation guidelines with her partner] caused a lot of arguments. He said I was being a sheep and just following everybody, [that] it was ridiculous, it wasn't real, it was just the government making up stuff to control us… Yes, it [arguing about how to adhere to the guidelines] caused a lot of conflict, definitely.”

Millie was also afraid her son, who was clinically vulnerable, would contract Covid-19 by the household not adhering to the self-isolation guidelines. She told us her partner preferred to prioritise his wellbeing over the family’s which she found distressing.

> “He [her son] should have been in that at-risk category. But his dad convinced me that he wasn't. He was, like, 'Well, he's not because he's not been diagnosed with asthma, he's not got a diagnosis of asthma.' I'm, like, 'Yes, but they're treating him for asthma, he's got all the side effects of asthma. They've just said they can't legally diagnose him because he's got to be older.' [Millie’s partner said] - 'Well, then, he's not got asthma, so he's not at-risk category.' I'm, like, 'Well, he is, really.' So, I tried to take those extra precautions and extra isolate him. Just felt his dad put him at risk. It's [partner’s approach to adhering to guidelines], like, 'Well, I can't just sit at home,' I was, 'Well, the whole country is sitting at home,' 'Well, I [partner] can't do that, I've got to have my time and my space.'”

The periods of self-isolation which did happen caused further arguments between the couple since they had to remain together in the same house. This made the household dynamic feel more stressful for Millie.

> “It [self-isolation] was lonely and it caused a lot more arguments. Even more than before. It was hard. When we did have to [self-]isolate, he did [self-]isolate sometimes. But then it just caused more arguments because we were just on top of each other.”

Millie remembered an instance where she had been contacted by the contact tracing app about having come in close-contact with a person who had tested positive for the virus. However, she felt her partner had pressured her not to not self-isolate, even though the guidelines recommended it.

> I'd be pressured to, [partner reported speech] 'Oh, don't be ridiculous, it's just them tracking you. You don't need to [self-]isolate, you haven't been in contact. It's probably just a dude that we walked past for three seconds the other day.' So, there were times when I was required to [self-]isolate technically, but we didn't because he said not to."

Millie shared that this type of controlling behaviour continued throughout the pandemic which made trying to follow self-isolation very difficult and stressful. She especially worried about her son's wellbeing and the risk to him.

People working to support domestic abuse survivors or those at risk of abuse, living at home, also remembered how distressing they found situations where they knew affected people were self-isolating.

> I regret nothing about my actions during that time, but I feel nothing but disdain and at times visceral hatred to the people allegedly in charge of the country who did their own thing whilst I was driving round my area to check on women who were now trapped with abusive men in their homes, conducting meetings from a phone or laptop in a carpark because my offices had been locked down and I could not make it back to my house between visits and emergencies, whilst I was ferrying emergency food parcels to families who were self-isolating with no family support around to help them, whilst I was trying to make sure children were not being hurt and abused in their homes."
>
> – Every Story Matters contributor

6 Suggested improvements for the future

This chapter describes contributors’ suggestions for improving the test, trace and isolation system. It starts with a discussion of contributors' reflections on improvements to the system as a whole, before separately addressing suggestions for how testing, contact tracing and self-isolation could be improved in a future pandemic.

Contributors recognised that the test, trace, and isolate system as a whole was put in place rapidly and under exceptional circumstances. Many understood the importance of it, and it provided some reassurance about controlling the spread of the virus as they came out of lockdown.

> It was a way for people to be able to go out. It enabled people to go out, you know, 'sign in and you can have food in this restaurant'. It meant that if you did come into contact, you could [self-]isolate, and it almost gave you that urge to go, 'Actually, I should probably do a test.’”
>
> – Every Story Matters contributor

However, there were a number of improvements suggested, which are explored within this chapter.

Information and Communication

Contributors desired greater consistency and clarity in government policies and messaging. Contributors said they found it difficult to keep up with guidelines, which many felt were continuously changing (ie around self-isolation requirements and timeframes). They also suggested that the same guidance and information across the devolved nations would have been helpful – especially for people on the borders who had to adhere to both sets of rules, for example, (eg one set of rules for where they lived, one set of rules for where they worked).

> I think you have to have a standard over the UK. You can't have something different in [each UK country]. When you live so close to a border, you could be working in England and living in Wales, or vice versa, and you've got two different guidelines."
>
> – Every Story Matters contributor

> The government guidance/information was also very helpful. The criticisms, often based on political views, was unhelpful. Constant comparisons with Scotland or Europe or wherever were not useful - stats can be used in various misleading ways."
>
> – Every Story Matters contributor

In Scotland, some contributors were positive about government communication. This was the case for general updates about Covid-19 but also the whole test, trace and isolate system. Clear and regular messaging from officials helped to build confidence in people that they were doing the right thing.

> I think, say that communication was vital but I actually think in Scotland, the communication was good. The First Minister was coming on television every single day. Medical officers were speaking every single day. So, I do think that people couldn't really be expecting anything more than that and it was a unique situation."
>
> – Community member who supported people to self-isolate

> In Scotland the Government were good at giving the information and I really admired [them for putting] Scotland and its people first."
>
> – Every Story Matters contributor

People we heard from also wanted better prevention of misinformation about the test, trace and isolate system as this was viewed to have influenced behaviour.

> There was a lot of disinformation and misinformation concerning the NHS Covid app for smart phones. I was quite happy to use the app because I thought it was a useful tool but a lot of people I know either didn't download it or removed it from their smart phones because they thought the government was monitoring their movements and there was some issue with the app development."
>
> – Every Story Matters contributor

We heard several suggestions about how information could have been easier to understand so more people would use the contact tracing system. This included information available in different languages relevant to local contexts via a call centre with translators, and letters through doors to explain the guidance. Disabled people suggested that there could have been more use of videos, visuals and easy read formats (for example within test kits). Contributors identifying as Deaf also suggested providing information in Sign Language, to help this audience better understand what was required of them to adhere with the system.

> When you arrived at the test centre, you had to do the test in your car but there was only space to put the window down a little bit. I think a benefit would have been maybe having a QR code. So, I could have used my phone and got all of those instructions on how to do the test from a QR code in Sign Language, that would have been amazing."
>
> – Deaf person

Community leaders reflected that they could have played a greater role in disseminating information about the test, trace and isolate system to their communities, and supporting adherence. This was because some groups found the information about the test, trace and isolate system difficult to understand. Instead, they often relied more on word-of-mouth information being spread in their community. Community leaders suggested they would have valued more discussion and materials about how the system worked so that they could then distribute this information accurately and adapt it appropriately for their local communities. Some contributors whose first language was not English, and those from Gypsy and Traveller communities, said they would have valued more practical in-person support.

> We're isolated, and none of us are literate, we can't read or write, no one actually came out and explained to us, like a health nurse, or someone from the health profession, came out and had the talk with us, or a meeting, just a distant one. We didn't understand."
>
> – Person from a Roma ethnic background

> Hands on….support that, yes, this is what you do, this is what you-, in a leaflet, how you do the lateral flow test. All those things, if somebody came and showed this is what you do."
>
> – Person whose first language is not English

Accessibility for the people who are digitally excluded

A key improvement contributors suggested was greater accessibility and inclusivity for older people and digitally excluded. They perceived that many people were excluded from using the app and online versions (of the tracing system/ of test booking system) due to lack of skills or access to digital technology. They would have liked to see more options available such as telephone call centres to book appointments, non-tech-based systems to deliver contact tracing and more of a hyper local response particularly in remote or rural areas.

> “I think the only thing I would say is just kind of, make it a bit more accessible for the elderly. I don't know how they'd go about that. I think a lot of it is obviously going to be smart phone related and app related.”
>
> – Every Story Matters contributor

Enforcement and Adherence

Contributors reflected on how they would have liked to see a greater level of public compliance with the test, trace and isolate system to feel reassured that it was working well. Some recognised that this was a difficult thing to achieve and could be dependent on the extent to which people felt connected in their community as well as their sense of responsibility towards each other – and views on how the test, trace and isolate system could have been better enforced were mixed.

We heard from some contributors who suggested stricter enforcement and penalties for non-compliance, such as greater policing, higher fines, and prison sentences. However, there was also a recognition that higher penalties would have been difficult to enact, for example recognising that prisons were already overpopulated and people may not be able to pay higher fines, and would likely be ineffective as a result.

> “If the fines were really high, people would be more inclined to obey more and so, enforcement... Apps with trace and contact were all there, but how was it really enforced? Who [was] really enforcing those rules - and what were the penalties?”
>
> –Person working with children

There were also suggestions for exploring incentives to improve adherence rather than imposing penalties for not participating. Typically, suggestions focused on financial incentives.

> …if you're giving them an incentive to follow the rule, then they're going to be more likely to do it…if you're offering the right incentive, I think you can get the right result."
>
> – Carer

A few contributors also suggested that there could have been greater efforts to educate the public on the need for the test, trace and isolate system so there was greater buy-in to the system which they felt would have meant more people would have used it.

> It's really educating them, just remind people, 'Look, this is what's happening.' Like, nursing homes and things, you could see it on the television. You must [self-]isolate because you're dealing with people's lives. So, it would be very important to adhere to all the rules, making the rules, results, and prosecution so trying to put the fear into people with that."
>
> – Person who accessed mental health support

Improvements to testing

Contributors generally felt that testing processes worked well. The widely available and free tests gave weight to the seriousness of Covid-19 and were valued.

Improvements to the testing element of the system focused on making the tests even more widely available and easy to access. One of their suggestions – for tests to be delivered to home – was already available during the pandemic. This indicates there could have been more availability, or promotion of home-delivery of tests to people. Contributors also suggested that establishing smaller test centres in more locations, and therefore closer to home so people could travel shorter distances to get a test would have been helpful.

Many contributors found the instructions for testing easy to understand. However, there were also suggestions for how they could be improved: for example, by using and promoting photo and video instructions to explain how to administer both PCR tests and LFTs. Those in the Deaf community and people who didn't speak English well felt this would improve accessibility.

Improvements to contact tracing

When reflecting on contact tracing, many contributors told us that the idea was good in principle, and the system was straightforward – particularly for those who were comfortable with using apps and webpages. However, contributors generally felt that in practice the system did not work well. This was largely because of a perception of poor adherence from others, their own non-compliance, and the flaws in the system they experienced (discussed earlier).

> “What's the point of 10% of the population having the app and giving the right telephone number and everything and being told to [self-]isolate, when maybe 90% of people aren't doing that, so it's either all in or all out. It becomes a bit of a nonsense otherwise, for me.”
>
> – Every Story Matters contributor

Most suggestions for improvements focused on ways to ensure the system was more specific to individual cases. For example, contributors wanted more clarity on what a direct and indirect contact was so they could take action accordingly. This could include rapid and accurate information about the time and location of a contact that people could link directly to where they had been and who they had been with. They felt that this would encourage more trust in the system.

> “Maybe if it was a system that had pathways. So, you basically popped in your details, what date you had a positive test and whatever. And it worked out for you. It was more specific to your case as opposed to just being blanket information they were just giving out there and open to misinterpretation.”
>
> – Person working in health and social care

There were also some suggestions for more personalised guidance provided with a notification of contact. For example, providing a specific date of when self-isolation should stop, or the guidance considering their vaccination status. Another example of this personalised contact was having a way to identify front line workers, so they are not constantly being notified.

> “Let's say you've had the app. You've been unwell, you've had a positive test. Then the app will then tell you, 'Okay, you need to [self-]isolate up until this amount of time and test again on this date, and this information is specific to you and you only.' Rather than it being a bit hit and miss as to when the dates correspond.”
>
> – Person working in health and social care

Other suggestions included being able to choose contact preferences, so that people could opt out of cold calls, for example.

Improvements to self-isolation

Overall, the isolation part of the system was viewed by contributors as necessary to limit the spread of the virus. Improvements to self-isolation primarily focused on different ways of providing people who are self-isolating with support.

A top priority for many contributors was supporting people who were self-isolating with the impacts it was having on their mental health and anxiety. Many were not able to provide specific examples of what improvements could be made around mental health support, but simply would have liked to see more support especially for vulnerable individuals and those living alone, to make this period more manageable. Those who did make suggestions said that improving access to online therapy or checking in with people (e.g. over the phone) as they self-isolated to help with loneliness could have helped. Drawing on community-based support to reach out to people self-isolating was one way contributors suggested this could have been achieved.

> “I think if a situation like that ever repeated itself, knock on wood that it doesn't, but if it does there should be more priority on mental health, I believe, because I think not just for myself but from what I understand mental health was at the all time low across the different ages. There weren't enough resources.”
>
> – Person whose first language is not English

Some contributors also would have liked better financial assistance for individuals who needed it during self-isolation. This included financial assistance to people who could not work while self-isolating and did not get sick-pay from their employers.

> “I suppose that if you did have to [self-]isolate, you would still get paid, rather than - there's an awful lot of people in industry that don't have sick pay, so if you are having to [self-]isolate for whatever reason, they just weren't paid for two weeks.”
>
> – Carer

Contributors also suggested that the promotion of information about what financial support is available and how to access this support could have been better – this was especially the case for contributors whose first language was not English.

> For me, [what could be improved] was more information, like proactive information, as you mention, the help with food, I didn't really know much and the support for financial support, I knew some people had but I never understood, never knew how they get it.”
>
> – Person whose first language is not English

7 Appendix

Module 7 provisional scope

The provisional scope of Module 7 was used to guide how we listened to people and analysed their stories. The scope for the module is outlined below and can also be found on the UK Covid-19 Inquiry website here.

This module will look at, and make recommendations on, the approach to testing, tracing and isolation adopted during the pandemic in England, Wales, Scotland and Northern Ireland from January 2020 until 28 June 2022. This includes Test and Protect (Scotland), Test and Trace (England), Test, Trace, Protect (Wales) and Test, Trace and Protect (Northern Ireland).

The module will consider the policies and strategies developed and deployed to support the test, trace and isolate system by the UK government and the devolved administrations. It will consider the decisions made by key bodies, other options or technologies that were available and factors that may have influenced public compliance.

In particular, this module will examine:

1. The test, trace and isolate policies and strategies developed and deployed, taking into account modelling, capacity of the systems throughout the pandemic and the rationale, appropriateness and data available for the decisions of the UK and devolved administrations and wider border policy considerations.

2. The availability, use and effectiveness of different test, trace and isolate technologies, policies and strategies including lateral flow and PCR (polymerase chain reaction) tests, testing for variants, digital contact tracing and other testing techniques.

3. The structure of the test, trace and isolate system and the key bodies involved in decision making in the UK and devolved administrations. It will include the efficacy and impact of the models adopted, the use of the private sector and other institutions and the cost.

4. Enforcement of testing, tracing and isolation procedures and factors influencing compliance, such as the adequacy of and trust in messaging, financial and practical support to those required to self-isolate and the availability and use of data in decision making.

5. The preservation of infrastructure, capacity and research to improve and develop test, trace and isolate schemes for future pandemics.

How people shared their story with us

There are three different ways we collected people’s stories for Module 7:

Online form

Members of the public were invited to complete an **online form via the Inquiry’s website** (paper forms were also offered to contributors and added via the online form for analysis). This asked them to answer three broad, open-ended questions about their pandemic experience. These questions were:

- Tell us about your experience
- Tell us about the effect on you and people around you
- Tell us what you think could be learned

The form asked other demographic questions to collect background information about them (such as their age, gender and ethnicity). The responses to the online form are submitted anonymously.

By its nature, those who contributed to the online form were those who chose to do so, and they shared only what they were comfortable with.

For Module 7, we analysed 44,775 stories related to Covid-19 test, trace and isolate system. This included 36,879 stories from England, 3,665 from Scotland, 3,783 from Wales and 1,973 from Northern Ireland (contributors were able to select more than one UK nation in the online form, so the total will be higher than the number of responses received).

The responses were analysed through natural language processing (NLP), which uses machine learning to help organise the data in a meaningful way. A combination of algorithmic analysis and human review is then used to further explore the stories.

The NLP analysis identifies repeated language patterns within free-text data. It then groups this data into 'topics' based on terms or phrases commonly associated with that topic (for example, the language used in a sentence about anxiety might be very similar to that used when talking about depression, which is grouped into a topic on mental health). It is known as a 'bottom-up' approach to text analytics since it approaches the data with no preconceptions about the topics it contains, rather it allows topics to emerge based on the contents of the text.

Stories were selected for inclusion in the topic model in two ways. First all responses to each question were taken from the online form and blank data was removed. Second, responses were filtered based on their relevance to Module 7.

Stories were considered relevant if those who shared them had selected any of the below responses at the question 'What would you like to tell us about?':

- Living with Long Covid;
- Official government information, for example, advice on self-isolating at home
- Covid-19 testing and vaccinations;
- Health services, for example the NHS or HSCNI (Health and Social Care Northern Ireland), including GP surgeries;
- Care, for example, care homes or social care;
- Everyday life, for example, holidays, going out, shopping or sports;
- Mental health, for example, feeling sad, angry, anxious or stressed;
- Education, for example school or university;
- Having Covid-19; and
- Community, for example, neighbours or places of workshop.

Following the identification of relevant data, a topic model was run per question. This identified a total of 193 topics across all responses at Q1, 240 at Q2, and 221 at Q3. Since contributors could select multiple responses to the question 'What would you like to tell us about?' it was possible that responses selected for inclusion contained data not relevant to Module 7. For this reason, following the initial topic modelling the research team at Ipsos reviewed all topics for relevance and removed topics not relevant to Module 7 from the final stage of analysis. This left a total of 57, 131 and 57 topics per question respectively. This means that 57 topics sit within 13 overarching themes. To demonstrate these themes, they are described in Appendix 1 below.

Following the removal of topics not relevant to Module 7 a statistical factor analysis was conducted to map relationships between topics and group them based on terms commonly occurring next to or near each other. For example, topics talking about distrust of government, distrust of the media were automatically grouped into a factor about distrust of mainstream narratives. The factor analysis produced 17 overarching factors across the 57 topics relevant at Q1, 22 factors at Q2, and 17 factors at Q3.

Following the topic modelling and factor analysis a codeframe was generated based on those topics relevant to Module 7. This involved human review of the most common words and phrases, both in the full dataset and within each topic, to identify keywords and patterns that could be used to group stories into appropriate topics and sub-topics. In doing so, this provided the research team with a much more accurate quantification of the size and elements of topics, to inform the approach to analysis.

Since more people had shared their story with the Inquiry between the topic modelling and the keyword matching, an additional set of stories were provided to Ipsos for this latter stage of analysis. In total, 44,775 stories were included at this point, and these were no longer filtered by the question 'What would you like to tell us about?'. This decision was taken to ensure all relevant stories were captured, based on the words people used.

Researchers then reviewed the different topics relevant to Module 7 to explore the stories. These were brought together with stories shared with the Inquiry in other ways (described below) to include in this record.

The diagram below shows the themes included in the online form and the number of times each theme was mentioned by a contributor in their response. The size of each block represents the volume of responses related to the theme. Note that contributors may have mentioned multiple themes within their response and may therefore be counted a number of times.

Appendix 1: NLP themes- The diagram illustrates which overarching themes contributors mentioned in the online form and how often themes came up. Larger blocks mean a theme was mentioned by more contributors.

Shielding and Prevention
Missed events and celebrations
Social distancing
Affect education and learning
Healthcare professional experience

Poor government and institutions' performance
Negative emotions - Anger and Frustration
Covid symptoms
Mental health

Covid test experience
Employment and financial impact
Individual choice and social responsibility
Grocery shopping experience

Listening events

At the time of writing this record, the Every Story Matters team **travelled to 33 towns and cities across England, Wales, Scotland and Northern Ireland,** to give people the opportunity to share their pandemic experience in person in their local communities. Listening events were held in the following locations:

- Belfast
- Birmingham
- Blackpool
- Bournemouth
- Bradford
- Brighton
- Builth Wells
- Carlisle
- Cardiff
- Derry/ London Derry
- Edinburgh
- Enniskillen
- Exeter
- Folkestone
- Glasgow
- Inverness
- Ipswich
- Leicester
- Lisburn
- London
- Llandudno
- Luton
- Milton Keynes
- Middlesborough
- Newport
- Norwich
- Oban
- Paisley
- Preston
- Ruthin
- Skegness
- Stockton-on-Tees
- Wrexham

Virtual listening sessions were also held where that approach was preferred. This included bereaved families and individuals, people living with Long Covid, clinically vulnerable families, disabled people, youth groups, carers, refugees, people from ethnic minority backgrounds and healthcare professionals. Short summary reports for each event were written, shared with event participants and used to inform this document.

Targeted listening

A consortium of social research and community experts were commissioned by Every Story Matters to conduct in-depth interviews and discussion groups to understand the experiences of specific groups, namely those with particular health conditions which may have impacted their ability to self-isolate, including physical and mental health conditions and disabilities, as well as family members or supporters of those required to self-isolate, those with caring responsibilities, and members of community groups set up to help people to self-isolate. These interviews and discussion groups focused on the Key Lines of Enquiry (KLOEs) for Module 7, information on which can be found here. In total, 340 people across England (160), Scotland (71), Wales (57) and Northern Ireland (52) contributed in this way between July and October 2024. This includes 217 in-depth interviews with:

- People with particular health conditions which may have impacted their ability to test or self-isolate, including physical and mental health conditions and disabilities.
- Family members or supporters of those required to self-isolate (particularly those supporting older people, those with pre-existing health conditions, or those clinically vulnerable or shielding).
- People with caring responsibilities.
- People living in crowded or cramped accommodation.
- People from Gypsy, Roma and Traveller communities and Nomadic people.

All in-depth interviews and discussion groups were conducted by trained researchers who followed a discussion guide. Where needed, researchers would probe contributors for further information about their experience. Each interview lasted up to 60 minutes and all focus groups lasted up to 90 minutes. Interviews and discussion guides were recorded, transcribed and coded and analysed via human review to identify key themes relevant to the Module 7 Key Lines of Enquiry (KLOEs).

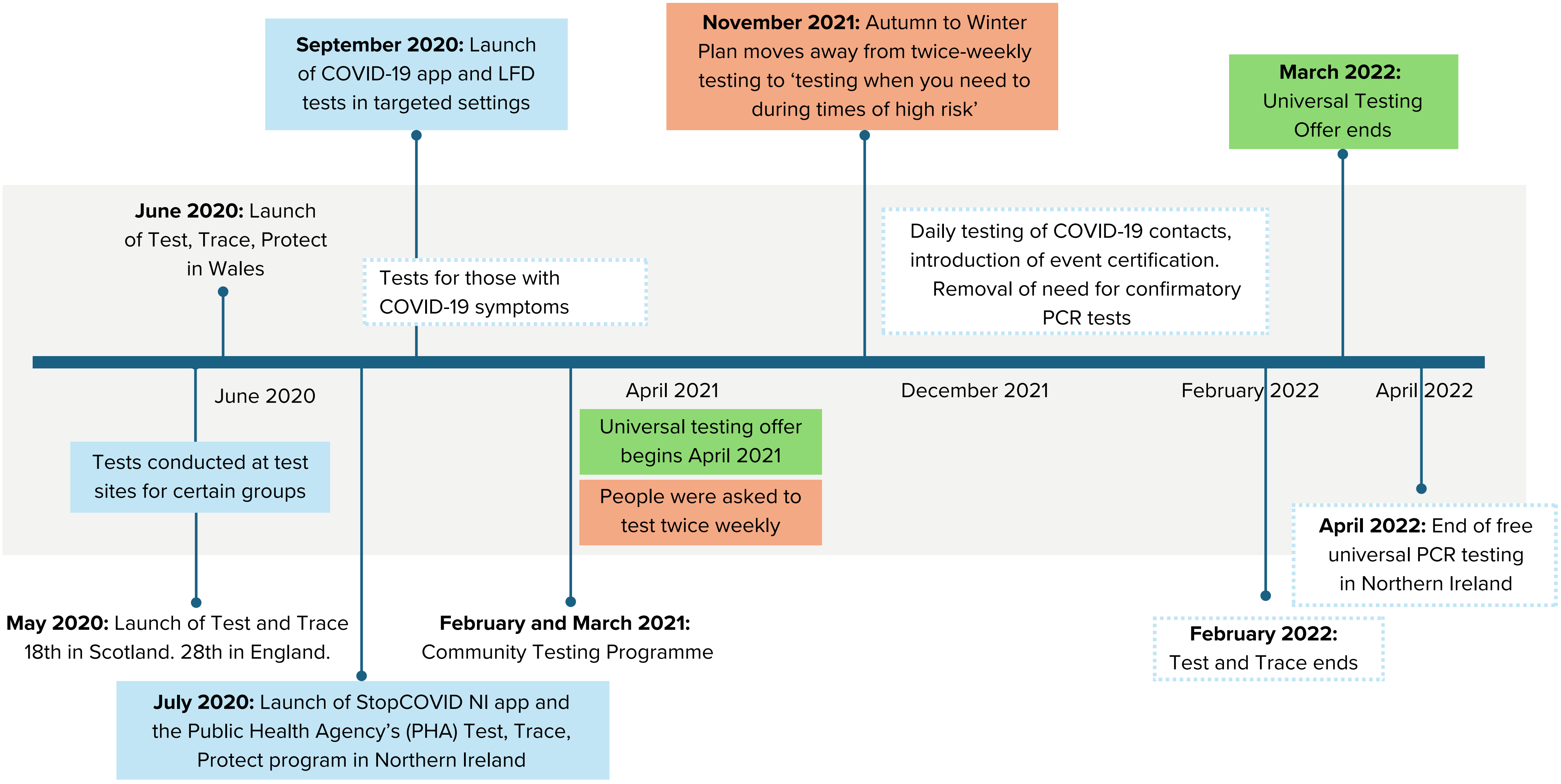
The tables below outline the number of interviews and discussion groups across the general public and with people who were disproportionately impacted by Covid-19 in relation to the Test, Trace and Isolate System.

Table 1: Covid-19 Test, Trace and Isolate System – targeted listening

Discussion groups	
General public	69 participants across 12 discussion groups
People working in health and social care settings during the pandemic	20 participants across 4 discussion groups, including 11 participants from ethnic minority groups
People working in education or childcare during the pandemic	22 participants across 4 discussion groups
In-depth interviews	
People with health conditions or disabilities	70
People with language and or literacy difficulties	33
People with caring responsibilities and those who supported and helped people to self-isolate	48
People from different households	66
Total	**340**

Appendix 2: Timeline stimulus used in discussion groups

Main Covid-19 testing events



June 2020

April 2021

December 2021

February 2022

April 2022

May 2020: Launch of Test and Trace 18th in Scotland. 28th in England.

Tests conducted at test sites for certain groups

June 2020: Launch of Test, Trace, Protect in Wales

July 2020: Launch of StopCOVID NI app and the Public Health Agency's (PHA) Test, Trace, Protect program in Northern Ireland

September 2020: Launch of COVID-19 app and LFD tests in targeted settings

Tests for those with COVID-19 symptoms

February and March 2021: Community Testing Programme

Universal testing offer begins April 2021

People were asked to test twice weekly

November 2021: Autumn to Winter Plan moves away from twice-weekly testing to 'testing when you need to during times of high risk'

Daily testing of COVID-19 contacts, introduction of event certification. Removal of need for confirmatory PCR tests

February 2022: Test and Trace ends

March 2022: Universal Testing Offer ends

April 2022: End of free universal PCR testing in Northern Ireland

This publication is available at covid19.public-inquiry.uk

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