

Some of the stories and themes included in this record include descriptions of death, near death experiences and significant physical and psychological harm. These may be distressing. 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 provided on the [UK Covid-19 Inquiry website](#).

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Foreword

This is the second Every Story Matters record for the UK Covid-19 Inquiry.

The subject of Covid-19 vaccines is, for some, an emotionally charged issue. There were those for whom the topic of coronavirus vaccination was the main topic they wished to raise with the Inquiry.

Contributions varied and, in summary, they included:

- those who felt immense relief that a vaccine, produced and distributed during the pandemic, meant life could potentially return to ‘normal’.
- those who remain concerned about how quickly it was developed and are still cautious, or even sceptical, about its benefits versus its risks.
- those who felt they had been given little choice during the pandemic about whether or not to take the vaccine and perceived social or work pressures to seek a vaccination.
- those who still feel glad they had chosen not to take a vaccine while others celebrated that they had.
- those who expressed the view that there had not been, and still was not, enough information about the vaccine and any potential side-effects, and this vacuum of information left space for rumours, conspiracy theories and ongoing worries.
- those who believe that taking the vaccine caused them injury or significant side effects, some of which are ongoing.

- those who felt their concerns had not been properly addressed by experts or the medical profession.

People held these differing views within families and groups of friends and their experiences of the vaccines also differed. This had sometimes caused relationship problems with the people closest to them.

The people who chose to share their experiences with us were usually motivated by strong feelings, often negative ones, on the subject of vaccines and therapeutics. We heard fewer stories and experiences from people who said they had taken the vaccine and were happy with their decision, presumably because they were less motivated to share their vaccine stories.

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.

We should emphasise, therefore, that this record does not represent the views of the Inquiry itself; rather it is a reflection of the stories and experiences that were shared with us on a topic that gives rise to strong and often divided opinion.

The Every Story Matters Team

Acknowledgements

We would first like to convey our deepest gratitude to all the bereaved families, friends, loved ones and those whose lives continue to be impacted by the pandemic. Thank you for sharing your experiences, or the stories of your loved ones, with the Inquiry.

The Every Story Matters team would also like to express its sincere appreciation to all the organisations listed below for helping us capture and understand the voice and vaccine experiences of members of their communities. Your help was invaluable to us reaching as many communities as possible. Thank you for arranging opportunities for the Every Story Matters team to hear the experiences of those you work with either in person in your communities, at your conferences, or online.

- Age UK
- Bereaved Families for Justice Cymru
- Clinically Vulnerable Families
- Covid19FamiliesUK
- Disability Action Northern Ireland
- Khidmat Centres Bradford / Young in Covid
- Mencap
- Muslim Women's Council
- Race Alliance Wales
- Royal College of Midwives
- Royal College of Nursing
- Royal National Institute of Blind People (RNIB)
- Scottish Covid Bereaved
- Scottish Vaccine Injury group
- Self-Directed Support Scotland
- Sewing2gether All Nations (refugee support group)
- SignHealth
- UKCVFamily

To the Bereaved, Children and Young Peoples', Equalities, Wales, Scotland and Northern Ireland forums, and Long Covid Advisory group, we truly value your insights, support and challenge on our work. Your input was instrumental in helping us shape this record.

Full record

1 Introduction

This document presents the stories shared with Every Story Matters related to Covid-19 vaccines and therapeutics.

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 has been analysed and the insights derived have been turned into themed documents for relevant modules. 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 vaccines and therapeutics for Covid-19 during the pandemic.

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 the impact on children and young people are explored in other modules and will be included in other Every Story Matters records.

How people shared their experiences

There are several different ways we have collected people's stories for Module 4. This includes:

- 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.

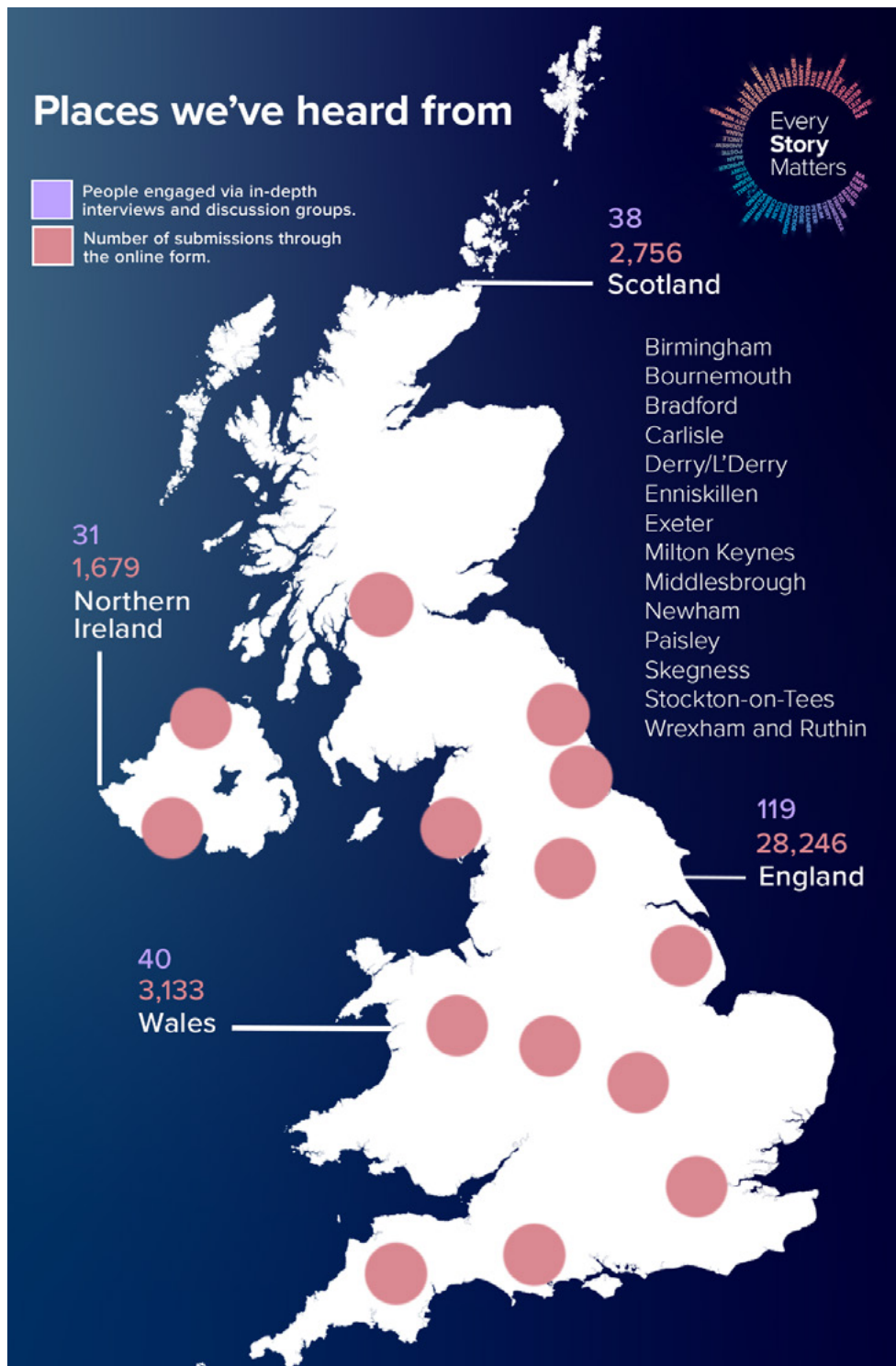
For Module 4, we analysed 34,441 stories. This included 28,246 stories from England, 2,756 from Scotland, 3,133 from Wales and 1,679 from Northern Ireland (contributors were able to select more than one UK nation in the online form, so the total will be higher than the number of responses received). 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 in order to explore the stories further.

- The Every Story Matters team went to **25 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. We worked with many charities and grassroots community groups to speak to those impacted by the pandemic in specific ways. This included bereaved families and individuals, people living with Long Covid, clinically vulnerable families, disabled people, people who are vaccine injured, youth groups, carers, refugees, people from ethnic minority backgrounds and healthcare professionals. Short summary reports for events with these groups were written, shared with event participants and used to inform this document.
- A consortium of social research and community professionals was commissioned by Every Story Matters to conduct **in-depth interviews** and **discussion groups** to understand the experiences of specific groups, based on what the module legal team wanted to understand. This included those with particular health concerns which may have impacted their vaccine decisions (such as those who were clinically vulnerable or clinically extremely vulnerable¹ and those who were pregnant or breastfeeding when offered a vaccine) and groups where there was relatively low uptake of the Covid-19 vaccines. This also included members of the public who had received at least one vaccine to understand experiences of the vaccine rollout. These interviews and discussion groups focused on the Key Lines of Enquiry (KLOEs) for Module 4, information on which can be found in the appendix to this document. In total, 228 people across England, Scotland, Wales and Northern Ireland contributed in this way between October 2023 and December 2023. All in-depth interviews and discussion groups were recorded, transcribed, coded, and analysed to identify key themes relevant to the Module 4 KLOEs.

¹ Among contributors to Every Story Matters it is not always possible to identify those who are clinically vulnerable and those who are clinically extremely vulnerable. This is because not all contributors provided this information when sharing their stories. Where possible, we have included information about whether contributors are clinically vulnerable or clinically extremely vulnerable. When this is not the case, we talk about all those who were asked to shield during the pandemic as ‘clinically vulnerable’ contributors.

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, see the appendix.

Notes about the presentation and interpretation of stories

It is important to note that the stories collected through Every Story Matters are not representative of all experiences of Covid-19 vaccines during the pandemic nor of UK public opinion. 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 have tried to reflect the range of stories which we heard, which may mean some stories presented here differ from what other, or even many other, people in the UK experienced.

Some stories are explored in more depth 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.

Throughout the record, we refer to people who shared their stories with Every Story Matters as 'contributors'. Where appropriate, we have also described more about them (for example, their ethnicity or health status) to help explain the context and relevance of their experience.

Stories were collected and analysed throughout 2023 and 2024, meaning that experiences are being remembered some time after they happened.

Structure of the record

This document is structured to allow readers to understand how people experienced Covid-19 vaccines.

It starts by exploring how people experienced information received on Covid-19 vaccines (Chapter 2) before moving on to discuss the factors which informed people's decisions to receive or not to receive a vaccine (Chapter 3). It then describes experiences of the vaccine rollout among those who chose to receive a vaccine (Chapter 4), before looking at impacts related to the availability of treatments (therapeutics) for Covid-19 among those at risk of severe illness (Chapter 5).



2 Experiences of public messaging about Covid-19 vaccines

This chapter describes what contributors told us about the information they received on Covid-19 vaccines during the pandemic. We gathered people's views about the official guidance from the government and the NHS. We also heard about other sources of information which were used, including traditional and social media, friends, family, faith settings and community groups.

How contributors first heard about the Covid-19 vaccines and what they felt

Very few contributors could recall exactly when they first heard that a vaccine for Covid-19 had been developed. They often reflected that vaccines had been a topic of conversation since the first lockdown in the UK. This meant vaccines were something that they had discussed regularly with friends or family, and that they had seen, heard, or read about in the news or on social media.

“ It was just so much a part of it – there was nothing else to talk about, there was nothing else on the news. Nobody was talking about anything apart from Covid vaccinations”

– Every Story Matters contributor

Most associated early information about Covid-19 vaccines with hearing about them on TV news. Some contributors working in healthcare settings also said they were discussed at their workplace.

“ I would say when I first saw it, it was on the news... I was quite happy about that, for them to be producing this quickly for us so we could just try and get back to normal life.”

– Every Story Matters contributor

“ I first heard about it through work, and being a keyworker, we were fast-tracked to be able to get it, and that’s when I first heard of it. I don’t remember the exact dates.”

– Every Story Matters contributor

Hearing that a vaccine had been approved for use was met with a huge range of emotions. For some, positive feelings of relief and hope dominated. This included many of those who were clinically vulnerable or clinically extremely vulnerable, were caring for a vulnerable friend or family member, or who were older themselves. A vaccine was seen to offer the first realistic chance for their lives to return to normal: many had been shielding or been otherwise cautious about mixing with people since the pandemic began.

“ When it was confirmed that the vaccine was available, the first thing I felt was, personally, it brought me hope, because I was in a hopeless situation at that time, and that’s why I wanted to be first on the list. It felt like there was light at the end of the tunnel, that was very reassuring.”

– Clinically vulnerable contributor

“ I’ve got asthma and also my father-in-law has cancer, so it was a massive sigh of relief for everybody in our family when we heard about the vaccines.”

– Every Story Matters contributor

However, others described having more mixed or negative feelings about the vaccines. These contributors spoke about feeling cautious or sceptical of the vaccines. Often this related to concerns about the speed at which the vaccines had been developed, which raised questions about their safety and effectiveness.

“ So, for me, I didn’t have an issue with having the vaccine. My issue was, ‘was the vaccine safe enough for me to have it?’ Had it gone through all the checks for it to be safe for me to have it, because I know vaccines work and they do help. So, that was my dilemma but at the time the vaccine was being rolled out. I was sceptical that it had gone through all the ethical checks and all the checks that were needed for it to be safe for me to have. So, that was my issue at the beginning.”

– Every Story Matters contributor

“ I think it’s fair to say that the speed at which it came out did leave a little bit of reticence with some people. It was rolled out very quickly, where other vaccines have taken years to get to market. So there was naturally a little bit of I think general fear.”

– Every Story Matters contributor

Official guidance on Covid-19 vaccines

Contributors thought of the official guidance on Covid-19 vaccines as being the information they saw on the news, in government briefings or received directly from the NHS (in appointments with healthcare professionals, online, through the NHS app, etc). Letters and messages inviting people to take the vaccine were also viewed as official information.

Opinions were mixed about the clarity of official guidance on Covid-19 vaccines. In general, contributors felt that the guidance on the prioritisation of certain groups and the process for obtaining a vaccine was clear. However, some felt that the guidance around vaccine safety and effectiveness was confusing. Contributors assumed that anyone who received a vaccine would be very unlikely to contract Covid-19 (based on their experiences of some vaccines for other illnesses). When they or someone they knew who had received a vaccine later contracted Covid-19 it raised questions for them about whether the vaccines worked. This confusion was not felt to have been addressed by the official guidance available on Covid-19 vaccines.

“ From what I remember, I think it was pretty clear. You got your letter, it was all over the news what they were telling you to do. The advice was definitely there.”

– Every Story Matters contributor

“ I had the injection and still I got COVID. I felt that once I had my injection then I wouldn’t be able to catch COVID, that’s what I was thinking, but why is it that I took the injection and still I had COVID? So I feel like the injection was not working.”

– Every Story Matters contributor

Contributors were also concerned about how potential adverse side effects of the vaccines were communicated in the official guidance. In particular this was important for those with pre-existing health conditions who wanted to know how the vaccine might interact with their condition and whether this put them at heightened risk of adverse effects.

“All of the facts should have been made available, including potential side effects from the jabs, in order for an informed decision to be made and informed consent to be given.”

– Every Story Matters contributor

“There wasn’t a lot of research into the impact that it could have medically regarding whether you had an ongoing health condition. I was a little wary about the long-term effects of the vaccination and what could happen.”

– Person with a long-term health condition

Contributors also reflected that the language used and the concepts included in the official guidance were often jargon-heavy and included medical language. This made it difficult for some to understand the guidance, and they spoke about feeling unable to make an informed decision as a result. One specific area of confusion was around the different types of vaccines available to the public.

“I wouldn’t say there was enough information that I understood – but I think there was enough information out there that, if someone that understood it was able to explain it to me better, I probably would have understood it then.”

– Every Story Matters contributor

“I didn’t understand the difference between the two vaccines, the Pfizer one and the other one. I remember one of our friends had got one, and the other one had got the other one, and I was like, ‘How do you know which one to get?’ So that’s another thing that I felt they didn’t really explain.”

– Every Story Matters contributor

There were some contributors who described finding it difficult obtaining information in a format accessible to them. This included those with visual impairments or those for whom English was not their first language.

“I think if you do understand English, then it was okay, but if I think about my broader community, some of them don’t necessarily understand English that well, and it was difficult for them, and I didn’t come across the information in a different format...it would be nice if they had thought to find the opportunity to make that information available for people who don’t speak English, to find a community link leader, an Imam, or something like that.”

– Every Story Matters contributor

“ My daughter helped us get lots of information off the internet, but we were frustrated that we didn’t have information in accessible formats. There were a lot of visual images that assistive technology can’t read.”

– Person with sight loss

“ In future we need a lot clearer messaging, especially for disadvantaged communities. People get weary of trusting medical professions and different communities have different language barriers. There was this sense of communities being culled, family members were saying ‘they are out here to get us, do not get the vaccine.’ Very little was done to reassure people in their own language, a lot of young people took on the burden of translating this.”

– Every Story Matters contributor

There were also those who felt that the official guidance did not address concerns related to their religious beliefs. For example, some Muslim contributors spoke about finding it difficult to find information about whether or not the vaccines were halal.

“ I literally had to call up my NHS colleague, because I was working for the NHS at the time. I called up my colleague and I said, ‘Look, I want to know the ingredients of each of the vaccinations, because depending on what’s in the ingredients, if there’s animal fats or things like that in there, then we can’t take it. It’s got to be suitable for vegetarians or vegan friendly.’ And then they went back and they said that, ‘this one is fine. All people of that faith, you’d be able to take that vaccination.’ So, I was an individual that made that query. That information wasn’t readily available.”

– Person of a Muslim faith

However, many acknowledged the challenges faced by the government during the pandemic. They described the government as doing what it could at the time, based on what was known about the vaccines.

“ The vaccines were a life-saving intervention, and, I guess, in our lifetime, this will be one of the highlights that we have witnessed. They saved hundreds of people, including myself. I’m glad that I managed to take this vaccine. The process was really good. The government did as much as they could do, I guess, because there’s nothing perfect.”

– Every Story Matters contributor

“ I think, to be honest, kudos to them because of the way that they handled it. At the end of the day, it was a pandemic, there were people really struggling out there, we were in lockdown, and they were doing everything they could to do what they could. They’re only human.”

– Every Story Matters contributor

Relevance of official guidance for people who were pregnant or breastfeeding

At the beginning of December 2020, the advice from the Joint Committee on Vaccination and Immunisation (JCVI) was that because there was no data on the safety of Covid-19 vaccines in pregnancy, pregnant women should not be offered a Covid-19 vaccine. On 30th December 2020, the updated JCVI advice was that pregnant women could be offered vaccinations where they were at particularly high risk of exposure or serious complications due to Covid-19. In April 2021, the JCVI updated its advice again, to advise that pregnant women be offered a Covid-19 vaccine since there had been no specific safety concerns identified with any of the Covid-19 vaccines in relation to pregnancy.

The changing nature of the official guidance on vaccination during pregnancy was confusing for many of the women we spoke to. Some who were pregnant during the pandemic questioned why the advice had changed as they saw no shift in evidence or available information to explain it. For those who felt this way the changing guidance caused them additional stress and anxiety during what was already a worrying time.

“ I remember them specifically saying, ‘Anyone who is pregnant or trying to conceive should not have the vaccine.’ There was a whole ordeal over it and I remember it was very important that you should not have the vaccine. We were trying to conceive and then when I did fall pregnant obviously I didn’t have the vaccine, it was confirmed by the midwives that I shouldn’t, it wasn’t recommended at the time. And then all of a sudden halfway through my pregnancy there was a change of circumstances and pregnant people were allowed the vaccine which I just thought was very, very strange and very worrying.”

– Woman who was pregnant when offered a vaccine

The primary concern among the women we spoke to was that the vaccine may cause them to miscarry or may harm their unborn child. They told us how the official guidance did not do enough to address these concerns, which were compounded by a sense that even health professionals were unsure what advice to give. For some, this uncertainty led them to decide not to take the vaccine until they had given birth.

“ I was pregnant at the time so because they had said not to get it while you’re pregnant and then the decision was made very quickly to say that they could, that alarmed me. Because it was just a change in the decision, like, overnight. So, in my head I constantly thought about, ‘Well why did they say no in the first place?’ And then I decided, because I’d had a miscarriage and I didn’t want anything in my body that could cause anything to harm this pregnancy. So I decided not to get the vaccine while I was pregnant. I did get it after.”

– Woman who was pregnant when offered a vaccine

“ We couldn’t go out to our pharmacies, GPs, and be like, ‘right, okay, what exactly is this?’ because we didn’t really have that option. And I don’t think even many of the health professionals knew either.”

– Woman who was pregnant when offered a vaccine

Similar concerns were raised by some of the women we spoke to who were breastfeeding when offered a vaccine. These contributors spoke about being worried about how the vaccine might impact the child they were breastfeeding: would it make their baby ill, or might it provide them with protection against Covid-19? Again, it was felt that the official advice did not provide clarity for those in this position.

“ My biggest question was, I was breastfeeding, so is it going to affect my child... is it going to go into my breast milk, is it going to affect my newborn child, is it going to do anything, is it going to make me ill?”

– Woman who was breastfeeding when offered a vaccine



Information on Covid-19 vaccines in the media

Contributors described seeing different kinds of information about Covid-19 vaccines in the media during the pandemic. This included information about the development and testing of the vaccines and regular updates on the progress of the rollout once this had begun.

Views were mixed on the information in the media about the Covid-19 vaccines.

Some contributors perceived that the information available intended to encourage uptake, rather than provide a balanced debate about the risks and benefits associated with taking a vaccine. This led them to tend to distrust the information available via traditional media and seek information from elsewhere.

“What I saw, maybe from the government, but in the news and online was just, ‘Get it, you need to get this, you have to get this vaccine.’ That’s really all it was, it was like it was getting forced on you!”

– Person who chose not to receive a vaccine

“Mainstream media was very much positioned, you know, ‘Well, it’s great. Here it is’, and whatnot. However, there were different stories then on YouTube. You never got a negative on mainstream media, everything was all positive and still is positive. However, if you delved a bit deeper and you wanted to believe what you saw on these other channels it wasn’t so positive.”

– Person who chose not to receive a vaccine

However, others found the regular updates provided through traditional media sources a useful way to keep on top of the development of the vaccines. Others mentioned feeling overwhelmed by the amount of information and discussion about vaccines and the pandemic more broadly, which led them to ‘switch off’ and try to ‘escape’.

“Everywhere you went there were signs, every channel, every outlet you can imagine, it was just all about this Covid-19 vaccine. There was no breather, that’s how I remember it feeling. It’s been quite a while but I just remember feeling bombarded with Covid information, in fact it was so bad that I remember switching the news off, I no longer listened because I had had enough.”

– Every Story Matters contributor

Information about Covid-19 vaccines on social media

Contributors recalled seeing information about Covid-19 vaccines across a range of social media platforms, including Facebook, Instagram, TikTok, Twitter, Snapchat, YouTube, and WhatsApp. **Often they felt that the tone of the information shared on social media was predominantly negative, particularly as the rollout got underway.** Contributors recalled growing numbers of stories about people who had experienced severe adverse reactions or those who had died following a vaccine. Many reflected that these stories led to an atmosphere of fear and suspicion around the vaccines. In turn, they felt this allowed rumours about the vaccines to gather pace.

“ On social media, you heard horror stories, and I feel like you’re probably always going to hear that kind of thing. I remember there was something about one of them being linked to blood clots at one point or something. I feel like knowing what I do now, I feel like that was completely blown out of proportion.”

– Every Story Matters contributor

These negative experiences led some to feel that there was a lot of mis- or dis-information about the vaccines online. We heard from many who said they did not trust what they saw on social media. However, even some of those who did not trust social media thought that the messages they saw may have influenced their perceptions of the vaccines, and potentially shaped their decisions about whether or not to receive one.

“ I know that the stuff on social media wasn’t really reliable but I think because I’d seen it then it played a massive part in my head when I was thinking about whether or not I wanted to get [a vaccine].”

– Person who chose not to receive a vaccine

Despite these reflections, **there were some who felt that social media allowed them to hear directly about negative experiences of Covid-19 vaccines in a way that was not possible via other sources.** These contributors thought that negative experiences of the vaccines had been under-reported by traditional media outlets and the government, and therefore relied on social media to hear these stories.

“ I remember that was the only place I saw bad truthful stories, on social media, the news wasn’t really reporting anything bad about the vaccines from what I can remember.”

– Every Story Matters contributor

Other sources of information on Covid-19 vaccines

Contributors often sought information on Covid-19 vaccines from sources beyond the official guidance and information available via traditional and social media. This included healthcare professionals, friends and family members.

Healthcare professionals

Healthcare professionals were an important source of information on the Covid-19 vaccines, particularly for those who were clinically vulnerable, clinically extremely vulnerable, pregnant or breastfeeding. These contributors trusted that the advice of doctors, nurses and midwives was based on a medical knowledge of the vaccines and their associated risks and benefits. They also felt that the advice provided was tailored to them since these people understood their personal medical history.

“ My consultant sent me out information for my [health condition]. There was some stuff that was published widely for the public...and I was given more sort of specific information. He broke it down a bit for people that have [condition] and the possibilities of it. He took all the jargon away a little bit and did a bit of an idiot’s guide to what it meant for us.”

– Clinically vulnerable contributor

However not all contributors received tailored advice from their healthcare professionals. Some described receiving very limited information about what the Covid-19 vaccines could mean for their specific health condition(s) or pregnancy.

“ I remember very clearly there wasn’t very much information available, I had to ring and chase and try to get more information. So I know for my part, I was the one doing the work. You couldn’t get to see the GP at all.”

– Clinically vulnerable contributor

More broadly, contributors who were not clinically vulnerable or at heightened risk from Covid-19 told us that the support available from their healthcare provider was limited. Many said they would have valued receiving information from their GP about the vaccine to help inform their decision. Some described receiving information at the vaccination centres, which was welcomed but was thought to have come too late.

“ You couldn’t really get to speak directly to the GP about it...it might have been helpful, but there was limited access, it wasn’t as accessible.”
 – Every Story Matters contributor

“ I remember going for my first Covid vaccine, having a leaflet given to me, and thinking, ‘this is the first time I’ve seen some of this information, and actually I don’t feel like I’ve really had time to digest fully what this means, and I’ve got to go and have my injection in a second.’ The proper information, it felt like that came too late.”
 – Woman who was breastfeeding when offered a vaccine

Friends and family

Many of those we spoke to mentioned discussing the Covid-19 vaccines with friends and family. Contributors described how they spoke to others to share information, get a better understanding of the vaccine, and talk through their decision-making process.

“ It was a mixture of friends, family, and colleagues, because everyone had different opinions, and everyone had different stories. You heard stories of people actually passing away with Covid-19, so that made you think, okay, maybe it’s good to get the vaccine, and then you had people that said the vaccine killed someone they knew.”
 – Every Story Matters contributor

Those with family and friends who were healthcare professionals often turned to them for advice. These individuals felt reassured by those in their networks who understood more about science and how vaccines are developed.

“ There were a lot of conspiracies, and there still are. So, in amongst that time, especially when you’re isolated, you’re getting WhatsApp messages and you’re getting links to different videos from around the world, so-called researchers, etc. Sometimes you didn’t know what to believe. So, if you’ve got somebody who’s actually working in that area, is seeing things with their own eyes and can tell you their experience, then that was something you relied on as well.”
 – Every Story Matters contributor

We also heard examples of people discussing the vaccine with those in similar circumstances, including being pregnant or breastfeeding or clinically vulnerable.

“ Whilst I was pregnant and breastfeeding, I had a number of close friends who were in the same situation, so we did speak quite extensively about it. That was a nice support actually. In the absence of a lot of information and in the absence of being able to sit face-to-face with somebody you know, it was nice to be able to have those conversations. Just to have a discussion with somebody who felt that way because they were in the same boat.”

– Woman who was breastfeeding when offered a vaccine

“ I’m on a Facebook group with people with [health condition] so there was quite a lot of discussion there because many of us were on the vulnerable list.”

– Clinically vulnerable contributor

Some felt that their discussions with friends or family did little to help them decide whether to receive a vaccine. These contributors spoke of tensions between individuals and different generations, and pressures from family members both for and against the vaccines.

“ Yes in my family, the older generation, I found that they looked at you as being a selfish person if you didn’t want it.”

– Every Story Matters contributor

“ I had pressure from my father, he’s a very well-educated man. He’s the person I’ve always gone to for advice and guidance on everything, from finance to health to all sorts. And that was a real pressure because he said, ‘You shouldn’t have this, because there’s talk about it impacting fertility and you want more children.’ So, we did discuss it, but it didn’t necessarily help. More, it added to the fear.”

– Woman who was breastfeeding when offered a vaccine

Those with religious beliefs sometimes described hearing about the vaccines through their faith community. Some trusted this information over that shared by other sources.

“ I’m a Jehovah’s Witness, and our world-wide society are very clued up on the whole vaccine rollout. They did a lot of research and let us know, as an organisation, the vaccine information.”

– Jehovah’s Witness

“ There were certainly some concerns from a Muslim perspective. I can’t honestly remember what they were. But I remember that the Muslim Council, I think they issued something to say ‘actually you do need to take whatever steps necessary to prolong life, and it is in your hands and therefore you have to be proactive in this’.”

– Person of a Muslim faith

“ There was a lot of information coming from different places. I didn’t really trust anything that was in the media, but my faith community, there were updates from my faith community around the vaccine. They had done a lot of research into it. And I trusted that.”

– Every Story Matters contributor

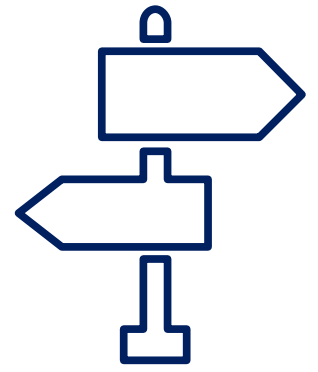
Personal research

Some of those we spoke to said they did their own research about the vaccines in order to inform their decision whether or not to receive one. We heard examples of contributors consulting a range of sources, including scientific journals such as The Lancet and the British Medical Journal, medical studies and data from the clinical trials for the Covid-19 vaccines, blogs and social media pages, news articles, and other internet searches.

“ I was doing quite a lot of my own research, so I was looking for information, I was going to companies, which ones were working on it, and I was reading all about it.”

– Every Story Matters contributor





3 Deciding whether or not to take a Covid-19 vaccine

This chapter explores the factors that informed contributors' decisions about whether or not to receive a Covid-19 vaccine. It shares what they told us about how they came to their decisions, including both the experiences of those who chose to receive a vaccine, and those that did not.

Deciding whether or not to receive a Covid-19 vaccine

Many contributors told us that their decision whether or not to receive a Covid-19 vaccine was relatively straightforward. These contributors said that they made their decision quite quickly.

“ I hadn't really ever considered not getting it. So yes. I always had the mindset that when it was offered to me, when I was able to take it, that I would go and get it.”

– Every Story Matters contributor

“ I have never not had a vaccine when a vaccination was on offer. Or was deemed as something that would be beneficial for me and my wellbeing. But, you know, I think right from the off, literally when I started to think about, 'Was this something I wanted?' I was insistent and adamant, that no, I didn't...I think it was just one of those, you hear something, and your immediate, innate response is, 'Yes, I want to do that', 'No I don't' and my innate response was 'I don't want that.'”

– Person who chose not to receive a vaccine

However, we also heard from contributors who found their decision difficult. These contributors described how they often moved back and forth between different positions, weighing up multiple competing factors before coming to their final decision. This was the case both for those who chose to receive a Covid-19 vaccine and those who did not.

“ So many people were dying from [Covid-19] and then it was this breakthrough of, ‘Yes, we’ve got a vaccine,’ which I thought was fantastic. But then it was just little things afterwards that I thought, ‘Okay, how have they got it so quick, and were there trials for it?’ And that was when I started questioning things, started to think in my head, ‘How was this done so quick.’”

– Every Story Matters contributor

The factors described below are those that were reported as important in informing decisions about the first dose of a Covid-19 vaccine. These factors were often also important in informing decisions about subsequent vaccine doses, although a small number considered other factors when deciding whether or not to receive later doses of a Covid-19 vaccine.

Why contributors chose to receive a Covid-19 vaccine

No strong reason not to do so

We heard from several contributors who said that the primary reason they chose to receive a Covid-19 vaccine was because they saw no strong reason not to do so. These contributors often described trusting in the advice of government and the NHS, assuming that neither would recommend something that was unsafe. For these contributors their decision was relatively straightforward: when a vaccine was offered to them, they took it.

“ It never crossed my mind to not have the vaccination. I was always really surprised whenever I heard anybody saying anything negative about it, and shocked and bewildered.”

– Every Story Matters contributor

To protect themselves and others from serious illness or death

Many contributors told us that an important reason why they chose to receive a Covid-19 vaccine was because they believed it would help protect them and their loved ones. These contributors worried what would happen if they or a loved one

became seriously ill with Covid-19 and saw the vaccines as the best way to protect themselves and others from serious illness or death. This was often important for those with friends or family members in at-risk groups (such as older relatives, newborn babies, or other vulnerable people) or those who were at higher risk of severe Covid-19 illness themselves.

“ I had to take [the vaccine] for elderly relatives, I wanted to keep them safe. So, 100% I decided to take it.”

– Every Story Matters contributor

“ I’d already experienced it without a vaccination, and lost somebody that was really dear to me, and there was no way that I would want to put my own son through that. I just did what I had to do.”

– Clinically vulnerable person

Workplace requirements

Contributors working in health and social care during the pandemic often said that their decision to receive a Covid-19 vaccine was informed by workplace vaccine requirements. Opinions about this were divided: some thought that taking a vaccine was important since they believed it would help to protect them and the people they cared for.

“ I was working in a care home, and it was safe for me, and I was safe for them as well. So that was my concern, that at least I can work at my workplace safely, and I’ll go back home, I’ll feel comfortable, and I’m safe.”

– Care home worker

“ Yes I decided to take it. I was working with patients who were very unwell because I had been moved into a unit where my patients were on ventilation, so I had to have it – I couldn’t afford to put them at risk.”

– Frontline worker during the pandemic

However, others argued that those working in health and social care should not have been put under pressure to receive a vaccine by their job. These contributors often pointed to a lack of long-term data on the vaccines as a result of their being newly developed, and thought people should be free to make their own decisions about receiving one. We heard this from some health and social care staff but also other contributors reflecting on workplace vaccination requirements.

“ I felt pressured to be honest. I didn’t get a letter or a text message. I had a phone call off of one of my managers, I think. It was just pressure. It’s not a nice feeling to have – and I don’t think you’d find that in many instances when it’s to do with your health in general, because you make those decisions by yourself don’t you? You don’t normally have anyone else included.”

– Frontline worker during the pandemic

“ There were close to 1,000 members of staff who did not want to be vaccinated, however the service handled this by using coercive behaviour, putting pressure on staff, ringing them on rest days, sending emails and in some cases were bullied because they chose not to put something into their bodies that was still in trial with no long-term safety data. This was utterly appalling behaviour that had a detrimental impact on many staff. I had given over 18 years’ commitment, done my job to the best of my ability, had never had one complaint, however I was set to be sacked if I did not put this experiment into my body.”

– Frontline worker during the pandemic

Ending the lockdowns

We heard from some contributors who said they thought that the vaccines would bring an end to the lockdown restrictions and provide the opportunity for their lives to return to the way they were before. We often heard this from those who were young, fit and healthy, and did not perceive Covid-19 to be as great of a risk to their health as it might be for others, such as clinically vulnerable people.

“ I just thought that the sooner everybody got vaccinated, the sooner we could start to re-establish work and play and travel and, you know, all the rest of it.”

– Every Story Matters contributor

For many, the desire not to be restricted by the limitations placed on travel and socialising was a key factor in their decision to receive a Covid-19 vaccine. For this group, vaccination became a means to an end, and they accepted it as something they needed to do in order to travel or socialise.

“ There wasn’t much of a choice. They said you can’t go to university, you can’t go to nightclubs, bars, on holiday. They stripped you of everything if you didn’t have a vaccine. You had to take it if you wanted to have your life back.”

– Every Story Matters contributor

Trust in the judgement of authority figures

As previously discussed, for some contributors the advice of scientists and healthcare professionals played an important role in informing their decision to receive a Covid-19 vaccine. These contributors trusted in the guidance provided by these groups, who were believed to be making judgements about the vaccines based on scientific evidence rather than opinion.

“ I never remember her name, but I saw a documentary with the academic from Oxford, the female academic who was instrumental along with others in pulling together that vaccine, and by the end of the documentary I knew that I would take it if I was offered it. She answered all the questions.”

– Person who chose to receive a vaccine

“ You build a relationship with [your healthcare professionals] and it is a relationship based on trust, and mine were just really fantastic. They were so lovely and so I trusted them wholeheartedly. So, yes I did listen...and it did make a difference to me. It did impact my decision.”

– Clinically vulnerable person

Those who had healthcare professionals as friends or family often turned to them for advice on the Covid-19 vaccines, with their trust in science reinforced by their trust in their loved one.

“ My sister is a dentist, so she [had a Covid-19 vaccine] and she said ‘nothing happened to me’ you know. She was one day, arm pain. My son was a medical student, [...] so he had to do it as well. So, these people, my close family members, because they did it and nothing happened, they were fine, and they were encouraging, because they were in the health service.”

– Relative of frontline workers

Societal pressure

Others described feeling a **more general pressure from society to be vaccinated.** For some, this pushed them to receive a vaccine. Those that felt this way expressed anger at the way in which information about the Covid-19 vaccines had been communicated to the public.

“ I had my first one and the booster one because of that, kind of, external pressure. You know, you’ve got to do this. You’ve got to protect everybody. Protect the NHS. Protect your family. Protect your colleagues [...] so I think I felt pressured. I felt under duress to get the vaccination. I felt scared of getting it because I didn’t know the real implications and what that would have on me, on my daughter, and I felt pretty annoyed about the whole situation.”
 – Woman who was breastfeeding when offered a vaccine

Why contributors were hesitant to receive a vaccine, or chose not to do so

Lack of confidence in the safety of Covid-19 vaccines

Safety concerns were an important factor for many of the contributors who were hesitant to receive a Covid-19 vaccine or who chose not to do so. Those who mentioned this often spoke about the speed at which the vaccines had been developed: this raised questions about whether the development process had been done properly.

“ There was some element of wondering whether it was safe, because of the speed at which it was developed, so that’s what I thought. My initial reaction was, wow, that’s quick. Second immediate reaction, if it’s that quick, is it safe?”
 – Every Story Matters contributor

Safety concerns were of particular importance for those we heard from with long term health conditions or people from ethnic minority backgrounds. These contributors worried that in seeking to develop the vaccines at pace, appropriate testing on people like them had not happened. They worried that this would mean they were at greater risk of an adverse reaction to the vaccines.

“ I chose not to have the Covid vaccine [...] I have an auto immune disease and there were no people with auto immune disease in the trials for the vaccine.”
 – Clinically vulnerable person

“ I wanted to know whether the vaccine had been tested across demographics because vaccines are a big thing, whether they’re for Covid or not. We’re talking about injecting the thing into you. It’s a controversial health area. I

was worried about the vaccine having been tested on majority non-ethnic minorities or very little, if at all, ethnic minorities having been tested and what those results were. Under normal circumstances you could find that information easily...but that information was not available. Rightly so, it was a new drug so there wasn't much experience with it, but still, whatever experience or efficacy as they call it, they used at that point, did it include a sizeable number of Black and minority ethnic groups? Or Black Afro-Caribbean or Asian groups, to warrant us having that little bit more comfort in it?"

– Person from a Black ethnic background

More generally, a lack of long-term data on the perceived safety and effectiveness of the vaccines was important to many contributors who chose not to receive a vaccine. They described how the Covid-19 vaccines were different from other vaccines they had received previously: those vaccines had been around for years and there was long-term evidence on their safety and effectiveness. This was not the case for the Covid-19 vaccines. These contributors described feeling angry that these concerns were not explicitly addressed in government guidance on the vaccines.

“ I didn't have any particular concerns, like, 'it might cause this, it might cause X, Y or Z disease, or impairment, or whatever, or, you know, infertility.' I didn't think about anything specific. I just thought that there could be some negative side effect of it, you know, long-term. We don't really fully know because it's just so brand new.”

– Person who chose not to receive a vaccine

Lack of confidence in the effectiveness of Covid-19 vaccines

For many contributors, hearing that those who received a Covid-19 vaccine might still contract Covid-19 raised questions about whether or not the vaccines worked. These contributors assumed that the Covid-19 vaccines were designed to stop people from contracting Covid-19 (based on their experiences of vaccines for other illnesses). When they thought that this was not the case (for instance when friends or family members who had received a vaccine subsequently contracted Covid-19) this led to a sense of distrust in the Covid-19 vaccines which influenced their decision not to receive one.

“ That was, kind of, what it came down to. I just thought, 'What's the point in going and getting vaccinated when I could still get Covid afterwards?'"

– Every Story Matters contributor

Not perceived to be necessary

Some contributors felt that their risk of severe illness from Covid-19 was low and therefore considered that the vaccines were not relevant to them. This view was more common among those who had had Covid-19 before they were offered a vaccine and did not fall ill or only suffered mild symptoms. They felt that they did not need protection from something they had already experienced, as they now had natural immunity, and they did not suffer severely.

“ I was completely against it [...] mostly health-wise. What are the side effects? What are the long-term side effects? And again, because I had had Covid and I had had no symptoms and I wasn't high risk. I had already gone through it. I tested positive, however, nothing happened [...] and everyone in my family got it. There were about 18 of us and we all had Covid at the same time. And again we felt like it was unnecessary. It was just a really bad cold.”

– Person who chose not to receive a vaccine

A few of those we heard from told us that they chose not to receive a vaccine because they considered that their immune system should be able to deal with the virus naturally, particularly if they kept themselves fit and healthy. These individuals often followed other Covid-19 rules (such as wearing face masks) and trusted the information about the vaccine. However, they did not think it was necessary for them to be vaccinated.

“ I'm young, I'm fit and healthy, and obviously if I get it I'll probably be able to just fight it off.”

– Person who chose not to receive a vaccine

Current and historic experiences of discrimination and racism

Some contributors shared how recent experiences of discrimination and racism were important in informing their decision not to receive a Covid-19 vaccine.

These experiences were more often discussed by contributors from ethnic minority backgrounds. Contributors described how previous experiences of discrimination and racism had led them to distrust the government and the health system more broadly, which in turn led them to feel fearful and uneasy about the Covid-19 vaccines. A lack of information on the risks and side effects of the vaccines for particular ethnic minority groups exacerbated their concerns.

“ I’m Black... that means my community is not taken care of in any aspect of my life, of my community’s life. They are at the bottom of the barrel, if even in the barrel. And so, I wouldn’t have trusted anyone to have given me any real specific information about how it would affect me. There’s still no trust there.”
– Person from a Black ethnic background

“ I write as someone who is Black and whose life has been directly affected by Covid-19 [...] high numbers of Black people refused to have the jab because of the inherent mistrust of the medical establishment.”
– Person from a Black ethnic background

Perceived racism in medical science was also important in informing how contributors from ethnic minority backgrounds considered vaccines. Some contributors felt there was a historic legacy of Black communities being experimented on, leading to present feelings of distrust.

“ We asked questions around, like, how reliable is it, who has it been tested on. Because there’s this misconception about, you know, ethnic minorities are always used for vaccinations and if we survive, then the White community are safe and the vaccine will be applied to them. And this has happened to Black communities, and so the slavery trade and all that, all those vaccinations were used [...] So, I wanted that fear to be addressed and settled, so I participated in that campaign just to understand. I said that, you know, ‘I want to know whether we are being used as guinea pigs or whether genuinely that you are satisfied that this vaccine is legit and it works and what have you.’”
– Person from an Asian ethnic background

Distrust in authority

A few of the people we spoke to told us how the narrative around the Covid-19 vaccine being something people ‘just had to do’ made them less likely to want to do so. This group described distrust towards government generally, and did not think they should feel forced to do something they did not want to do.

“ I am 70 and I refused any vaccines. No government has the right to try to force or coerce its citizens into having an experimental procedure.”
– Person who chose not to receive a vaccine

“ I just thought, ‘I’m not being told what I can and can’t do on the strength of whether I’ve had a vaccination.’ Because, actually, at the end of the day, this is my body, and I should be allowed to choose freely whether I take that, which obviously I was able to do. But I shouldn’t have restrictions imposed on my life because of a decision I’ve made about my own health. And I think when it got to that point, I was just like, ‘Absolutely, I’m not engaging with this.’ And I really did, much to the bemusement of those around me.”

– Person who chose not to receive a vaccine

Personal attitudes towards medicine

A few contributors spoke about being cautious about medical interventions more generally, including vaccinations, which led them to choose not to receive a Covid-19 vaccine. Many of these individuals decided early on that they would not have a vaccine because they did not like to ‘put anything in their body’.

“ I do not take any medication without really needing it and knowing everything about it, I certainly wasn’t going to risk my life having an untested vaccine as a single parent, that would not be in my children’s best interest.”

– Person who chose not to receive a vaccine

Factors that informed decisions about subsequent doses of Covid-19 vaccines

People’s decisions about the initial dose of a Covid-19 vaccine typically applied to their decisions about subsequent doses. However, a few spoke about considering different factors when making decisions about receiving further doses.

Among this group some became less worried about the risks of severe illness or death because of Covid-19 as time went on. They might have chosen to take their first or second dose of a Covid-19 vaccine but then for subsequent doses decided not to receive it. Often this was because they felt that the benefits of vaccination no longer outweighed the risks.

“ I think just, [in 2021] it was just quite a scary thing. My baby was still really little and we were worried that if we didn't have it that something bad might happen. I might get ill, I might get really poorly, or die. Whereas in 2022, I kind of knew more about it and I'd had Covid and I was okay, and I thought, 'actually, I'm not going to go down the route of the vaccine', because I was pregnant at that point.”

– Every Story Matters contributor

Some described how negative experiences with the first dose of a Covid-19 vaccine informed their decision not to receive subsequent dose(s). These contributors had often experienced more severe adverse reactions to their initial dose which made them hesitant and sometimes fearful to take another dose.

“ I had a severe reaction to the first vaccination which was a shock as I didn't know I was a significant risk. The symptoms were worse than those I had experienced with Covid-19. Severe fever and chills with a hideous headache (worse than a migraine), I couldn't stand up...I did have the second dose and a boost but I am reluctant to have more.”

– Every Story Matters contributor





4 Experiences of the vaccine rollout

This chapter brings together experiences of the vaccine rollout. It starts by describing what contributors understood of the recommendations for vaccine eligibility and prioritisation made by the Joint Committee on Vaccination and Immunisation. It then moves on to discuss experiences of the vaccine rollout specifically, including booking appointments, receiving a vaccine, and any experiences immediately following doing so.

Understanding of the recommendations on vaccine eligibility and prioritisation made by the Joint Committee on Vaccination and Immunisation.

Many felt that the approach taken to the prioritisation of Covid-19 vaccines was fair and reasonable. Contributors often reflected that there were a limited number of vaccines available and agreed that those most at risk from Covid-19 should be prioritised over others.

“ I personally think that the way they rolled it out was very, very good. Priority was given to the people that absolutely needed it [...] And after that, the rollout was quite good, it was done according to age. So they started from 85 onwards, and then 80, then 70, and then the rest followed. But that was in quick succession.”

– Every Story Matters contributor

“ I think they got that right, the prioritisation. I thought it was a sensible approach, that part.”

– Every Story Matters contributor

Some clinically vulnerable and clinically extremely vulnerable contributors questioned why other members of their household were not eligible for a vaccine at the same time they were. These contributors argued that in vaccinating household contacts of clinically vulnerable people it would form a ‘protective bubble’ around them and further reduce their chances of catching Covid-19. Clinically

extremely vulnerable contributors appreciated the change in guidance regarding prioritisation of household contacts of people with severe immunosuppression that came later in the rollout.

“ I feel like the rollout would have made more sense that if you had a vulnerable person in your household, everybody in that household would be jabbed. Because otherwise you could still run the risk of people getting unwell.”

– Clinically vulnerable contributor

A few contributors were worried that prioritising clinically vulnerable and clinically extremely vulnerable people could expose them to additional risk. These contributors pointed to potential vaccine side effects and long-term impacts.

“ I get it, but also, you could probably see it from another perspective that, ‘Oh okay. You’re vaccinating the most vulnerable person first and if something is going to go wrong, you know, it’s going to be harder for them to get over it and recover from it.’”

– Every Story Matters contributor

Some clinically vulnerable and clinically extremely vulnerable contributors mentioned being unable to take a vaccine when it was offered to them. Some had chosen to pay to receive Evusheld² as an alternative.

“ I learned that immunosuppressed people often do not respond well or at all to vaccines. After one vaccine I had no antibodies and very low amounts after 2 vaccines. By the time a third primary dose was granted my antibody response had long dwindled to nothing and I was having a third primary dose, with a starting point of zero...I ended up paying for Evusheld at the hugely inflated (and VAT inclusive) private mark up price, which bought me a few months of freedom at the tail end of its effectiveness.”

– Clinically vulnerable contributor

Some contributors felt that others should have been included in high priority groups to receive a vaccine. This included some who were parents or worked in schools and felt that vaccinating children would have reduced transmission in education settings. Others who were key workers (for example those working in prisons or supermarkets) or who were unpaid carers described how they felt that people in their position should have been prioritised.

² Evusheld is a ‘pre-exposure prophylaxis’ treatment, meaning it is taken to prevent Covid-19 before the risk of acquiring infection. Source: Medicines and Healthcare products Regulatory Agency

“ It was disappointing that teachers were not considered to be key workers and that many of my staff were juggling looking after their own children as well as delivering a full programme of online learning...in addition, my staff felt very undervalued when they were not eligible initially for the vaccine.”

– School teacher during the pandemic

“ As carers, why weren't we vaccinated at the same time as the people that we're looking after? It was insane, my mum was being vaccinated, they came to the house, it was ridiculous. Couldn't they have just done me at the same time and then we would know that she was being looked after, there was no joined up thinking.”

– Carer

“ I work in a prison and we were left with no support and no access to early vaccines! It baffles me that a whole segment of society was just ignored and I had 88 men in my prison wing, 2-3 staff depending on how many people were sick and having to manage frustrated, scared prisoners and staff. We did not qualify as a 'care setting' despite having many older prisoners in a very small space and therefore I had to look after Covid positive prisoners with little PPE and not having had my own Covid vaccine. My age was 36 at the time so I had to wait a long time to be eligible.”

– Prison worker during the pandemic

Experiences of the vaccine rollout

Being invited for a vaccine and booking an appointment

Contributors described various ways in which they were invited to receive their first dose of a Covid-19 vaccine. Many recalled this being via a letter or text message from the NHS. Some said they were contacted by their GP directly, while others saw information in the media or online that said that people of their age were now eligible to book.

In most cases, this communication informed those that received it that they could now book an appointment and gave them details of how to do so. Some said an appointment had already been booked for them.

“ I received the letter, I think, and a message as well, I think. It was very clear, it was close to where I was living and it was just a week before. I can't remember exactly, but it was quite convenient, it wasn't a problem at all.”

– Every Story Matters contributor

“ I think it worked well. I got mine over the phone, I called the number and they gave me options for the time, date and location and I booked it.”

– Every Story Matters contributor

Contributors generally found the vaccine booking process straightforward. Many reported having booked online via the government website or NHS app. Some booked directly with their GP surgery.

Appointment availability was usually described as good, with only a small number of contributors mentioning problems finding an appointment at a date, time, and location that worked for them. Some living in more rural areas would have preferred to have an option to receive a vaccine closer to home.

“ Oh, it was dead simple yes. You went on the website, you picked your location, and it gave you three places where you could get it, for me anyway.”

– Every Story Matters contributor

“ We didn't have much choice...I think because we're in a suburb, there are several small communities nearby, so everyone had to go to this one centre. There was only one centre in our area.”

– Every Story Matters contributor

There were a small number of people who described finding the booking process more difficult. These included people with older relatives or family members who spoke limited English, or those who were visually impaired.

“ For myself, it was easy because I know how to work a computer. But I do remember that for my nana and grandad, it wasn't easy.”

– Every Story Matters contributor

“ People who come from Bangladesh, who have been living here for a while but who still haven't managed to learn English that well, they have difficulties accessing technology. They have to rely on someone.”

– Person from a Bangladeshi background

“ The vaccine appointment process was totally inaccessible to screen readers as it used a map for one process and a calendar for another.”

– Person with a visual impairment

Some wanted to know what type of vaccine they would receive when booking their appointment. This was typically linked to concerns about the perceived side effects associated with some vaccines compared with others. These contributors reflected that after the change in guidance regarding the AstraZeneca vaccine this information was then made available on the online booking system.

“ On the day that I went for my vaccination, I didn’t know which one I was going to get, and there was no way for me to find out. With the complications of some of the other ones, and knowing there was no information around breastfeeding and the vaccine, I went in to get my vaccination thinking, ‘I’m not having this unless I’m able to have a Pfizer one. I’m happy to leave this clinic without having it, and that will be my stance.’”

– Woman who was breastfeeding when offered a vaccine

Some contributors used a walk-in clinic rather than booking an appointment. **For these contributors this often offered the chance to receive a vaccine earlier than they otherwise would have done, or before they were officially eligible.** For example, we heard from some younger people who were keen to receive a vaccine quickly so they could return to travel and socialising. Others said they had used a walk-in clinic for ease.

“ I remember when the vaccines first got released and there would be time slots available and everyone would rush to book an appointment and if one of your mates found out there was a centre that had spare, they’d be messaging saying, ‘Guys, book in here. Quickly head down there. There’s space, there’s spare vaccine.’”

– Every Story Matters contributor

“ I went to a walk-in centre for it, it’s easier isn’t it? I could literally just do it in my lunch hour at work because it was in the same town so I just went and did that. I was in and out in about ten minutes.”

– Every Story Matters contributor

Receiving the first dose of a Covid-19 vaccine

Contributors were generally positive about their experience receiving a first dose of a Covid-19 vaccine. Vaccination centres were described as being well-organised and well-laid out, and staff were seen as friendly and welcoming. Contributors found the process easy to understand and for many it was relatively quick.

“The system was just amazing. There were hundreds of us in a queue and it was all methodical and so efficient, it was unbelievable how they could organise something so good. That’s how it felt. We were given the vaccination and we were told to sit for about 15 minutes before we could leave in case we had any side effects. And once we got home, we had a number to ring if something went wrong, but nothing went wrong in my case. I was perfectly okay.”

– Every Story Matters contributor

“When I got to the centre it was all very well organised and the volunteers and the staff, the nurses, doctors, they were all so helpful and cheerful which was really good. There was no sense of doom really. It was like, you’re all here for this vaccination and we’ll just get on with it. And I think that was quite, well it was a relief for one thing to get the vaccine. But it was also quite optimistic, I think.”

– Every Story Matters contributor

“It was amazing how all those vaccination centres were set up and how well organised they were. It felt as if we were all working together to get on top of it.”

– Every Story Matters contributor

The use of social distancing measures meant that many said they felt safe when they received their first vaccine.

“Everything was really well run, they had loads of volunteers that were helping out, everyone was really well space apart and I think they encouraged everyone to wear a mask, I’m pretty sure everyone wore a mask at the time, I don’t remember seeing anyone that didn’t. Yes, it felt safe.”

– Woman who was pregnant when offered a vaccine

“ Everyone observed the two-metre rule, they were wearing face masks, doors were open. Everything was well ventilated.”

– Every Story Matters contributor

People with a disability sometimes described facing barriers to accessing vaccination centres. Examples included local centres that did not have disabled parking or wheelchair access, or where interpreters were not available for d/Deaf people and staff lacked deaf awareness. In these cases, those affected suggested it would have been useful to receive information on the accessibility of facilities in their appointment letter.

“ I couldn’t access the pharmacy vaccination service because I am mobility disabled and car parking is not guaranteed...all disability accessible vaccination centres were fully booked for months!”

– Disabled contributor

“ When I got to the vaccine centre I was so paranoid about everybody being in a mask, I had to take my daughter with me, and she had to interpret because we couldn’t get any interpreters at all. I shouldn’t really have been using my children to interpret for me. That’s not appropriate at all.”

– Deaf contributor

Some contributors who were unpaid carers described facing challenges finding a vaccine centre that could accommodate the needs of the person they cared for.

“ When people are on the spectrum, they can’t just go to normal places for vaccination. I had to go miles and miles to get [my son] vaccinated, they don’t facilitate people on the spectrum at all...so they’re not, you know, enabling people, [with] those sort of disabilities to be vaccinated.”

– Carer

Accessibility was also a problem for those living in more rural areas, with some reflecting on the challenges of getting to the vaccine centres without a car.

“ When the time came to start being vaccinated, we found that our small, isolated village played against us, we’d have to take long bus journeys or multiple buses to get to the vaccination centre, coming into contact with more and more people.”

– Every Story Matters contributor

However, some contributors with accessibility needs found the vaccination centres easy to access and accommodating for those with a disability.

“ I did find it accessible, yes. They had a ramp and everything, they had a waiting area, they put up some gazebos for people to have a sit down in for ten minutes or so after they receive their vaccine. They had all the arrangements in place.”

– Disabled contributor

Some who were breastfeeding when they received their first vaccine mentioned specific positive experiences. Contributors gave examples of being provided with a room to breastfeed, and others were allowed to move through the queue quickly. Some mentioned that they had been apprehensive about receiving a vaccine while breastfeeding but said staff handled their concerns sensitively, providing them with additional information.

While experiences of receiving a first vaccine were generally very positive, some contributors described feeling uncomfortable. They felt that vaccination centres were impersonal or clinical and that they had been made to feel as though they were on a ‘conveyor belt’.

“ It was very cold, it was very clinical, it was very regimented, you know? You had to stand on a spot on the floor and there were cameras and security guards. It felt like something out of an apocalyptic film. It was a real, like, dystopian, if that’s the word, a dystopian experience I guess. But nothing could’ve been changed about it because that’s the way things were at the time.”

– Every Story Matters contributor

“ Mine was in one of the hospitals. It was almost like a post-apocalyptic movie thing because it was in, you had these long corridors, with lines of people on either side of the corridor, and then batches of people were called in, they went into a side room. I think that actually made me more nervous, just the setting, rather than actually getting the vaccine.”

– Every Story Matters contributor



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

Contributors were often excited or hopeful following their first vaccination. For some, being vaccinated was seen to symbolise progress.

“ I felt a bit hopeful that maybe we were kind of getting somewhere, that we’d be able to start going back to life and seeing friends and family. I remember leaving the [venue] and I think they had a big billboard up where they had been updating the numbers of vaccines that had been administered each day. I just remember thinking – yes, quite hopeful, that was it – that we’d made some progress, I guess.”

– Every Story Matters contributor

“ It was just a huge relief to all my family that it was done, particularly as I had carers coming into the house, who obviously went into other people’s houses.”

– Every Story Matters contributor

“ The vaccination programme was amazing – the relief in getting vaccinated is indescribable, I cried when my husband got his.”

– Every Story Matters contributor

However, as described in the previous chapter, some mentioned feeling a sense of regret or fear following their first vaccine. Often this was because they had felt ‘forced’ into taking a vaccine by a broader sense of societal pressure or because it was required by their workplace or for travel or socialising.

“ I just remember thinking, ‘why have I bothered?’ but I wanted to tick it off, to go on holiday. I remember saying, ‘After this, I’m not getting any more.’”

– Every Story Matters contributor

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.

“ Just apart from, sort of, feeling a bit under the weather, very achy arm, I mean I always have, and even in pregnancies you have your flu jab, but I remember this being another level of achiness, I was in a lot of pain.”

– Woman who was pregnant when offered a vaccine

“ I just got the usual, a slightly sore arm and that was it. No side effects whatsoever.”

– Every Story Matters contributor

In a few cases contributors spoke about experiencing more severe adverse reactions following vaccination. A small number told us they had experienced, and continue to experience, these first-hand. Others gave examples of family, friends or other people they knew who had done so.

“ Vaccine injuries are very real - I speak from first-hand experience of clotting issues which landed me in hospital for 10 horrible days when I was not sure if I was going to survive or not.”

– Every Story Matters contributor

“ I have another friend who is seriously vaccine injured, doctors have acknowledged that. She had an anaphylactic shock in the chemist after she had the vaccine, she's 28 and she now doesn't have a life. She can't work she's not well.”

– Every Story Matters contributor

Some who described experiencing severe adverse reactions shared how frustrated and angry they were about how little was done to acknowledge and address the impact on them and their health. They felt that vaccine injuries were often underplayed, dismissed and ignored. These contributors gave examples of medical professionals failing to take them seriously or provide them with the care they needed.

“ I've been injured by the vaccine. All doctors have done is give me medication, that's it, they don't acknowledge that this is vaccine injury. It seems like I'm talking to a blank wall when I speak to the GP.”

– Every Story Matters contributor

Those who experienced vaccine injury personally or through others often discussed the physical impact, but also the impact on their psychological and social wellbeing. Some gave examples of how the adverse effects on their health had resulted in financial difficulties.

“ I have suffered a lot not just physically from this adverse event, but also mentally. There is a huge stigma with vaccine injury that is deeply unfair to those affected. Nobody wants to hear about it, some try and find any other reason they can to explain my illness.”

– Every Story Matters contributor

“ The aftermath of my vaccine injury was predominantly physical, with debilitating symptoms that left me unable to work for an extended period. This not only affected my well-being but also had a significant financial impact due to the loss of my job and the lack of support during this critical time.”
– Every Story Matters contributor

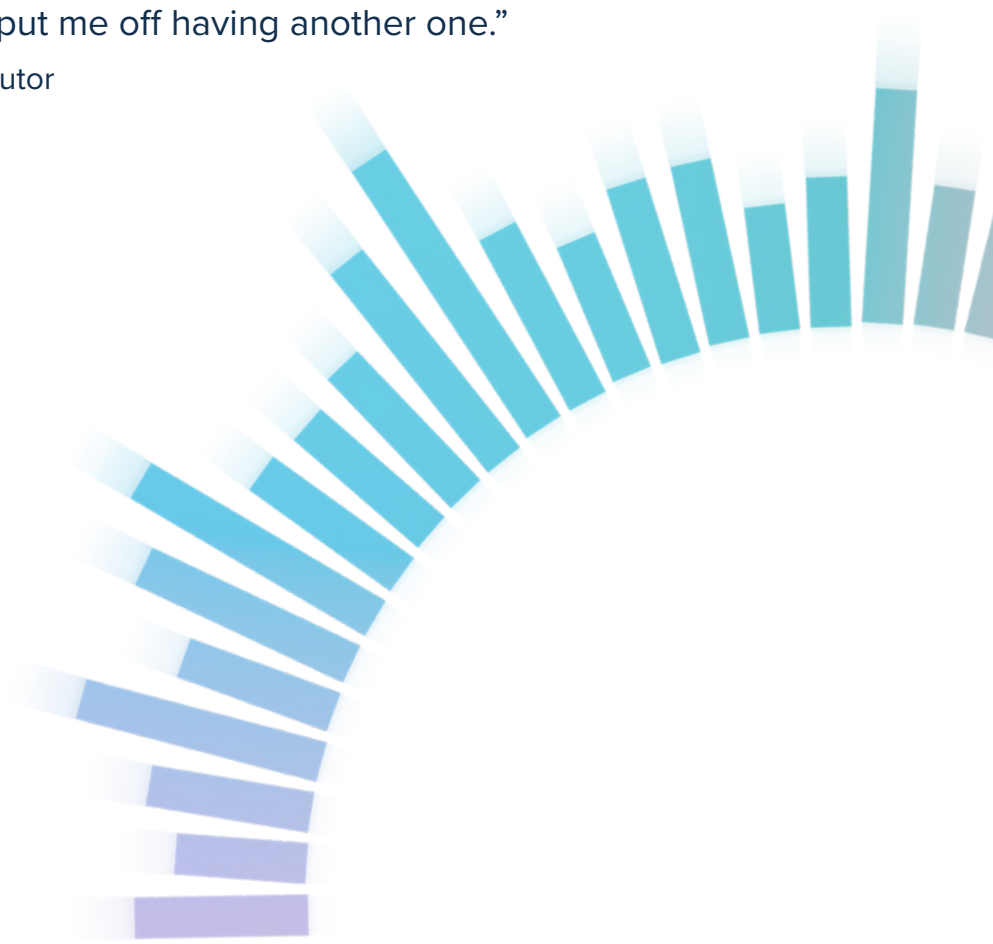
Experiences receiving subsequent doses of Covid-19 vaccines

Contributors who received subsequent doses of Covid-19 vaccines generally told us that their experiences were similar to their first dose. Many had booked their second dose at the same time that they booked their first dose and attended the same location to receive it.

“ Pretty similar really. I had them done in the same place, similar sort of reactions.”
– Every Story Matters contributor

For a few people, their experiences receiving a first dose put them off receiving any subsequent doses. Typically, this was because they had experienced distressing side effects following their first vaccine.

“ How ill I felt, it just really put me off having another one.”
– Every Story Matters contributor





5 Awareness and understanding of eligibility of therapeutics for Covid-19 among clinically vulnerable and clinically extremely vulnerable contributors

This chapter explores awareness and understanding of eligibility criteria for therapeutics for Covid-19 among clinically vulnerable and clinically extremely vulnerable contributors³. It starts by describing these individuals' understanding of their personal risk of severe disease from Covid-19, before moving on to discuss awareness of treatments for Covid-19 and understanding of the eligibility criteria for these treatments.

Perceptions of personal risk of serious illness from Covid-19 among clinically vulnerable contributors

Clinically vulnerable and clinically extremely vulnerable contributors generally considered Covid-19 a significant risk to their health. They described feeling frightened about contracting Covid-19 and how it would impact them and their families. Many worried about dying if they caught the virus. For this reason, most followed the guidance to shield until they received their first vaccine.

³ Among contributors to Every Story Matters it is not always possible to identify those who are clinically vulnerable and those who are clinically extremely vulnerable. This is because not all contributors provided this information when sharing their stories. Where possible, we have included information about whether contributors are clinically vulnerable or clinically extremely vulnerable. When this is not the case, we talk about all those who were asked to shield during the pandemic as 'clinically vulnerable' contributors.

“ I’ve had a tough life with my health, and I’ve been quite poorly at various points. But I’ve usually just got on with it. When Covid happened, if I’m honest, I never thought I’d be as scared of death as I was then, if that makes sense. I never thought that going out into the outside world would be scary. But when Covid hit, it changed within days. So one day I’m at work, and the next day we had to shut ourselves indoors...for things to change like that, to be scared for your life in that way, it was really scary.”

– Clinically vulnerable contributor

“ I am vulnerable because I have some relatively serious health problems. I was worried, I was concerned, but I just thought 'I’m going to need to take some practical steps to mitigate any potential problems'. While I was shielding, I was going for a walk and I would wear a mask. Sounds a bit extreme, but you never know right?...I couldn’t go and see my neighbours, I had to talk to them from a distance or on the phone, and I’m quite friendly with them. It affected not just my health but my mental health.”

– Clinically vulnerable contributor

Awareness and understanding of eligibility criteria for access to therapeutics for Covid-19

In response to the pandemic a range of therapeutics were made available for people at the highest risk of becoming seriously ill from Covid-19. Those available included nirmatrelvir plus ritonavir (Paxlovid), sotrovimab (Xevudy), molnupiravir (Lagevrio), and remdesivir (Veklury). The purpose of these treatments and medications was to help those at risk of serious illness to manage their Covid-19 symptoms and reduce the risk of becoming seriously ill.

Some of the clinically vulnerable people we heard from were aware of the therapeutics made by the health system for Covid-19. They had typically heard of the treatments through the NHS website or communications sent by the Chief Medical Officer. Others mentioned hearing about these treatments through local support groups for people with their condition where information about treatments for Covid-19 were discussed. They understood that these were treatments that were available for people like them, who were at greater risk of becoming severely ill from Covid-19.

“ I got letters from I think the Chief Medical Officer or some kind of Department of Health type letter and emails telling me about them...and I think people in my [health condition] Facebook group were discussing them.”

– Clinically vulnerable contributor

“ I heard about them but I wasn’t offered any of them. I heard that if we got infected with it, there was a treatment available to help us not suffer as much with it. But I never contracted it so I never had to have any of the treatments. So I didn’t know a lot about them but I knew there were treatments out there for us if we needed it.”

– Clinically vulnerable contributor

Experiences accessing therapeutics were mixed. Some found accessing treatments easy and straightforward. These contributors mentioned calling NHS 111 or being contacted by Test and Trace following a positive test. During these interactions they were asked a series of questions to determine whether or not they were eligible for treatment. Those considered eligible were either admitted to hospital to receive treatment or provided with a treatment to take at home. They often felt that these treatments helped to reduce the severity of their symptoms and they were grateful to have received them.

“ As mentioned, I received regular letters with updates from the Chief Medical Officer...one of these letters arrived just after I caught Covid advising that I could be considered for anti-viral treatment...on testing positive I was contacted by Test and Protect to advise I may be eligible for treatment and ask if I was interested. I had to go through a questionnaire relating to my Covid symptoms and details about my medical history. The person I was speaking to agreed that I was eligible for treatment, but due to my medical history he wished to discuss Covid and the possible treatment with my hospital consultant before I was treated. I was advised I would receive another phone call the next morning with the next steps once the discussion had taken place. I was called early the next day to make arrangements for me to receive the medication...they arranged to transfer me to hospital immediately and I was lucky enough to receive antibody treatment in the form of IV.”

– Clinically vulnerable contributor

Others described facing challenges accessing treatment. These contributors expressed confusion about who was and was not eligible for treatment. Some understood themselves to be eligible based on information they had received from the NHS and Chief Medical Officer during the pandemic. However, when they

contacted the NHS or spoke with Test and Trace they were told that they were not eligible for treatment. Those who experienced this felt angry and frustrated but also scared about what might happen to them as their infection progressed.

“ I felt very cross and disappointed when I learned that respiratory patients are not eligible for anti-viral medications. They were sent numerous letters telling them to shield yet were not considered ill enough to warrant anti-viral. All our friends were back to enjoying some sort of normality but still we were scared to mix much in fear of the effect Covid would have on a vulnerable person. I wrote to numerous politicians... asking them to fight for anti-virals for people with chest conditions. This was useless. Yet some people in other parts of the UK are entitled to anti-viral treatment. It seems like a lottery.”

– Family member of a clinically vulnerable contributor

Some expressed concerns at the speed of assessment, with this sometimes taking longer than the 48 hours within which they understood treatment should start.

“ My husband got Covid-19 after not leaving our flat at all until May 2021. We called NHS 111 and various other phone numbers constantly trying to find out how we could find out when he would know whether he would be admitted to hospital, but when he said he wasn't having trouble breathing we didn't hear anything. After three days he received a call saying his information was being reviewed by a doctor at our local hospital – this was already more than 48 hours after his positive test and outside the window that antiviral treatment was recommended to start.”

– Family member of a clinically extremely vulnerable contributor

Feelings of frustration were exacerbated by a perceived lack of consistency across the NHS. Some contributors mentioned being given conflicting advice by NHS staff, or hearing of people with their condition who had been given treatment elsewhere but which they were told they were not eligible for.

“ The nurses seemed upset and confused that they couldn't give me antiviral treatment, which wasn't nice to see them upset. My [health condition] team definitely needed to be more involved and better informed as soon as I caught Covid.”

– Clinically vulnerable contributor

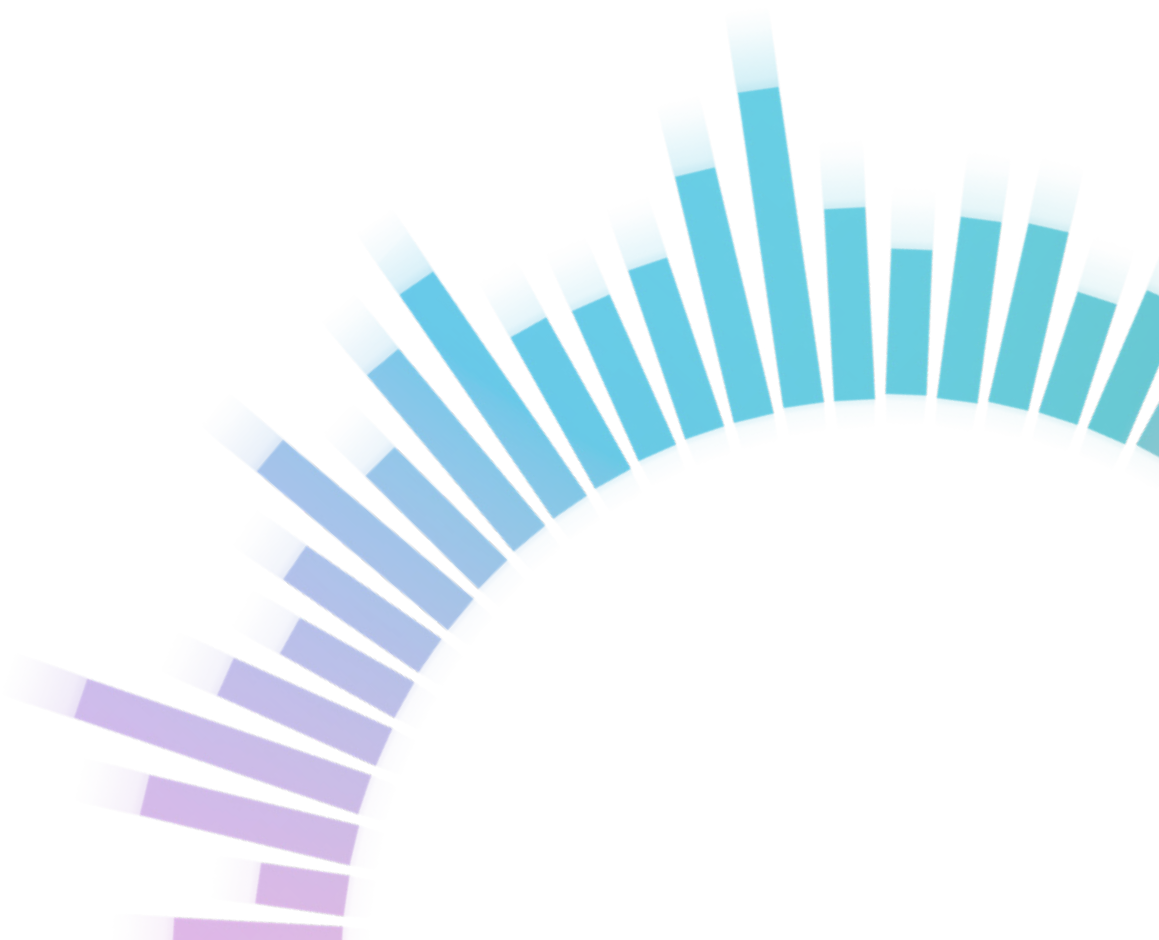
“ We need to look now at the total chaos surrounding clinically vulnerable people trying to access antiviral treatments when they catch Covid. There are absolute horror stories within this group of being told when catching the virus to contact their GP, who knows nothing, NHS 111, who ask them to then ring the GP, or to attend an A&E department with unmasked patients and medical staff.”

– Clinically vulnerable contributor

A few mentioned being contacted for treatment even though they believed they were not eligible.

“ When antiviral drugs became available to treat people infected with Covid-19, I received an email alerting me that I was eligible for this treatment if infected, although only if treated early, and that to aid early detection, I would be sent a PCR kit to use if I suspected infection. I was surprised as I am not in any of the at-risk groups and had never been advised to shield. I received the kit and put it to one side. When I became infected, I followed advice and submitted the sample. I then received a phone call to initiate the antiviral treatment. The agent advised that I had been recorded as having had an organ donation, which is not the case. We agreed that I had been added to this list incorrectly and we did not proceed with antiviral treatment.”

– Every Story Matters contributor



6 Appendix

Module 4 provisional scope

The provisional scope of Module 4 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 consider and make recommendations on a range of issues relating to the development of Covid-19 vaccines and the implementation of the vaccine rollout programme in England, Wales, Scotland and Northern Ireland. Issues relating to the treatment of Covid-19 through both existing and new medications will be examined in parallel. There will be a focus on lessons learned and preparedness for the next pandemic.

Thematic issues relating to unequal vaccine uptake will be examined, to include the identification of groups which were the subject of unequal uptake, potential causes of such unequal uptake, and the Government response.

The module will address issues of recent public concern relating to vaccine safety and the current system for financial redress under the UK Vaccine Damage Payment Scheme.

In particular, this module will examine:

1. The development, procurement, manufacture and approval of vaccines during the pandemic, including the effectiveness of UK-wide decision-making, in particular, the role of the UK Vaccine Taskforce. What lessons can we learn from innovative practices that were successfully introduced during the pandemic for future pandemic preparedness?
2. The development, trials and steps taken to enable the use of new therapeutics during the pandemic.
3. Vaccine delivery in England, Wales, Scotland, and Northern Ireland, including rollout procedures such as: arrangements on the ground and public messaging: Joint Committee on Vaccination and Immunisation recommendations on eligibility/prioritisation and decisions

taken by policy makers; the ethics of prioritisation decisions and impact on particular groups such as those with comorbidities. Vaccine as a Condition of Deployment, in particular its effectiveness in limiting transmission and impact on vaccine hesitancy.

4. Barriers to vaccine uptake, including vaccine confidence and access issues and the effectiveness, timeliness, and adequacy of Government planning for and response to inequalities relevant to vaccine uptake.
5. Vaccine safety issues including post-marketing surveillance, such as the Yellow Card monitoring and reporting system and a suggested correlation between Covid-19 vaccines and cardiovascular issues.
6. Whether any reforms to the UK Vaccine Damage Payment Scheme are necessary.

Please note that the targeted research for Module 4 focused on Key Lines of Enquiry (KLOEs) 3 and 4.

How people shared their story with us

There are three different ways we collected people's stories for Module 4:

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 4, we analysed 34,441 stories related to Covid-19 vaccines. This includes 28,246 stories from England, 2,756 from Scotland, 3,133 from Wales and 1,679 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. Firstly, all responses to each question were taken from the online form and blank data was removed. Secondly, responses were filtered based on their relevance to Module 4.

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?':

- Covid testing and vaccinations
- Official government information, for example, advice on isolating at home
- Something positive that you experienced

Following the identification of relevant stories, a topic model was run for each of the three open-ended questions included in the online form. From this we identified a total of 110 topics across all responses to Q1, 129 at Q2, and 132 at Q3. Since contributors could select multiple responses to the question 'What would you like to tell us about?' it was possible that the stories selected for inclusion contained information not relevant to Module 4. 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 4 from the final stage of analysis. This removed a total of 28 topics at Q1, 49 topics at Q2, and 73 topics at Q3, leaving a total of 82, 80, and 59 topics per question respectively.

Following the removal of topics not relevant to Module 4 a statistical factor analysis was conducted to map relationships between topics and group them based on those commonly occurring together or within three sentences of each other. For example, topics about scientific evidence, public health and statistics and data were automatically grouped into a factor about government data. The factor analysis produced 16 overarching factors across the 82 topics relevant at Q1, 19 factors at Q2, and 19 factors at Q3.

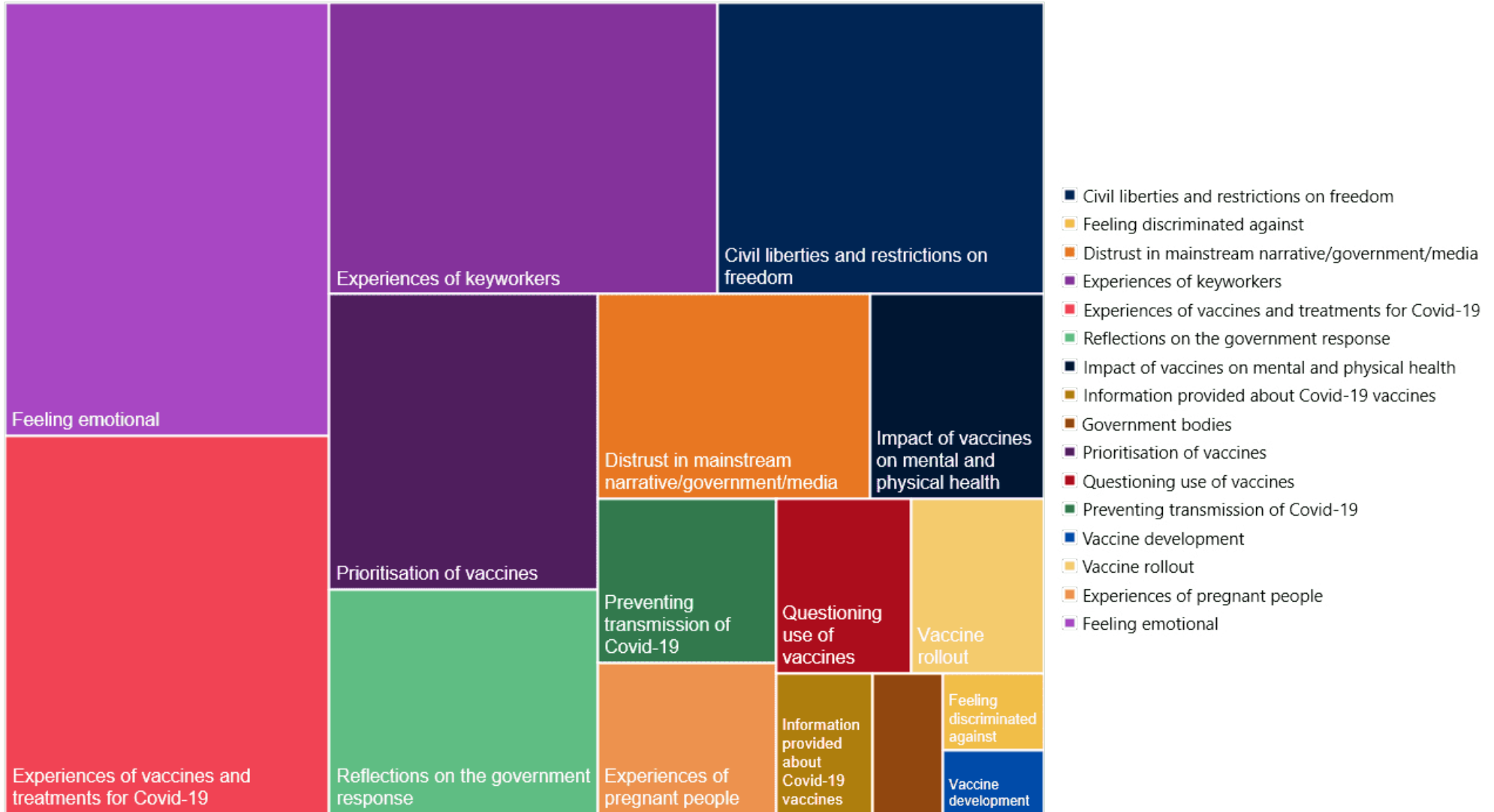
Following the topic modelling and factor analysis a codeframe was generated based on those topics relevant to Module 4. This involved human review of the most common words and phrases, both in the full dataset and within each topic, to identify keywords and patterns that could be used to group stories 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, 34,441 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 4 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 overleaf 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.

Figure 2: Online form themes



Listening events

The Every Story Matters team **travelled to 25 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:

- Carlisle
- Wrexham and Ruthin
- Newham
- Exeter
- Paisley
- Derry / Londonderry
- Middlesbrough
- Enniskillen
- Bradford
- Skegness
- Stockton-on-Tees
- Birmingham
- Milton Keynes
- Bournemouth

Virtual listening sessions were also held where that approach was preferred. We worked with many charities and grassroots community groups to speak to those impacted by the pandemic in specific ways. This includes bereaved families, people living with Long Covid and Paediatric Inflammatory Multisystem Syndrome (PIMS-Ts), clinically vulnerable people and their families, disabled people, 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 professionals 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 concerns which may have impacted their vaccine decisions (including clinically

vulnerable and clinically extremely vulnerable people and people who were pregnant or breastfeeding at the time they were offered a vaccine) and groups where there was relatively low uptake of the Covid-19 vaccines (including people from Black African, Black Caribbean, Pakistani, and Bangladeshi groups) as well as those less likely to respond in other ways. These interviews and discussion groups focused on the Key Lines of Enquiry (KLOEs) for Module 4. In total, 228 people across England (119), Scotland (38), Wales (40) and Northern Ireland (31) contributed in this way between October 2023 and December 2023. This includes 121 in-depth interviews with:

- People who are immunosuppressed/clinically vulnerable and were shielding during the pandemic.
- People who were pregnant or breastfeeding at the time that they were offered a vaccine.
- People from Black African, Black Caribbean, Pakistani, and Bangladeshi groups.
- People who chose not to receive a Covid-19 vaccine.

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 30 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 4 Key Lines of Enquiry (KLOEs).

The tables below outline the number of interviews across the healthcare system and with people experiencing health inequalities.

Table 1: Covid-19 vaccines – targeted listening

Participant type	Interviews complete
General public who had received at least one dose	107 participants across 18 discussion groups
People who chose not to receive a Covid-19 vaccine	20
People who were pregnant or breastfeeding when offered a vaccine	30
People who are immunosuppressed/clinically vulnerable	30
People from ethnic minority backgrounds	41
Total	228



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

Contact information for Ipsos: everystorymatters@ipsos.com

Any enquiries regarding the design of this publication should be sent to: creative@covid19.public-inquiry.uk

