


# Every Story Matters

## Healthcare

June 2024





<b>Contents</b>	<b>1</b>
<b>Foreword</b>	<b>2</b>
<b>Acknowledgements</b>	<b>4</b>
<b>Overview</b>	<b>5</b>

# Foreword

This is the first record produced by the Every Story Matters team at the UK Covid-19 Inquiry. It brings together the experiences shared with the Inquiry relating to its investigation into healthcare systems and has been submitted by the team to the Chair of the Inquiry, Baroness Hallett.

Baroness Hallett made it clear from the outset that she wanted to hear from as many people as possible, particularly those who had suffered hardship and loss, as set out in the Inquiry's Terms of Reference. So we created Every Story Matters to help us hear from people in a way which suited them - in writing, online or on paper, at an Every Story Matters event around the country, by videoconference, using sign language or on the telephone. Stories are powerful and personal and they bring to life the human impact of the pandemic.

By launching Every Story Matters, the Inquiry gave people the opportunity to share their experience with us, to have someone listen to them, to have their experience recorded and to contribute to the Inquiry. Our contributors will provide Baroness Hallett with the kind of information she needs before reaching her conclusions and making recommendations. In that way, they can help ensure the UK is better prepared for the next pandemic and that the response to it is more effective.

When we started listening to the people of the UK about their experiences of the pandemic, we knew the experiences would be varied. For many people the impacts of those years, and the years since, were far reaching. In some cases they were and are extremely painful, and for some almost too painful to talk about. For many people the pandemic was

devastating and many are still dealing with the consequences be they bereavement, long term medical conditions, or other kinds of loss and hardship. We also heard that some people want to move on and not talk about the pandemic anymore. Sometimes we heard more positive things, where people had formed new connections, had learned something or had their lives changed in some way for the better.

Every Story Matters has been designed to protect people's identity, avoid re-traumatisation as much as possible and provide them with choice about how to contribute. Collecting and analysing stories in this way is unique for a research project; Every Story Matters is not a survey nor a comparative exercise. It cannot be representative of the entire experience of the UK nor was it designed to be, but it has enabled us to identify themes amongst people's experiences and cases that do not fit into any particular group.

In this record we cover thousands of experiences that demonstrate the impact of the pandemic on patients, their loved ones, healthcare systems and settings, and key workers within them. There are thousands more experiences that do not feature in this record. All experiences shared with us will flow into future Every Story Matters records. As these records are tailored to the different modules, we use people's stories where they can add most insight to the areas under investigation. We continue to encourage people to share their experiences with us, because it is their stories that can support and strengthen the Inquiry's recommendations and help reduce the harms of a future pandemic. Please check the Inquiry website for the latest information and timings.

We have been enormously supported by individuals, groups and organisations which have given us feedback and ideas and helped us to hear from a wide range of people. We are very grateful to them and we acknowledge many of them on the next page.

Delivering Every Story Matters has touched all those involved. These are stories that will stay with all those who hear or read them for the rest of their lives.

*The Every Story Matters Team*

# Acknowledgements

The Every Story Matters team would like to express its sincere appreciation to all the organisations listed below for helping us capture and understand the voice and healthcare experiences of members of their communities. Your help was invaluable to us helping ensure that we reached into 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.

- Association of Anaesthetists
  - British Geriatrics Society
  - Carers UK
  - Clinically Vulnerable Families
  - Covid-19 Bereaved Families for Justice Cymru
  - Covid19 Families UK and Marie Curie
  - Disability Action Northern Ireland, and the ONSIDE Project (supported by Disability Action Northern Ireland)
  - Eden Carers Carlisle
  - Enniskillen Long Covid Support Group
  - Foyle Deaf Association
  - Healthwatch Cumbria
  - Long Covid Kids
  - Long Covid Scotland
  - Long Covid Support
  - Long Covid SOS
  - Mencap
  - Muslim Women's Council
  - People First Independent Advocacy
  - PIMS-Hub
  - Race Alliance Wales
  - Royal College of Midwives
  - Royal College of Nurses
  - Royal National Institute of Blind People (RNIB)
  - Scottish Covid Bereaved
  - Sewing2gether All Nations (Refugee community organisation)
  - Self-Directed Support Scotland
  - Trades Union Congress
  - UNISON
- To the Bereaved, Children and Young Peoples', Equalities, Wales, Scotland and Northern Ireland forums, and Long Covid Advisory groups, we truly value your insights, support and challenge on our work. Your input really was instrumental in helping us shape this record.
- Last but not least, we would like to convey our deepest gratitude to all the bereaved families, friends and loved ones for sharing their experiences with us.

# Overview

## How stories were collated and analysed

Every story shared with the Inquiry is analysed and will contribute to one or more themed documents like this one. These records are submitted from Every Story Matters to the Inquiry as evidence. This means the Inquiry's findings and recommendations will be informed by the experiences of those impacted by the pandemic.

People shared their experiences with the Inquiry in different ways. The stories that described experiences of healthcare during the pandemic have been brought together and analysed to highlight key themes. The approaches used to explore stories relevant to this module include:

- Analysing 32,681 stories submitted online to the Inquiry, using a mix of natural language processing and researchers reviewing and cataloguing what people have shared.
- Researchers drawing together themes from 604 research interviews with those who were involved with healthcare during the pandemic in different ways including patients, loved ones and healthcare workers.
- Researchers drawing together themes from Every Story Matters listening events with the public and community groups in towns and cities across England, Scotland, Wales and Northern Ireland, including among those who experienced specific pandemic impacts. More information about the organisations the Inquiry worked with to organise these listening events is included in the acknowledgements section.

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

Throughout the report, we have referred to people who shared their stories with Every Story Matters as ‘contributors’. This is because they have had an important role in adding to the Inquiry’s evidence and to the official record of the pandemic. Where appropriate, we have also described more about them (for example, different types of staff working in healthcare) or the reason they shared their story (for example as patients or loved ones) to help explain the context.

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

*In giving voice to the experiences of the general public, some of the stories and themes included in this report include descriptions of death, near death experiences, and significant physical and psychological harm. These have the potential to be upsetting and readers are encouraged to take steps to support their wellbeing as they do so. This might involve taking breaks, considering which chapters feel more or less tolerable to read, and going to colleagues, friends, family or supportive others for help. Readers who experience ongoing distress related to reading this report are encouraged to consult with their healthcare provider to discuss options for support. A list of supportive services are also provided on the UK Covid-19 Inquiry website.*



## The stories people shared about healthcare during the pandemic

People told us about the many life-changing impacts the pandemic had on them as patients, loved ones and healthcare workers, and some are still living with these impacts today.

Many people faced problems accessing healthcare during the pandemic, whether in emergency situations, for acute health conditions, or for more routine appointments.

We heard about the devastating loss experienced by those who were bereaved during the pandemic. We heard about lives that have been disrupted and damaged by catching Covid-19, developing and living with Long Covid and delays to receiving treatment for other serious illnesses. Clinically vulnerable and clinically extremely vulnerable people told us about the physical and emotional toll of shielding and the ongoing impact of Covid-19 on their lives.

We also heard about positive things that happened during the pandemic. Healthcare services continued to support many patients and there were examples of good patient care. Healthcare workers reflected on all they did to adapt how they treated and cared for people and the ways they supported patients' loved ones in uniquely challenging circumstances.



## Changes to healthcare during the pandemic

The fear of catching Covid-19 meant many people were reluctant to access healthcare services, particularly early in the pandemic. Fears were strongest about going to hospital but also applied to other in-person healthcare settings. Many patients and their loved ones were scared they might be separated because of visiting policies.

“ To be honest, nobody wanted to go to hospital at that stage. Unfortunately, I had no option. I was ambulated in. I really fought not to go to hospital each time, but it was dangerous, and I needed to be there, and I understood that.”

– Person hospitalised with Covid-19

“ I didn't want Dad to go into hospital, my dad didn't want to go into hospital either. We were both of the same opinion. He didn't want to go into hospital, he loved being at home, if he's going to die, he wanted to die at home. We knew if he went into hospital, I would wave goodbye at the door and the chances are I would never see him again and he would die alone in hospital.”

– Bereaved family member

The fear of catching Covid-19 and public awareness of the pressures on healthcare systems meant there was broad acceptance of the need to reorganise how healthcare was provided during the pandemic. Contributors shared many examples of how challenging these changes were for patients, their loved ones and healthcare workers.

One important change was that many more services were delivered remotely, either online or by phone. Patients, loved ones and clinicians were often unconvinced that symptoms could be properly assessed without a face-to-face consultation.

“ I have to send photographs to my doctor’s WhatsApp group. My GP surgery has a WhatsApp telephone number where you send your name, date of birth and the photographs...it’s just not the same.”

– Person living with Long Covid

There was some confusion about the guidance in place during the pandemic – especially for visiting loved ones or attending appointments with them. We also heard about guidance not being applied consistently and the problems and frustration this caused.

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**“At the time the government guidelines were much more liberal than the rules the hospital actually chose to apply, which was hugely frustrating and had a detrimental impact on my mental health. Other hospitals were far more accommodating, with use of compassion and common sense.”**

– Hospital patient

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For patients worried about Covid-19 infection, Personal Protective Equipment (“PPE”) was often seen as reassuring because it would reduce the risks they faced. For others, PPE created a barrier that felt unnatural or frightening, adding to their anxiety about being ill during the pandemic. Some healthcare workers agreed that PPE placed an obstacle between them and patients and made providing care more challenging than before the pandemic.

Hospital visits not being allowed or being restricted was frustrating and often frightening for patients. Loved ones found not knowing what was happening incredibly distressing, particularly when patients were very ill or nearing the end of their lives. Similarly, many healthcare workers shared how upsetting they found not being able to communicate in the usual way with loved ones who were distressed.

“ 48 hours later, you’re calling them up to tell them that their relative is dying and they don’t believe you and why should they? And they’ve got questions that you can’t answer, and you’ve got answers that they don’t want.”

– Hospital doctor



## Problems accessing healthcare

People found it hard to access healthcare during the pandemic, in some cases with serious and lasting impacts. There were several common problems noticed by patients, loved ones and healthcare workers:

- Many patients shared how hard it was to book GP appointments, leaving them with no way to get routine medical help.

“ There was no need to shut down the GP practices and reduce that. I think a lot of people could have still been seen, people who’ve got lumps and bumps or need things removing. I think they could have dealt with that. I think maybe that might have saved a few lives as well.”

– GP patient

- Non-Covid-19 hospital care was scaled back, leading to long delays for treatment, in some cases for serious illnesses or ongoing health conditions.

“ I have several cases in my mind of people who suffered with benign but limiting conditions, that were very easy to fix had they had access to acute healthcare sooner. But, you know, it was very difficult for them to get access to healthcare, to see the person they needed to.”

– Hospital doctor

- Those who tried to access emergency care were sometimes unable to get help or faced significant delays, even when they or their loved ones were very ill.

“ Usually there might be 30 calls waiting at any one time. At peak points in the pandemic there were 900 calls waiting.”

– NHS 111 call handler

Contributors reflected on how anger and frustration about accessing care increased as the pandemic went on. Many of them blamed these problems for people having to live with pain and other symptoms, reducing their quality of life and leading to worsening health. Some directly linked delays, cancellations or mistakes across healthcare during the pandemic to serious health problems or the death of a loved one.

Patients, loved ones and clinicians were often frustrated that treating Covid-19 and reducing the spread of the disease was prioritised over other serious healthcare needs. Many contributors argued that more could have been done to avoid the negative impacts on non-Covid patients.

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**“In the lockdown, people were still poorly. Someone was diagnosed with cancer and couldn’t get an appointment. Don’t neglect people with other treatment needs. The chemo treatment was cancelled, the cancer progressed, and they died.”**

– Healthcare worker

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We also heard about the many specific barriers to accessing care – and receiving good care – encountered by people with a disability, those who do not speak English and those without digital technology or reliable internet.

“ Understanding information, being deaf, not being able to communicate, lots of things online, and having to use English and write, you know, e-mails and stuff like that and text messages wasn’t really accessible for me.”

– Deaf person

Some contributors also highlighted how the pandemic worsened existing inequalities.

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**“I witnessed firsthand the impact of Covid-19 on a community that was already disadvantaged by many social disadvantages including poverty. Again, I witnessed that black lives don’t matter. Covid-19 ripped through [where I lived] as Covid-19 has adversely impacted front line workers, people of colour, people on zero hours contracts who would not be furloughed and could not afford to stop working.””**

– Person from an ethnic minority background

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**“** I would say I’m one of the most confident people to ask questions, but even me I sometimes feel a bit embarrassed, ‘Am I asking too much? Or can people understand what I’m trying to explain?’ You know? I knew some people, not only language was a barrier, actually it’s the literacy bit as well. It’s, like, they can’t read, they can’t write, they don’t understand the language. Even when you explained it in Chinese, the medical term was too complicated for them.”

– Person who speaks English as a second language

## Experiences of Covid-19

Some healthcare workers felt motivated to work directly with Covid-19 patients. They wanted to do what they could to help, despite the fear of being directly exposed to the virus. Many healthcare workers were worried about catching Covid-19 themselves and passing it on to their families.

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**“Every day I would go in and see death and every day I would wonder if this is the day I take it home to my small children.”**

– Healthcare professional

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Some shared how they lost colleagues to the disease.

“ All three of us who went for training became ill... with Covid-19 symptoms. Another friend and I (all nurses and paramedics) improved but within two weeks our other friend was dead, found by paramedics at home alone after calling for help because at the time people were getting advised not to travel to hospital. She was 29 years old and died alone.”

– Healthcare professional

Healthcare professionals treating Covid-19 patients told us they did their best despite the huge challenges they faced, sometimes without the equipment and staff resources they needed. This put them under enormous strain and many described feeling stressed and exhausted. They told us their experiences had a negative impact on their mental health. Despite the challenges, those who treated Covid-19 patients also shared how the care they offered improved as the pandemic progressed and more was learned about the disease.

“ I know that I see a lot of trauma a lot of the time, but this... was on a different kind of level. It was something that none of us had experienced. And everyone was sort of just winging their way through this situation, that no one really knew how to handle it, but we were trying our best.”

– Paramedic

Many Covid-19 patients described how afraid they were about being hospitalised unexpectedly with Covid-19 and how confusing it was. Some struggled to remember much about their time in hospital because they were so ill.

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**“One day I woke up in ICU unable to move, speak, eat, drink etc. I was totally reliant on staff go wash me, feed me, etc. I was hooked up to oxygen, had a catheter, wearing a pad, and remains of a tracheostomy in my throat. Apparently, I’d been in an induced coma for two months.”**

– Patient hospitalised with Covid-19

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Some patients who were hospitalised with severe Covid-19 told us they are still traumatised by their experiences. We heard how disturbing it was to witness the deaths of other Covid-19 patients, and how this added to fears about the disease.

“ A few weeks after, my son’s mental health deteriorated, he was having visions of being back in his hospital ward and the man from the bed next to him in hospital was standing in his room and was angry that he didn’t help him ... he is crying in Tesco because the beeping of the tills took him back to the monitors beeping in the hospital.”

– Carer for a patient hospitalised with Covid-19



# Impact of the pandemic

## End-of-life care and bereavement

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Many bereaved families, friends and colleagues shared their loss, devastation and anger. They were often not allowed to visit and had little or no contact with their dying loved ones. Some had to say goodbye over the phone or using a tablet. Others had to do so while keeping their distance and wearing full PPE.

Bereaved families and friends had much less involvement in decisions about their loved ones than they usually would. We heard about loved ones struggling to contact healthcare professionals to find out what was going on. This often meant the situation felt out of their control, leaving them scared and helpless. Advocating for their loved ones and their care from afar was much harder than under normal circumstances, and sometimes impossible.

“ My husband was taken into hospital and basically written off because of age and other conditions... he was negative for Covid and he was put on a ward where it was rife. We were not allowed to visit, had no idea of what was happening. He passed away and I received a phone call at 3:15am telling me he had gone.”

– Bereaved family member

“ You just couldn't get through to anybody, you couldn't talk to anybody, we were all ringing for an update... my father rang daily for her [grandmother] to be released to us... We have everything set up here [at home]. She even had an electric bed, we had wheelchairs and everything for her. We could have helped her.”

– Carer for an elderly family member

Those bereaved families, friends and colleagues who were able to visit often had to do so in extraordinary and very restricted circumstances, usually when the patient was at the end of their life. Some had to choose who would visit because numbers were limited. Many were not allowed to touch their

loved one and had to wear PPE. The restrictions meant some visited alone, without the support of family and friends. The experience was often disorienting and frightening.

We heard a lot about do not attempt cardiopulmonary resuscitation (DNACPR) notices and end-of-life care and how decisions were not always explained to loved ones. Some bereaved families and friends told us they did not know what decisions had been made until after their loved one had passed away, or still did not know.

“ The GP asked for a DNACPR to be in place, my dad knew about this and the possible consequences, he wanted to live, he didn't want one. Then I found out the GP had visited again unannounced with DNACPR request, and they never mentioned it to me.”

– Bereaved family member

As well as the many challenges bereaved loved ones faced, the stories included examples of healthcare workers offering excellent end-of-life care during the pandemic. Some described how supportive staff were and how much this improved end-of-life care. One common example was health professionals breaking Covid-19 guidance to provide physical comfort to their loved one who was dying.

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**“I remember, one nurse was like, ‘Oh, your dad wanted me to give you a hug, and say, ‘Here’s a hug.’” Obviously, she didn’t need to do that...you’re not even meant to be getting that close, but just that kind of humane feeling, and I was just like, oh my God, that is just so refreshing to see in a medical person.”**

– Bereaved family member

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For many, losing loved ones and not being able to say goodbye properly made their loss harder to accept and come to terms with. Some are left with the overwhelming guilt that they should have done more to protect them from Covid-19 or from having to die in healthcare settings alone.

## Long Covid

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Long Covid is a set of long-term health conditions and symptoms some people develop after being infected with the Covid-19 virus. Long Covid had – and continues to have – a dramatic and often devastating impact on people. Many people living with Long Covid told us how they wanted better recognition and more public understanding of the symptoms they continue to experience and the huge impact that it has on their ability to live their lives. Some also emphasised the importance of more research and development focused on treatments for Long Covid.

“ We’re left alone now; we don’t know what we can do. They need to recognise Covid is a long term or lifelong condition for some people.”

– Person with Long Covid

Those living with Long Covid shared the many ongoing health problems they have experienced, with different types and severity of symptoms. These range from continuous aches and pains and brain fog, to debilitating mental exhaustion. Many told us how their lives have been devastated, and how they are now unable to work, socialise and carry out day-to-day tasks.

“ I was unable to return to work or my normal life as it left me very debilitated with chronic fatigue, and dysautonomia<sup>1</sup>, chronic headaches, brain fog and poor concentration.”

– Person living with Long Covid

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1 Dysautonomia is an umbrella term describing a disorder of the autonomic nervous system, which controls bodily functions including regulating our heart rate, blood pressure, temperature, digestion and breathing. When dysregulation occurs, these functions can be altered, resulting in a range of physical and cognitive symptoms.

Accessing care has often been incredibly challenging for people living with Long Covid. Some shared how they felt their GP was disinterested in their symptoms or did not believe them. In conversations with GPs or other healthcare professionals they often felt dismissed. Sometimes, we heard healthcare professionals would suggest and/or seek to exclude an alternative cause of their symptoms such as issues with their mental health or pre-existing health conditions.

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## **“We had GPs refusing to believe in Long Covid here, with many others not getting testing for symptoms.”**

– Person living with Long Covid

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The experiences shared also highlight inconsistencies in how people with Long Covid have been treated. It has been draining for those with ongoing symptoms who have been passed between different parts of the healthcare system without receiving the care needed, if any – often while very unwell. They described feeling abandoned and helpless, and unsure where to turn.

“ Nobody wants to know, I feel invisible. I’m treated as collateral damage. The frustration and anger I feel is incredible; medical gaslighting, lack of support and the way other people treat me, the GP tells me I’m too complex, because I have so many medication reactions.”

– Person living with Long Covid

Some were referred back to their GP by specialists for further tests or to treat other symptoms, while others were referred to Long Covid clinics or directed towards online courses once these had been set up in some areas of the UK in late 2020. Some people living with Long Covid found clinics and online courses helpful but many received poor care without any tailored support or treatment.

“ So, we still feel that we’re being sent to the GP and the GPs don’t know what to do with us, GPs are busy with lots of other things. And even the sympathetic GPs with the best will in the world haven’t got a clue what to do with us. We need something more specialised basically.”  
– Person living with Long Covid

We also heard about healthcare workers who have been, and continue to be, impacted by Long Covid. Some contributors suggested the fact that healthcare professionals have developed Long Covid has reduced the capacity of healthcare services to provide care today.

### Shielding

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People who were clinically vulnerable and clinically extremely vulnerable told us they were very afraid of Covid-19 and understood why they were asked to shield. However, many shared how hard they found it to follow the shielding advice and the negative impacts this had on them and their families.

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**“I coped by doing other things but if I’d have gone a little bit longer, a few more weeks, I think I would have gone over the edge to be honest with you. I was getting to the stage where I couldn’t cope...and only having [my mother] really to speak to, that was a big thing because my whole life was quite social. I was lonely, and I tried not to let that affect me too much. It was driving me absolutely crazy.”**

– Person who was clinically extremely vulnerable

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People who shielded shared how doing so frequently led to isolation, loneliness and fear. Their physical and mental health often deteriorated. Some still feel afraid to leave the house – for them, the pandemic is not over.

“Collapse of routine, mental health suffered, physical health suffered. She [her mum] didn't eat a lot actually, she lost a lot of weight because she wasn't well...but yes, so she suffered a lot mental health wise and physical health wise from just lack of other people basically more than anything, lack of any kind of interaction.”

– Carer for someone who was clinically extremely vulnerable

Many were left stuck at home feeling confined, anxious or bored, and in some cases still are. They shared how frustrating it was not being able to exercise and look after their health properly.

“Being told I was so at risk of Covid-19 made me feel out of control of my health and incredibly stressed. I feared I would die if I caught Covid-19. By shielding, the real risk to me was not being able to manage my health condition which I do mainly through exercise.”

– Person who was clinically extremely vulnerable

Some contributors were more positive about shielding. This was often because they were comfortable at home or were able to keep busy and positive. Being able to develop a routine with meaningful things to do helped them cope.

“With the help of a garden...I was spoilt for things to do. So that probably saved me totally, mental health-wise... it didn't affect me probably as much, as someone in a housing estate or, high-rise apartments or something, that didn't have that outside space to go to.”

– Person who was clinically extremely vulnerable

Some clinically extremely vulnerable people described how they are still shielding because the risks associated with Covid-19 have not gone away for them. They continue to fear mixing with others and have often lost connection to their communities. They want more recognition that the impact of the pandemic is ongoing for those who are clinically extremely vulnerable.

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**“[One] of my friends is older, she’s in her 70s, she’s not come back to church... she really has no social life whatsoever anymore...her biggest challenge is around the fact that she feels that she’s being given this information, that tells her she’s vulnerable, that she needs to protect herself, she needs to stay away from people, she is at risk, and that her risk hasn’t changed, and that Covid-19 is still around. And so, she struggles to reconcile the fact that it feels like the advice has changed, and yet, the risk is still the same...And so, I think there’s a lot of, still, fear wrapped up around all of that for people.”**

– Person who was clinically extremely vulnerable

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## How the healthcare system adapted

As well as the impact on patients and their loved ones, healthcare workers also told us about their experiences during the pandemic. They described the work they did to continue offering care as best they could, with many pointing to the huge changes that were made in healthcare settings.

Many contributors working in healthcare said the pace of change was much faster during the pandemic than they had experienced previously. The stories shared with us highlight some tensions and disagreements among healthcare professionals caused by the challenges of implementing rules. These were often between those working directly with patients and those in management or senior leadership roles. For example, some contributors thought senior leadership often seemed to wait for guidance from the government or NHS Trusts on what to do rather than taking proactive action.

We also heard how some healthcare professionals increasingly questioned the basis for Covid-19 guidance as the pandemic went on. These concerns often focused on whether the guidance was based on evidence of what worked to prevent infection.

Healthcare professionals told us how they found out about guidance through the media and their employers and about differences in how Covid-19 guidance was implemented across different parts of the health service.

### **Personal protective equipment (PPE)**

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Healthcare workers across different settings told us they did not have the PPE they needed, especially at the start of the pandemic. The design and fit of some PPE also caused significant problems, making it harder for some to do their jobs and causing discomfort.



I had friends working in ICU wearing bin bags.”

– Community nurse



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**“I used to roll it up to my waist, get an apron and use the apron as a belt, and then hang a pen off that as well. So, the sizing wasn’t great and then you’re bigger than you think you are and you crash into a lot of items because you’ve got more width on you.”**

— Hospital nurse

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We heard examples of how PPE that did fit properly physically impacted some staff when they wore it for many hours. This included examples of rashes, skin sensitivity and impression marks from wearing masks for long periods.

PPE also made spoken communication between healthcare professionals and patients more difficult. This was a particular challenge for patients with additional communication needs, including hearing impaired and autistic people who depend on facial expressions for communication.

“ You say, ‘I’m deaf,’ and they’re talking to you through a mask, and I’ll say, ‘I’m deaf.’ They’re, like, ‘Oh, no, no, I can’t take my mask off. You might give me Covid-19.’ I’m like, ‘Well, you know, I’ll stand over here, you stand over there. Please take your mask down, I’ll be more than 2 metres away,’ and they still refused. That was really difficult and then you literally can’t see their mouth or their face, so you’ve got no hope of understanding them.”

— Deaf person

Healthcare workers in different settings had mixed impressions of the clarity of guidance and requirements when it came to testing. They recalled self-isolation guidance being particularly strict at the start of the pandemic, which meant they were unable to work at times when they were well.

## Primary care

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Those who worked in primary care often shared how adapting to the pandemic had been challenging and made it harder to offer good care to patients. Even so, they reflected on how much they managed to change and how this allowed them to look after many of their patients.

“ We did adapt, and I think we did change. I think we did what we had to do. It was dynamic the whole time really, wasn't it? It was changing all the time, and we did our best, I think, to go and do what we had to do.”

– GP nurse

Some felt that GPs and community pharmacists were not properly considered and consulted, and that the pandemic response in hospitals was prioritised. They were frustrated at rapidly changing guidelines, with little notice and often a lack of clarity about how GP surgeries or pharmacies were supposed to respond.

We heard about some local GP services collaborating to share ideas and pool staff and resources, and about ‘Covid-19 hubs’ to treat patients and reduce hospital admissions. These approaches were generally seen as positive, giving those working in primary care more confidence in assessing and treating Covid-19.

GPs reflected on how the pandemic caused some new health problems. For example, some thought social distancing had led to greater isolation, in turn contributing to more mental health issues among their patients.



## Hospitals

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We heard from healthcare workers about how hospitals made changes to manage the expected influx of Covid-19 patients. They told us about the upheaval across different roles in hospitals, not just among clinical staff. While some healthcare workers were positive about the way the response was managed, others said it was insufficiently thought through.

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**“There were enormous changes made. Reallocating areas, reallocating staff, everybody moving from place to place, changing what they were doing.”**

— Hospital nurse

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“ Many staff were redeployed to different clinical areas away from where they normally work to assist with the Covid response – these members of staff were “thrown in at the deep end” with little additional training and no choice about where they were sent. This also had an impact on many junior doctors’ training pathways.”

— Hospital doctor

Planning and delivering care continued to be challenging later in the pandemic. Many contributors shared how making changes to hospital care became more difficult due to staff exhaustion and low morale. Some described a lack of planning as to how to prioritise non-urgent care and treat more patients as pandemic restrictions began to ease.

“ There was no advice on how to step back from anything and there was absolutely no help with de-escalation. And it felt, to us, no sense of learning of, ‘Okay, what we did in the first wave’.”

— Hospital doctor

## Emergency and urgent care

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There was huge pressure on many emergency departments (EDs) during the pandemic, with challenges linked to the suitability of buildings, staff shortages and periods of increased demand for urgent care. The pressure they were under varied between different EDs and changed at different stages of the pandemic.

Many of those working in emergency care said they were at times unable to maintain infection controls because there were large numbers of patients and not enough space. Some ED staff told us about having to make decisions about prioritising care and transferring patients to intensive care (ICU or ITU), and about how difficult these were because of how serious they could be for patients.

“ We were being made to play God in deciding on who went to ITU – who was given a chance to live and who wasn't.”

– Hospital nurse

Other contributors who worked in EDs said that at times they saw fewer patients than usual because people were too afraid to seek treatment. Reduced demand allowed staff in some EDs to spend more time caring for individual patients than they were able to before the pandemic.

Paramedics told us how much pressure they were under and how much their roles changed. They described waiting outside hospitals in ambulances with unwell patients, often for very long periods. This meant paramedics had to care for patients in ambulances and alert hospital staff to changes in their condition.

We heard from some NHS 111 and 999 call handlers about the pressures of having to deal with large numbers of calls from very anxious and unwell people. They gave examples of the problems caused by ambulance shortages. This was particularly distressing for call handlers.

“ They [callers] would phone us, and we'd be like, 'Yes, but you do need an ambulance,' so then we'd go through to ambulance, and they'd be like, 'But we've got nothing to send.' That was distressing.”

– NHS 111 call handler

## The impact on the healthcare workforce

A sense of shared purpose motivated many healthcare professionals during the pandemic. But some said this sense of purpose fell away as the pandemic went on, increasing burnout among staff as waves of the pandemic continued.

“ You were helping other people. You actually were providing a service that was valuable. It made you feel proud of what you did.”

– Hospital pharmacist

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**“I think on a personal level, it just became harder and harder. You got more and more tired. It probably led to a degree of anxiety. Difficult to deal with things. I think those were the challenges.”**

– Hospital doctor

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Staff working across different roles and in different parts of healthcare systems often had to take on huge workloads. This added to their already stressful jobs. Healthcare workers consistently told us how colleagues being off sick or needing to self-isolate added to workload pressures.

We heard how staff were sometimes redeployed to ease the pressure on teams, but contributors said it was challenging to teach the specialist skills and expertise required to work in new areas at pace. For example, nurses who were transferred to work in Covid-19 ICUs shared some of the most challenging frontline experiences.

“ I felt disempowered when forced into unfamiliar roles without proper training.”

– Children’s community nurse

“ The ICU nurse was supervising...actually looking after the patient, as you were really only there assisting her, checking drugs etc. But after that... you were main carer with an ICU nurse looking over your shoulder if you were lucky... it changed dramatically from the first couple of days, and then beyond that, it was really you doing it.”

– Hospital nurse

Many healthcare workers shared the ethical dilemmas they faced around Covid-19 guidance. These were often specific to their role and pandemic experience, but there were some common themes. For example, some healthcare professionals described not following guidance so they could show more compassion for patients, families and colleagues.

One of the most upsetting and stressful experiences for many healthcare workers was dealing with death on a scale they had never encountered before. Some described the damage to their mental health as a result. They often said families not being able to see their dying loved ones was one of the hardest things they had to cope with.

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**“It was like a war zone, overnight 18 people became Covid-19 positive with nowhere to isolate them. They were dropping like flies, it was awful. You can’t underestimate what this did to nursing staff, not being able to offer comfort to patients was soul destroying.”**

– Nurse with Long Covid

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“ We became immune to it. It dehumanised us a little bit, I think, at the time. I felt that, and I felt that was difficult to deal with.”

– GP practice manager

When healthcare professionals experienced distressing situations and workload pressures, some were offered, and made use of, emotional support. Peer support within teams was also important to help staff cope with the challenges they faced. However, this was inconsistent, with some healthcare workers not being offered any support with their mental health.

“ I feel that we kept getting told what the hospital were doing for staff and things, but I don't think they ever asked the staff what would make a difference to being at work. I think it was also the little things, like they would have said being able to park...being able to go for lunch in a chillout space.”

– Hospital doctor

Some staff were quieter, or had quieter periods, during the pandemic because patients stayed away or because of how care was reorganised. While this usually reduced the immediate pressure and stress they felt, some felt guilty that other healthcare professionals were under greater strain. Those who were less busy also worried about the patients they would usually be seeing and whether they were receiving the care and treatment they needed.

Some contributors described a lasting impact from working in healthcare during the pandemic. They shared how their mental health was now poorer than it had been. We also heard examples of professionals who had faced personal problems like relationship breakdowns that they thought were at least partly due to their experiences in the pandemic. Sadly, some healthcare professionals told us about having to change roles or stop working because of how much their mental health deteriorated during the pandemic.

“ I don't think I've come back to 100% of how I normally was. It takes its toll. But it's almost like having this piece of paper, that's nice, and flat, and straight, and then you've crumpled it and then you try and straighten out that piece of paper again. It's still creased up, no matter how much you try and straighten it out.”

– Paramedic



## Rebuilding trust in decisions about healthcare

Some contributors shared how their trust in healthcare systems had been shaken by what happened and argued that this was a concern for many across society. This was often less about the care they received from individual healthcare professionals and more about the decisions that were made about organising and providing care.

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**“Trust in services from the public has gone due to how they were treated in the lockdowns.”**

– Every Story Matters contributor

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Many of their reasons for no longer trusting in the decisions made about healthcare have already been highlighted. They were worried about access to healthcare and whether healthcare systems will be able to recover from the pandemic. For many contributors, doing more to preserve and rebuild public trust in healthcare was seen as an important priority – both now and when dealing with future pandemics and emergencies.

*Thousands of people shared their experiences about healthcare systems during the pandemic with us. In this report we build on this summary, highlighting in more detail the key themes from the stories we heard.*





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