



Every Story Matters: Vaccines and Therapeutics Record In Brief

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

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

How Every Story Matters fits into the Inquiry's work

The Inquiry is committed to understanding the full picture of how the pandemic impacted lives and communities right across the UK. [Everyone can share their experience of the Covid-19 pandemic with the Inquiry through Every Story Matters.](#)

Each story is anonymised, analysed and fed into module-specific Every Story Matters Records. These records are entered into evidence for the relevant module and are published on our website once they are introduced at the hearing.

This summary relates to the Every Story Matters Record for Module 4, which will examine and make recommendations on the development and use of vaccines and therapeutics during the Covid-19 pandemic. Future Every Story Matters records will focus on different aspects of life during the pandemic such as social care, financial support and children and young people.

The record makes reference to significant harm and some of the stories and themes included in this record may trigger upsetting memories and feelings. It may be helpful

to take a break if reading the record is upsetting. A list of supportive services is provided on the UK Covid-19 Inquiry website:

<https://covid19.public-inquiry.uk/support-whilst-engaging-with-the-inquiry/>

Introduction

The Every Story Matters Vaccines and Therapeutics Record brings together people's experiences shared with us:

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

Every Story Matters is neither a survey nor a comparative exercise. It cannot be representative of the entire experience of the UK, and nor was it designed to be. Its value lies in hearing a range of experiences, in capturing the themes that have been shared with us, quoting people's stories in their own words and, crucially, in ensuring people's experiences are part of the Inquiry's public record.

This summary sets out some of the experiences shared by people about vaccines and therapeutics during the Covid-19 pandemic. We heard about both the positive and, in some cases, negative consequences of Covid-19 vaccines including debilitating injury, and about how people found the process of accessing vaccines and therapeutics.

Public messaging and official guidance on Covid-19 vaccines

Some of the areas people told us about were:

- Most contributors could not remember when they first became aware of Covid-19 vaccines, but many told us they heard about them through television news or through discussion online such as on social media. Contributors expressed a range of emotions about the news. Some remembered a feeling of relief, especially many of those who were more at risk, such as the clinically vulnerable, the clinically extremely vulnerable, older people, and those who were caring for a vulnerable person. Some told us that the arrival of vaccines brought a sense of hope that they could soon return to 'normal' life.
- Other contributors were cautious or sceptical at the speed with which the vaccines had been developed.

- Opinions were mixed about the clarity of official guidance on Covid-19 vaccines. In most cases, the details about the prioritisation of the groups to receive a vaccine were seen as fairly clear. However, some felt that the guidance around vaccine safety and effectiveness was confusing and contributors were concerned about how adverse side effects of the vaccines were communicated. This was particularly important for those with pre-existing health conditions, who wanted to know how vaccines might interact with their condition.
- Some contributors described finding it difficult to get information in an accessible format. This included those with visual impairments or for whom English was not their first language. Others expressed concern about taking vaccines, on account of their religious faith.

Relevance of official guidance for those pregnant or breastfeeding

Some of the areas people told us about were:

- The initial advice for those who were pregnant or breastfeeding was not to have a vaccine but this official guidance was changed as further evidence emerged. Some felt that there had been inadequate explanation for the change in advice. Some contributors were concerned about the risks associated with receiving a vaccine during pregnancy, with many feeling that official guidance did not do enough to address their concerns.

Information on vaccines in the media

Some of the areas people told us about were:

- While some contributors trusted the information provided on Covid-19 vaccines in traditional media, others expressed concern that it too heavily focused on encouraging uptake in alignment with government messaging around Covid-19 vaccines more broadly. This, in turn, led to mistrust and to some people looking elsewhere for information. Some felt overwhelmed by the amount of information, leading them to 'switch off' from the news.

Information on vaccines on social media

Some of the areas people told us about were:

- Vaccine related information was seen by contributors across a range of social media platforms. We heard from many who said they did not trust what they saw on social media. These contributors stated that the content they saw was predominantly negative, especially after the vaccine rollout had started. Many of the stories they saw referred to adverse reactions to the vaccine. Other contributors described feeling more positive about what they saw on social media, perceiving that it provided them with access to information which they felt to be underreported by traditional media sources. However, even some of those who did not trust social media thought that the messages they saw may have influenced their perceptions of vaccines, and potentially shaped their decisions about whether or not to receive one.

Other sources of information

Some of the areas people told us about were:

- Healthcare professionals were an important source of information on the vaccine for many contributors, especially among those who were clinically vulnerable and clinically extremely vulnerable, pregnant or breastfeeding, as they felt the advice they received was tailored to their specific circumstances. Many contributors who were not at heightened risk from Covid-19 felt that it would have been helpful to have more information from their GP about the vaccine to help inform their decision. While many welcomed the information provided to them at vaccine centres, some felt this was received too late.
- Many contributors got information from support groups, faith communities and through personal research. Some found having a friend or family member who was a healthcare professional very helpful. Others spoke of tensions between individuals and generations, and pressures from family members about whether or not to have a vaccine.

Deciding whether or not to take a Covid-19 vaccine

Some of the areas people told us about were:

- For many contributors, whether or not to have a vaccine was a quick and straightforward decision, as they just assumed they would take it. We also heard from contributors who found the decision more difficult, personally weighing up the case for having a first dose. Some also found deciding whether to take a subsequent dose difficult.
- We heard from several contributors that they chose to take the vaccine because they saw no strong reason not to have it. Some made the decision to take a vaccine as they felt it would protect themselves and their loved ones from serious illness. The hope that it may bring about the end of lockdowns and allow a return to 'normal' life encouraged many to have the vaccine, along with trust in the judgement of authority figures. Others described feeling a more general pressure from society to be vaccinated.
- There were some divided opinions among contributors working in the health and social care sector, whose decision to take the vaccine was due to workplace requirements. Whilst some of these workers thought that taking a vaccine was important, since they believed it would help to protect them and the people they cared for, others disagreed with the pressure they were put under by their employers.
- Among contributors who were hesitant about receiving a vaccine or chose not to, many expressed concerns about their safety, often related to the speed of development and perceived lack of data relating to the long term health impacts of vaccines. Safety concerns were particularly important for those with long-term health conditions. This was also the case for some contributors from ethnic minority backgrounds who described how previous experiences of discrimination and racism had led them to distrust the government and the health system more broadly.

- Other contributors considered the vaccine unnecessary, perceiving themselves as low risk from Covid-19, while others had a lack of confidence in the vaccine's effectiveness after hearing about people who contracted Covid-19 after receiving the vaccine. A lack of trust in government or healthcare authorities, experiences or perceptions of racism in medical science, and cautious personal attitudes to medical interventions were responsible for others deciding not to have a vaccine.
- Typically, a person's decision whether to have a vaccine or not applied to subsequent doses, unless they experienced an adverse reaction with the first dose, although some contributors were less concerned about Covid-19 as time went on and chose to decline subsequent doses.

Experience of the vaccine rollout

Some of the areas people told us about were:

- Many contributors told us that the approach taken to prioritisation of the vaccines was fair and reasonable. We heard from many that due to the limited number of vaccines available, they agreed that those most at risk from Covid-19 should be prioritised. A few contributors did express concerns that by prioritising clinically vulnerable people, they might be more at risk if side-effects or long-term impacts were identified at a later date. Some contributors questioned why key workers and the household members of clinically vulnerable and clinically extremely vulnerable people were not prioritised sooner in the rollout process.
- The booking system was generally considered to be straightforward by contributors. However, those with limited English, who had visual impairment or who were in rural areas experienced accessibility issues. Booking vaccination appointments and using vaccination centres were also considered to be efficient for most, including adherence to social distancing at the centres. There were some challenges for those who did not speak English, who were less comfortable with or unable to use the online booking service, or those who had accessibility requirements for the centres. The precise type of vaccine was important to some contributors, especially after adverse reactions were raised in relation to the AstraZeneca vaccine. Some contributors received an earlier vaccine than they otherwise would have done, through using walk-in clinics, rather than waiting to be called.

Experiences after receiving the first dose of a Covid-19 vaccine

Some of the areas people told us about were:

- Contributors were often excited or hopeful following their first vaccination. For this group, being vaccinated was seen to symbolise progress. However, contributors occasionally mentioned a sense of regret or fear following their first vaccine. Often this was because they had felt 'forced' into taking a vaccine by societal pressure, or because it was required by their workplace or for travel and socialising.

- Contributors often shared how they experienced minor side effects as a result of vaccination. Typically, this included mild symptoms such as a sore arm or fever or aches, similar to having a cold, or the effects of the flu vaccine.
- In a few cases, contributors spoke about experiencing more severe adverse reactions. These reactions included blood clots, severe migraine and anaphylactic shock. Other contributors spent time in hospital and some have been left with ongoing debilitating symptoms. Some of those who experienced vaccine injury personally or through others also discussed the impact on their psychological and social wellbeing. Some gave examples of how the adverse effects on their health had resulted in financial difficulties.
- Some were left feeling frustrated and angry about how little was done to acknowledge and address the impact of their experiences. They felt that vaccine injuries were often underplayed, dismissed and ignored.

Awareness / understanding of eligibility for therapeutics for the clinically extremely vulnerable

Some of the areas people told us about were:

- Some of the clinically vulnerable people we heard from were aware of the therapeutic options available, and had typically heard of these treatments through the NHS, communications from the Chief Medical Officer, or local support groups.
- Experiences accessing therapeutics were mixed. Some found accessing treatments easy and straightforward. Some were contacted by Test and Trace while others proactively made contact with medical services via NHS 111, and were assessed for eligibility for treatment by these services. On receiving these therapeutics, contributors reported feeling that these treatments helped to reduce the severity of their symptoms and they were grateful to have received them.
- Some contributors were confused about their eligibility and experienced delays in starting treatment. In some cases, contributors understood themselves to be eligible, based on some information, but found contradictory information or advice from other sources. Others had heard of people with their condition being given treatment elsewhere, whilst they were being denied the same treatment. For these people, not only were they frustrated and angry about the inconsistent approach, but left afraid of what might happen to them as a result of not accessing these treatments.

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