

# COVID SHIELDING VOICES REPORT



**VERSUS  
ARTHRITIS**

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# AUTHORSHIP AND CONTRIBUTION

The research team would like to thank all the participants for their contributions to this study.

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# FOREWORD BY DEBORAH ALSINA MBE

Chief Executive, Versus Arthritis

**During the pandemic, approximately 4.1 million people across the UK were identified as clinically extremely vulnerable (CEV) to COVID-19, and asked to shield for their own protection. This decision, made in the light of an unprecedented pandemic, would separate those with autoimmune inflammatory conditions, such as rheumatoid arthritis, from the rest of society for their own protection.**

Versus Arthritis saw first-hand the impact shielding had on people with autoimmune conditions, and through our information, helpline and online forums, supported thousands of people throughout this extremely difficult period.

*COVID Shielding Voices* – qualitative research led by Dr Charlotte Sharp, a consultant rheumatologist, Lynn Laidlaw who has an autoimmune rheumatic disease and had to shield, and patient contributor Joyce Fox from the Centre for Epidemiology Versus Arthritis at the University of Manchester – highlights the stories of people who lived through this. It details the impact on their daily lives, their physical and mental wellbeing, their work, and their relationships with their families and the rest of society.

This insightful research put co-production at its heart. This included a patient advisory group appointed to add depth to the understanding of the research and a commitment to inclusion throughout. The research also welcomed a wider range of qualitative evidence than just written testimony, with creative materials being part of the scope and forming a key part of this report. This is an approach Versus Arthritis continues to champion.

**The report details the four key areas where shielding affected people with autoimmune inflammatory conditions such as rheumatoid arthritis:**

- The mental and emotional toll shielding had on their daily lives.
- The impact on people's physical and mental health when their care was disrupted.
- The struggles encountered in people's day-to-day lives due to shielding.
- The impact shielding had on people's identity and the place they felt they had within society.

It also details how these key areas influenced individual approaches to shielding, including that which took place beyond the end of the formal shielding period.

This study has enabled the voices of those shielding to be heard and allowed for recommendations to be developed about how to support people who are CEV now and in future. These include ways to better prepare for future pandemics, mitigate the consequences if shielding is required, and better engage with people who are required to shield.

As the Covid Inquiry conducts its review, this timely report should serve as a reminder of the impact that COVID-19 had on those who had to shield. It highlights the areas for improvement and what more can be done to protect vulnerable groups such as those with autoimmune inflammatory conditions like rheumatoid arthritis. It should also serve as a useful tool for policymakers, healthcare professionals and the wider health system, to address how we can better serve these communities. We urge professionals to take on board and act upon the findings in this report.

On behalf of Versus Arthritis I would like to extend our thanks to Charlotte, Lynn and Joyce who pioneered this work. In addition, to the members of the patient advisory group, and those who participated in the study. Without your voice, this work would not have been possible.

# EXECUTIVE SUMMARY

*COVID Shielding Voices* examines the vast personal, professional, and societal impact that shielding from COVID-19 had on people's lives. The report is co-produced with people with autoimmune inflammatory conditions such as rheumatoid arthritis and captures the stories of people from across the UK who shielded during the pandemic, highlighting their full range of experiences. This includes how they were identified as CEV, how this was communicated, right through to the impact on individuals' daily lives.

These insights were generated from 28 interviews and two focus groups that took place from October 2021 – January 2022, which was 18 months after the beginning of the first lockdown, and after the end of formal shielding, to gain insights over and above those already reported.



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**The report highlighted four primary ways in which shielding affected this group. These are:**

- The emotional impact of, and emotional work generated by, being identified as CEV, being asked to shield, and then to manage personal risk in the context of significant uncertainty. This manifested itself through fear, anger, and guilt, which fluctuated throughout the pandemic and led to sizeable impact on mental wellbeing.
- The difficulties people shielding had managing their health during the period, including both COVID-19 and autoimmune condition-related treatments. This includes a broad perception of being asked to manage their condition alone without support from healthcare professionals and without being properly informed.
- The day-to-day impacts of the pandemic on accessing basic supplies, as well as the impact on work and home life. Overall, the general sense of helplessness of not being able to live their lives as they would like, and the need to make considerable changes to do so where possible.
- Impact on self-identity and perceived place within society on people separated from wider society for so long, as well as the abandonment and separation felt when the protection of shielding was so quickly removed.



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This report highlights the personal, professional and societal changes to their lives which may never be remedied. As one participant described it, “I’m not the same person before and after shielding I have to say”(ID19).

These findings have informed the development of a set of recommendations about how to support the clinically vulnerable now and in future. Recommendations for clinicians working in rheumatology services and wider health system caring for these patients were derived directly from the findings by the research team. Recommendations for policymakers, government and public health experts were developed by Versus Arthritis, drawing on the research findings and the charity’s policy expertise.

## Clinical practice recommendations

1. To acknowledge and recognise individual patients’ experiences of shielding and address ongoing anxiety around risk from COVID-19, if present.
2. To support individuals to make decisions around risk from infection including interpreting information with them according to their personal approach to risk and the evolving evidence, taking into consideration contextual factors such as family and work lives.
3. To continue to advocate for patients who may remain at risk from COVID-19 and other infections, not least because of reduced vaccine efficacy in this population.
4. To apply the principles outlined above when caring for patients at risk of infection during future pandemics.

## Policy recommendations

### Future preparedness

1. The UK Health Security Agency and public health bodies across the UK with responsibility for pandemic preparedness should develop an impact assessment framework for shielding, based on the four key areas of impact highlighted within the report. This should guide future decision making and subsequent evaluation and be produced in consultation with those who have shielded and are likely to have to shield.
2. NHS bodies across the UK must ensure that the methods of data collection, data sharing and means of generating the Shielded Patient List are

maintained and improved going forward to ensure these lists can be generated at speed in future.

3. NHS bodies across the UK must embed processes which ensure more effective communication between healthcare providers and from healthcare providers to patients for future pandemics to ensure that there is consistency regarding what information is provided to people shielding.

## Public engagement

1. When national public health bodies across the UK are designing approaches and content for people who are shielding there should be greater involvement of people with lived experience and charities at an early stage.
2. Integrated Care Systems and Health Boards should map any pandemic-related information and support available from third sector organisations (for example, helplines, online resources), and ensure that local healthcare providers are routinely signposting this to their patients.

## Mitigating the consequences of shielding

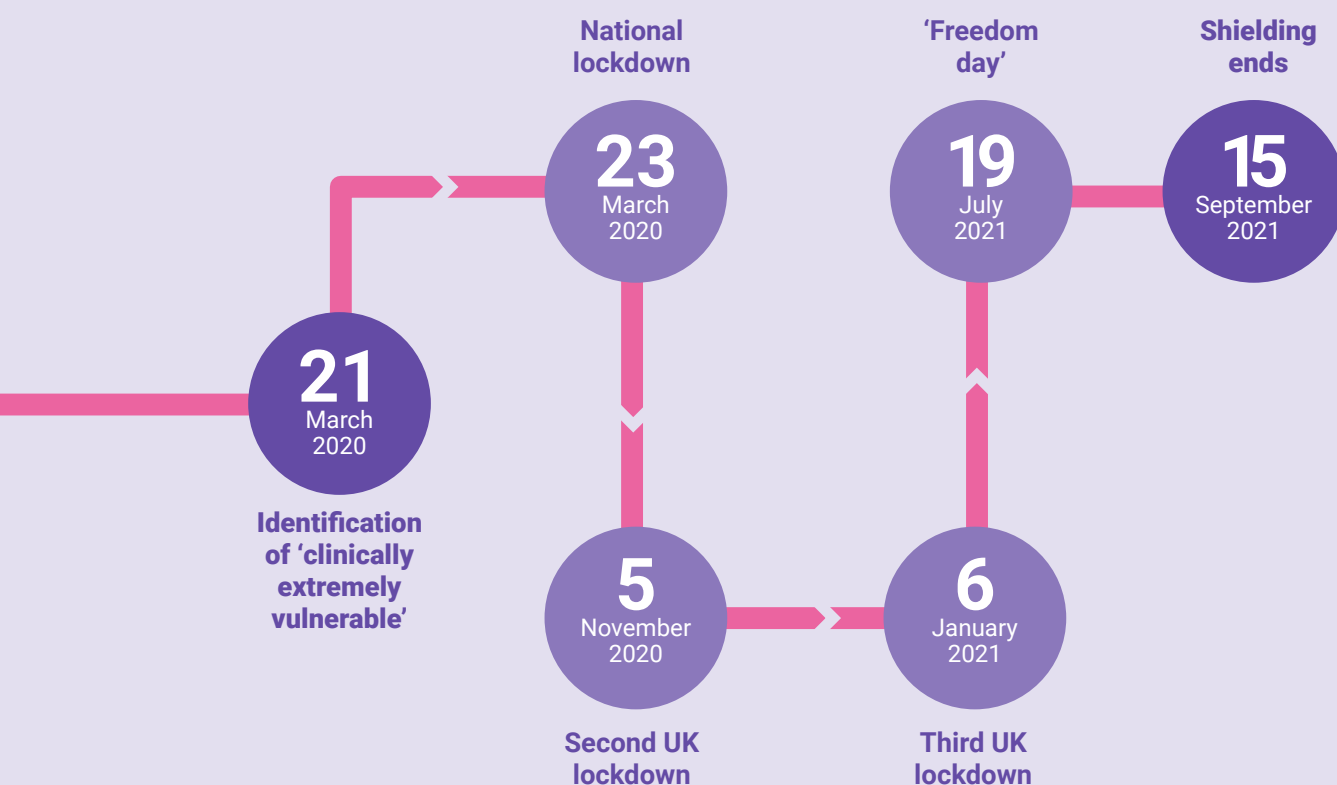
1. The Department for Work and Pensions should ensure that there is employment protection and enforceable access to workplace adjustments for immunocompromised or immunosuppressed people, including the duty to consider working from home wherever possible.
2. NHS bodies across the UK need to make greater provisions to ensure that people required to shield can access the essential health services they require. This includes an in-person offer, as well as online support.
3. Future mental health plans released by government health departments across the UK need to address the mental health needs of people who were required to shield, with funding allocated to support those with unmet needs resulting from the pandemic.
4. People who are advised to shield should receive clear information and guidance, along with a written record of this advice that they can use to show to employers and others as evidence of their needs.

# BACKGROUND

## When did shielding come into effect?

In March 2020, in anticipation that COVID-19 was likely to have worse outcomes for certain subgroups of the general population, people identified as having the potential for being at high risk of severe illness were classified as being “clinically extremely vulnerable” (CEV).<sup>1</sup>

Shielding first came into effect on 23rd March 2020 and ended on 1st August 2020. It was formally reinstated between 3rd November 2020 and 31st March 2021. Finally, from 1st April 2021, the advice to shield paused and from 15th September 2021 the shielding programme ended - although some people have chosen to continue shielding beyond that date.



## What were the shielding recommendations?

The original shielding recommendations asked individuals to remain in their accommodation, except for exercise or to attend medical appointments, and to maintain a 2-metre distance from people with whom they lived. In practice, this meant that people identified as needing to shield were required to stay at home and avoid all face-to-face contact with those outside their household. The exact detail of shielding advice has changed over time.

## How were people identified as clinically extremely vulnerable?

Across the UK, people were identified as being CEV and added to the Shielded Patient List based on pre-existing conditions recorded in their health records, or the clinical judgement of their clinician or GP. In England in February 2021, a population risk assessment algorithm was also used. Approximately 4.1 million people across the UK were identified as CEV and asked to shield.<sup>2,3,4,5</sup>

An initial list of conditions making people eligible for registration on the “Shielded Patient List” was devised, with 2.2 million people being asked to shield during the first period in England.<sup>6</sup>

Patients regarded as CEV were informed by letter from their general practitioner, or through communications from secondary care providers.



## How were people with autoimmune inflammatory conditions such as rheumatoid arthritis identified as being CEV?

People with autoimmune inflammatory conditions such as rheumatoid arthritis are at increased risk from COVID-19, both by virtue of their underlying condition and its impact on the immune response and because of the immunosuppressive effect of many of the medications prescribed to treat these immune-mediated conditions.<sup>7,8,9,10</sup>

Many hospital rheumatology departments developed their own systems for identifying patients at risk from COVID-19, some of which used national risk stratification tools, developed at pace.<sup>11</sup> Versus Arthritis also used the COVID-19 tool developed by the British Society of Rheumatology to create an online platform for people to assess their own level of risk. As the pandemic progressed, a COVID-19 Population Risk Assessment was used to identify additional individuals as potentially at high risk of serious illness from COVID-19, resulting in a further 1.7 million people in England being identified as CEV by May 2021.<sup>12</sup> Finally, it became possible for individual clinicians to add patients to the Shielded Patient list, based on their clinical judgement of risk of serious illness.<sup>13</sup>

## How were people notified about the need to shield?

The number of different routes to being identified as being CEV resulted in some people receiving letters from multiple sources, many of which contained conflicting advice. Others received letters from a single source, and some who expected to be identified as needing to shield, did not receive one. The process of identifying individuals to go onto the Shielded Patient List has been criticised for being based upon poor quality or inaccessible data and a “lack of joined up systems”,<sup>14</sup> leading to delays in identifying CEV individuals, and a postcode lottery, with large regional variation.<sup>15</sup>

## How did shielding affect people living with autoimmune conditions (including autoimmune inflammatory arthritis)?

Similar to all people who were advised to shield, practical implications included difficulties obtaining food and medical supplies, the ability to attend work and access health services,<sup>16</sup> along with negative impacts upon mental health.<sup>17,18</sup> Access to health services is of particular importance for patients with autoimmune conditions, many of whom require assessment of their disease activity and regular blood test monitoring in order to ensure the safe prescription of medication. Reviews of patient experience of ‘voluntary’ shielding early in the pandemic amongst haematology patients (another high risk group) identified that attending hospital visits was a particular source of anxiety around contracting the virus.<sup>19</sup>

## Research aims

This research sought to understand and explore the experiences of people with autoimmune inflammatory arthritis and other auto-immune conditions treated by

rheumatologists (such as rheumatoid arthritis, ankylosing spondylitis, systemic lupus erythematosus, vasculitis, connective tissue disease) who shielded during the COVID-19 pandemic. These insights were generated from October 2021 – January 2022, which was 18 months after the beginning of the pandemic, and after the end of formal shielding, enabling us to gain insights over and above those already reported. By including people who chose to shield as well as those who received formal notification, it aimed to capture the voices from the broader community of shielders. Finally, by using a combination of qualitative methods including semi-structured interviews and focus groups, a range of voices were heard, addressing people’s experiences in depth and breadth.

The **primary aim** was to capture patient stories to understand and explore the experiences of people with autoimmune conditions, including autoimmune inflammatory arthritis, who shielded during the coronavirus pandemic.

**Secondary aims** were to:

1. Capture experiences and opinions on the process for determining who is identified as CEV, and how this might be improved.
2. Capture experiences and opinions on the process for communicating whether individuals are identified as CEV, and how this might be improved.
3. Explore the impact of shielding upon individuals’ lives, including their ability to work, their ability to obtain food and medical supplies, their mental health, their autoimmune condition or arthritis, their interactions with healthcare providers, and how these experiences might be improved.

## Why is this research important?

Although much of the prevailing narrative around the COVID-19 pandemic is that it is ‘over’, uncertainty about the degree of risk for patients with autoimmune conditions remains. This uncertainty is likely to persist as COVID-19 remains endemic for at least the short-medium term. Those working in clinical practice, or in touch with networks of people with autoimmune conditions, are aware of people who continue to shield, three years from the pandemic’s onset. The practice of ongoing shielding and the fact that the threat posed by future pandemics appears much more realistic in the ‘post-COVID’ context, makes recommendations regarding the shielding process all the more pertinent. This study has enabled the voices of those shielding due to autoimmune conditions to be heard, and allowed for recommendations to be developed about how to support the clinically vulnerable now and in future.



# INCLUSIVE RESEARCH DESIGN

## Co-production

This research had at its core a co-production approach, which means that the research is co-produced with patients and the public. The idea for the research came from Lynn and Joyce who were members of a COVID-19 Patient, Public Involvement and Engagement group recruited by the Centre for Epidemiology Versus Arthritis, at the start of the pandemic. Lynn and Joyce highlighted the importance of bringing quantitative data about shielding to life using qualitative, co-produced methodology. They collaborated with Charlotte who took on the role of Principal Investigator for the study, and applied for funding together. They adopted a flat hierarchy and decisions were made collectively. Lynn and Joyce conducted most of the qualitative research alongside Charlotte.

There is a large and growing academic literature on co-production, including lots of discussion about what the term actually means.<sup>20,21</sup> Co-production is a complex methodology which needs to be resourced, planned, evaluated and reported. Crucially, it is enacted by working in a values and principles led way, working as equal partners. By working with patients and partners throughout the research cycle, it aims to ensure that research is as meaningful and relevant to patients, the public, and other stakeholders, as possible.

## Patient advisory group

In addition to the co-production approach taken by the co-investigators, a four-member patient advisory group (PAG) was appointed with the aim of increasing the quality and relevance of the research and associated findings. When recruiting the PAG it was important they had autoimmune inflammatory arthritis, and had personal experience of shielding.<sup>22</sup> An effort was made to ensure diversity and particular attention was paid to involving people of different ethnicities and ages, and with a range of conditions.

Working co-productively as a research team and with the PAG added depth to the understanding of people's personal shielding stories generated by this research.

## Keeping research participants involved

The *COVID Shielding Voices* team felt that communicating with research participants throughout the project, so that they felt included and informed about what we were doing with their data, should be an essential component of the study. This included sharing the results and future publications.

To this end, there was a question in the consent form asking participants whether they would like to be kept informed of the research findings. 100% of participants gave their consent for this. Interview and focus group participants were emailed individually on at least five occasions during the study to keep them informed of progress. This included updates about when we had completed data collection and moved into the analysis phase. More detail on the study's engagement with participants may be found in this [blog](#).

## Creative materials

The research team felt that inviting people to submit creative materials (creative writing, artwork, photographs, etc.) would enable the research to be more inclusive, giving people a choice over how they would like to share their shielding experiences. This would bring the research findings to life and highlight the emotional impact.



# METHODOLOGY



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**Adults (18 years of age and over) with self-reported autoimmune inflammatory arthritis or rare autoimmune rheumatic conditions who shielded because of this condition at any time during the COVID-19 pandemic (regardless of whether or not they received an 'official shielding notification') were eligible to participate in the study. Participants were recruited via open social media adverts on Facebook and Twitter, and charity and support group websites.**

People expressing an interest in participating were invited to complete an online screening survey which included questions about their personal characteristics. This enabled the researchers to purposively select participants from a range of different ethnic, socio-economic and geographical backgrounds in the UK. Participants were invited to participate in a single interview or a focus group, and/or to contribute creative materials (creative writing, artworks etc).

Semi-structured interviews and focus groups are designed to capture subjective viewpoints of participants without leading them or imposing the researcher's preconceptions. The topic guide questions were developed using the existing literature, the lived experience of the research team, and through collaboration with the patient advisory group. Questions aimed to encourage participants to reflect on, interpret, and give meaning to their experiences related to shielding.

Interviews were held at the participant's preferred date and time, via telephone or Zoom. Focus groups were held at a mutually convenient date and time, via Zoom. All interactions were audio-recorded. Participants were invited to contribute creative materials to illustrate their experiences of shielding.

**These creative materials can be seen throughout this report and the full collection is available online. [View online.](#)**

A reflective journal was kept by all members of the research team to facilitate the learning process and analysis. Peer debriefing took place at weekly analysis meetings between the core research team.

In all, 48 people participated: 28 interviews, two six-member focus groups, creative materials from 15 participants, seven of whom also participated in either interviews or focus groups.\*

\*Ten participants contributed to creative materials alone. Seven participants contributed creative materials, AND interview / focus groups.





“Shielding. The only word I could hear. It would constantly resound in my head. It became part of my daily life. Every letter. Every new announcement. The pain and uncertainty. The fear. Shielding saved me from an invisible enemy, it kept me alive, but it imprisoned my mind.”

# THEORETICAL FRAMEWORK

In order to understand and explain the findings from this research, we applied and built upon the theory generated by Corbin and Strauss in 1985 regarding management of chronic illness.<sup>23</sup> Corbin and Strauss described how people with chronic illness manage their illness 'trajectory' at home by navigating three lines of 'work'. These lines of work are 'illness-related work', 'everyday life work', and 'biographical work'. We build upon the original study by adding a fourth line of work; 'emotional work'.

- Illness-related work relates to the work required to manage a chronic illness, for example arranging blood tests to monitor the use of methotrexate, and remembering to take the medication on the same day each week.
- Life work relates to the everyday tasks which are necessary for us all to complete, including buying and preparing food, going to work or school, and managing relationships.
- Biographical work relates to how a person with a chronic illness views themselves as a result of their condition, which may change over time, and be affected by illness work and life work, and vice versa.
- In addition to these three lines of work originally described by Corbin and Strauss, this study proposes a fourth line of work; 'emotional work'. Emotional work is the work done to manage the burden of emotions elicited by, in this case, the experience of shielding. Participants experienced fear, abandonment, guilt, and a feeling of being out of control. These emotions and people's ability to cope with them had major impacts on the mental wellbeing of people shielding.

These 'lines of work' are then used to try to explain why participants made, and continue to make, certain decisions in regard to how they went about shielding; their 'shielding behaviour'.



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# RESULTS

## Illness work

Participants reported an increase in the amount of work required to manage their illness. This ranged from difficulties ascertaining whether or not they should shield, through to challenges in accessing health care including COVID-19 vaccinations. This illness work was increased further because of the amount of uncertainty and risk (often poorly defined) that they had to navigate at each of these decision-points and interactions.

## Managing uncertainty and risk

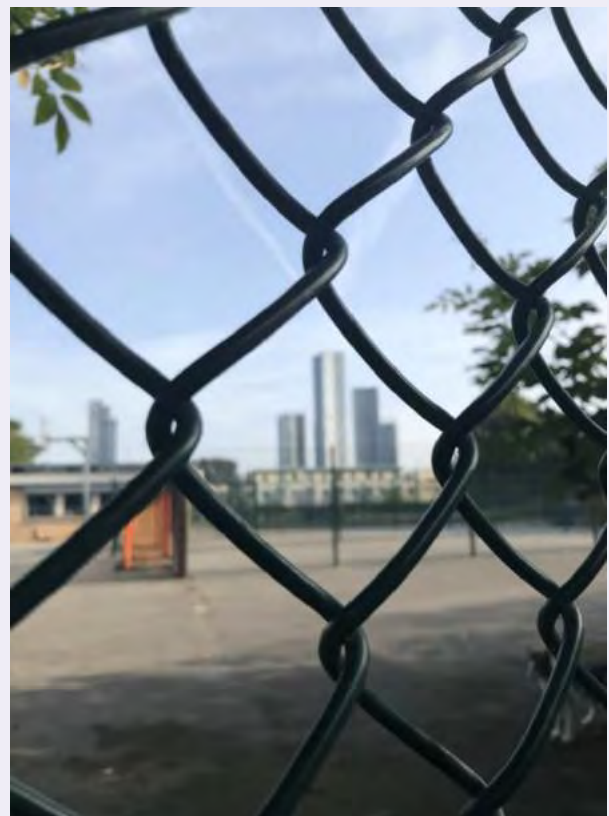
**Shielding notifications were received via a number of routes.** Experiences of this process varied, with some receiving a “bombardment” (ID23) of notifications: “they sent about a million letters” (ID20). Others experienced delays, requiring them to seek help from primary and secondary care clinicians: “It was the waiting for the letter, the anticipation, would it come, would it not... I was dreading receiving that letter” (ID8). The majority of participants eventually received official notification of the need to shield; two elected to shield because they felt at risk. Of those, one felt “annoyed” that they “fell through the net” (ID3), with another appreciating the “flexibility” (ID12) to decide their approach. For those experiencing delays in receiving their notification, help was sought from their primary and secondary care clinicians.

**Route of notification impacted participants emotionally,** with multiple notifications heightening anxiety. Text messages and emails were welcomed because of their immediacy, although text messages were thought to be “blunt” (ID7). Language used across all communications was viewed as “terrifying” (ID6) and “alarmist” (ID7), leading participants to feel “petrified” (ID10).

**Participants reported receiving inconsistent advice regarding whether and how they should (or should not) shield** “It just wasn’t clear as to what I should or shouldn’t do” (ID11), with opinions varying between healthcare professionals: “one consultant was saying one thing and one was saying the other” (ID9). Challenges in navigating these uncertainties were experienced: “there was lots of conflicting advice, lots of uncertainty. So, it was a worrying time” (ID4).

## Accessing healthcare

**Participants reported a broad range of experiences accessing health care. Some changes to care provision were regarded as wholly positive,** including bespoke services for shielders such as early morning appointments, alternative entrances provided by primary care, and medication delivery by pharmacies. The length of time between monitoring blood tests was increased for all rheumatology patients and was broadly welcomed. Participants valued the relationships that they had with their secondary care providers, describing relationships with consultants as “a lifeline” (ID1). For some, “none of [the treatment] has been delayed or interrupted” (ID9).



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**Delays in accessing care were also reported:** “I’ve not had treatment for a year and a half now” (ID26), with consultations being described as a “stripped back affair” (ID15). Some people reported that their disease management “has been a lot worse” (ID27), with one participant experiencing massive blood clots which went undiagnosed: “because the GPs were obviously only telephone appointments, it was remote, they couldn’t see you in person, nobody really noticed how swollen my abdomen was getting, and how actually unwell I was” (FG10). Experiences like these led some participants to feel “hopeless” (FG1), “on your own” (FG5) and like the “safety net [was] disappearing” (FG5). The time spent trying to sort out prescriptions and blood tests was described as a “full time job” (FG11).

**The onus of responsibility to care for this complex patient group was felt to have shifted from a predominantly secondary care model, to one much more dependent upon primary care.** This was because of acute changes to services resulting from the pandemic, including redeployment of hospital staff to care for patients with COVID-19. This was viewed as problematic: “There’s a reason why I have a biological nurse and the GP doesn’t deal with it” (ID8). Participants also reported difficulty obtaining answers on COVID-related enquiries from both primary and secondary care, with it being perceived that each party viewed responsibility for this as being someone else’s job.



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# LIFE WORK

Shielding had practical implications affecting all avenues of everyday life for shielders and those close to them, increasing the amount of work required to gain access to basic supplies. Being required to shield forced CEV participants to balance risks posed by COVID-19 with the detrimental impact upon their ability to work. It created additional work for participants who had to navigate the impact of shielding upon household members and their relationships. Personal circumstance had a significant impact on the nature of these challenges and how individuals were able to manage them.

## Accessing basic supplies

**Obtaining food and medicines was a major preoccupation for shielders:** “My priority supermarket thingy, which I know I’m banging on about that, but it was very, very important to me at the time” (ID2). Being assigned priority status, “was a really big deal” (ID25), making “delivery slots... instantly available” (ID2). Delays in receiving formal shielding notification created critical blocks in accessing supplies. Work-arounds included getting “up at weird hours of the night, online in the queue, trying to get a slot” (ID6) and requesting help from a range of sources including supermarket chief executives, pharmacists, their children’s schools, and local MPs. These actions reflect the persistence and tenacity required to bypass the formal routes to priority deliveries. Participants recognised that they were fortunate to have these skills, and expressed concern for others who did have the time and or skillset required to navigate these systems.

**Participants “ended up having to have food parcels** because we were so desperate, we’d literally ran out of everything” (ID27). Receiving free food made people feel “uncomfortable” (ID27), “guilty” (ID4) and “super-emotional” (ID25). Some of the discomfort around receiving these goods centred upon concern that others in greater need might not have access to them. Those who could not access food had to consider breaching the shielding recommendations: “what are we meant to do, we’re trying to follow these rules but we haven’t...you know, we literally haven’t got any food, can’t get any food? ... it was quite scary” (ID10).

## Work

### Shielding impacted participants’ working lives.

Early in the pandemic, those able to work from home felt on an equal footing to non-shielders because they were all in a similar position. Those whose work required them to attend in person had more mixed experiences. Positive experiences included employers pre-empting government advice to start shielding, “contacting me every day making sure I was okay” (ID22), and making adjustments to make the workplace “COVID-19 secure” (ID8). Negative experiences included a lack of contact from employers and NHS staff who reported being actively mocked for following the actions set out in their occupational health assessment, such as avoiding clinical areas: “[colleagues were] tutting and eyes rolling...” (ID23). Some were made redundant. Others were forced to make difficult choices based on the perceived risk of attending work, forcing them to choose “between having enough money to live comfortably, or my health” (ID20).

### As shielding ended and workplaces started to open up, shielders faced more difficulties regarding working face to face.

Some felt under “pressure” (ID7) to return to working in person. Even when people were supported to continue working from home, they felt disadvantaged because they were “missing out on those important conversations” (FG9), “feeling very, very isolated” (FG11) and “excluded” (ID4). Some people were fearful of how their status as CEV would impact future job prospects “And I’m negotiating a job offer right now and I have to get a feel for, like, are they going to – pardon my French – like give a s\*\*\* about my condition?” (FG1).



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## Home and family

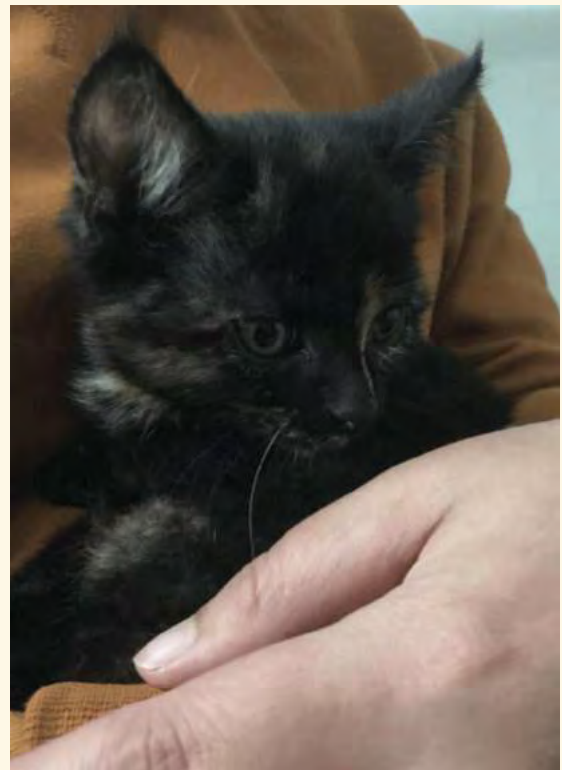
**COVID-19 lockdowns impacted the home context for almost all UK citizens.** The more stringent recommendations and longer periods spent shielding compared with national lockdowns impacted shielders' home lives over and above the impact felt by the general population. Caring responsibilities and shared accommodation created additional complexity for shielders. Shielding impacted relationships with family, friends, partners and children because the need to shield affected all members of the household, impacting family members' freedom to attend school and work. There was emotional work involved in navigating the predicament shielders found themselves in and in keeping relationships going under strained circumstances. Participants reported feeling that their relationships had been put under the "microscope" (ID1) and described how their partners felt under pressure to "protect" (ID4) them.

**Both the size of the home and cultural norms influenced people's ability to shield** strictly in accordance with the rules: "there isn't the concept of families not mixing ... in [my] culture the family is together all the time. So there are some friends we've not seen until more recently, because the idea of not mixing and not kissing each other and giving each other a hug just doesn't work culturally..." (ID11).

**Shielders went to extraordinary lengths and made considerable personal sacrifices to enable their children to attend school whilst protecting themselves.** One mother moved out of the family home; another parent built and moved into an extension on their house. Work and school initially made helpful adjustments. Once formal shielding ended, shielders had to make difficult choices, balancing risks from using external childcare with the challenges of trying to work whilst caring for and / or teaching children at home, and the impact of social withdrawal upon their children. "My brother... asked my daughter... if you could wish for anything, what would you want for your birthday? And [she] said, I would go back to school, and it broke my heart. I was like, right okay, so January we're getting [her] back into school, no matter what. And so it was January that I moved, for the first time, into the flat" (ID25).

**Many of the participants with children struggled with the lack of specific guidance** for their situation and felt painfully conflicted as to how to decide on the best course of action:

"Is putting them [children] first sending them to school and letting them live a normal life and not knowing anything about it? Or is putting them first protecting their mum so that there's less risk that they one day don't have a mum? Where do you draw the line, what's more important? They're equally important, you're constantly battling with yourself over what's the right thing to do for your children because there is no right answer and there's absolutely zero guidance on it either (ID 27)."



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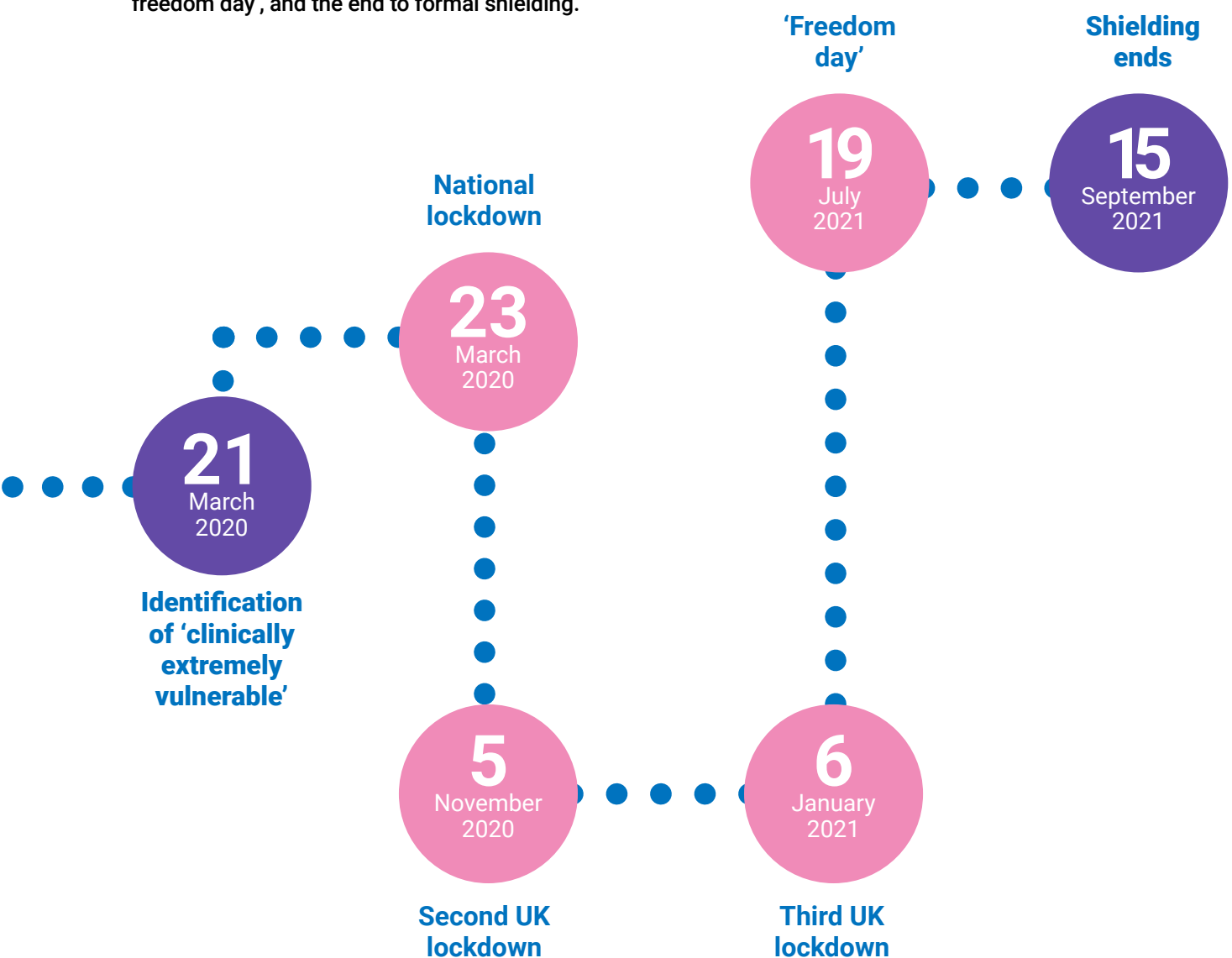


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# BIOGRAPHICAL WORK

Biographical work relates to how a person with a chronic illness views themselves over time, for example as someone with a disability, or as someone who is not impaired by their chronic condition. The way that people who shielded viewed themselves changed as the pandemic progressed.

Key milestones were the initial notification that they should shield, end of national lockdowns (whilst shielding continued), the introduction of vaccines, 'freedom day', and the end to formal shielding.



## Self-identity

**Being classed as clinical extremely vulnerable led many participants to re-assess their self-identity,** particularly marked for those who were clinically well: “then suddenly this comes along and you’re told, you’re really high risk, you’re really vulnerable, you’re really, and you’re like, oh am I? Receipt of the first notification heightened people’s sense of vulnerability, was stressful, devastating, and caused “shock and disbelief” (ID23).

**Being asked to shield changed people’s perception of their illness from “something that happens to me every now and then, to having a chronic condition”** (ID12), with the realisation that they were CEV making them feel “more disabled”(ID28). Others objected to the depersonalisation of being ‘reduced to a risk score’: “my rheumatology department, they had a big list of medication and everyone you were on added up a certain amount of points, and if you’re at a certain threshold, that’s how much you had to shield. And I had literally been reduced to the highest number, and that was like all I was” (FG3).

With the end of formal shielding and the knowledge that they remained vulnerable, people viewed themselves differently in the longer term: “I mean part of me worries that I won’t ever be normal again, this is really honest, I don’t think I’ve ever expressed it that way to anyone before but I don’t live a normal life at all” (ID25).

## Perceived value to society

**At the beginning of the pandemic, our shielding participants reported that they felt more equal with the healthy population for the first time.** This was because suddenly everyone was potentially at risk from COVID-19 and therefore “finally understanding what it was like to be vulnerable” (ID1). Some described how they were able to participate in the same activities as their peers on an equal basis for the first time since becoming unwell: “when you put everyone on an equal playing field and now everyone stays at home, I’ll be honest, I was actually thriving... It was mixed feelings because I would not like to go back to [shielding], I found them dreadful, and I don’t think I would last not seeing my friends again. But also it was nice that I felt almost equal in what my limitations were” (FG3).

**The consequences of ‘freedom day’, which released the rest of society from COVID-19 restrictions, were far-reaching and in direct contrast to the start of the pandemic.** The cost of freedom for the majority of the population was seen as “incarceration” (FG2) for participants, who felt abandoned by society. Some felt “left behind” (ID13), with weekly Zoom chats petering out and little understanding from friends and family of why shielders did not feel able to meet them indoors. The perception that participants felt, “we are expendable, we are cannon fodder” (FG2), “devalued” (ID26), “invisible” (ID17), “forgotten about” (FG2) and that “shielding people are real second-class citizens now” (ID17,26) came across strongly.



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**The notification that shielding would suddenly end, in the context of the dissolution of wider COVID-19 restrictions, was traumatic.** People felt like they’d “been thrown to the wolves” (ID6). People felt that the policies relating to CEV people exposed ableist views amongst some parts of society, making people feel less valued than ‘healthy’ members of the population. Participants perceived that shielders were regarded as not “[having] any life..., so we don’t really matter” (FG11), when in fact, up to this point, they had been able to live fairly normally, despite their diagnoses. Shielders highlighted the lack of “legislation to protect them” (FG6) leading them to ask why “my freedom isn’t as important as a healthy person’s?” (ID 26). Participants noted that reports on the number of COVID deaths were always prefaced by the percentage that were “clinically vulnerable” which “I think it reinforces that sense of when you’re a chronically sick person, you’re kind of worth a bit less” (ID5).

## Invisible illness

**Participants perceived that the 'invisible' nature of their conditions meant that others questioned their illness:** "nobody understands invisible illness" (FG2) with some suggesting that it would be easier if they had a "cast" (ID1) or some other outward manifestation of their conditions to justify why they were CEV. In addition, it was felt that there was a low level of understanding amongst the general population of the need for immunocompromised people to be protected from COVID-19, compounding their frustrations around having such 'invisible illness'. Participants detailed how challenging it was when family members and close friends did not understand their vulnerable status, being told that they should return to "normal" and stop feeling "paranoid" (ID19). "I must be boring everybody else by going on about this. I just don't think that people, in general, understand the predicament of people who are immunocompromised for whatever reason it may be" (ID2).

**Formal shielding forced individuals to disclose their previously confidential health status.** This affected both private and professional circumstances. Consequently, they felt that "confidentiality has gone out of the window and you basically have to declare yourself as a vulnerable individual, which you would never have identified as before (FG6)". This contributed to making participants feel like they had lost control over this personal information: "If there's a social gathering, even outside and we're distanced, I still have to say, hi, I'm [name] and I have rheumatoid arthritis x, y, z, and then just, almost as a disclaimer, please don't cough on me. It doesn't feel too great" (FG3).

The change from an initial feeling of being protected by a combination of lockdowns and shielding policy, to this sense of abandonment, created a large amount of biographical work for participants to do, over a relatively short time frame. The longer-term status of being CEV beyond the end of shielding has had a continued impact on participants' self-identity, their perceived value to society and the work they need to do to navigate these elements of their biography.



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"I took this image as I sunk to the floor in utter despair my kitchen. I cried for losses, grieving my independence, my diminished abilities, feeling lonely and isolated. Lost my job as a result of disability discrimination. I lost my PIP benefits, No financial income whatsoever. Impact on my marriage has been detrimental and I do not have any family. My cat died, I had her for 16 years. Everything had fallen apart, and the pandemic rages on. Struggled to see the light."







# EMOTIONAL WORK

**Illness work, life work and biographical work** all had a significant emotional impact on our shielding population. The emotional impact of being identified as CEV, asked to shield, and then to manage personal risk in the context of significant uncertainty when the various lockdowns ended and 'freedom day' was announced, was profound. Key emotions experienced included fear, abandonment, guilt, and a feeling of being out of control. Emotions were changeable over time, they became more and less intense, were often extremely tumultuous, and did not necessarily occur in a linear fashion, occurring at different paces for different people. Emotions were multi-level and directed at participants themselves, friends and family, government, and society. Sometimes opposing emotions were experienced simultaneously. Whatever the order or intensity of emotion, all our participants experienced an additional array of emotions in response to shielding which were over and above those normally experienced whilst living with a chronic condition, or by the non-shielding population during the pandemic. The strength of these findings has led us to add a fourth line of work to Corbin and Strauss's three lines of emotional work.



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## Fear

**Fear was the dominant emotion experienced when participants first became aware of the need to shield, because of the implication that they were at risk of severe illness or death:** "the term 'extremely vulnerable' just sounds so scary" (FG10). Others described feeling "petrified" (ID10). Participants reported being fearful of what being labelled as clinically vulnerable might mean for their care if they became very unwell with COVID-19, in relation to "certain people not getting to go into ICU (intensive care unit)" (FG7). At the same time, and in tension with those negative feelings, shielding notification made people felt relieved, safe and protected "it was actually a real blessing" (ID6), and "I felt safe being locked in, in a way. I thought, well at least we are safe. And I was thankful they had created this thing called shielding" (ID10).

## Anger

**As time passed, for many, fear turned to anger and frustration:** "I stopped feeling anxious and started to feel angry" (ID8), which was the most widely expressed emotion. Anger was expressed towards: government for problems with identifying who needed to shield and the mechanics of shielding; society for perceived selfishness of others and calling COVID-19 "just a cold and it's just a bit of flu"(ID13); health services for the challenges experienced in navigating care including access to vaccines for themselves and family members; and individual people's failure to recognise the potential impact on the CEV: "I've had a couple of rages against people, because they just don't understand it. Don't understand. You know, people moaning about certain things, and I would just snap back, saying, you know, I'm living in a separate house from my family, and you're bloody going on about I don't know what" (ID13). People felt really angry and upset at the situation they found themselves in: "so there were lots of tears, feeling really awful, feeling very angry about things, not so much frightened. I wasn't frightened of COVID, if you like, I just didn't want to be in the position I was in" (ID 23).

## Guilt

### **Guilt was experienced by many participants.**

Initially this was felt in relation to receiving assistance due to their CEV status, for example food parcels. As society began to return to normal and the experience of shielders began to depart from the rest of the population, this extended to professional and social settings: “The guilt at not being at work was horrendous” (ID23); “And I’ve had to miss a few weddings because I just don’t feel I can go in a room with 150 people with tables of ten. But it’s very difficult to justify that now because the world’s gone back to normal” (FG6). Participants felt guilty about the impact that shielding had on their relatives, for example partners who did not go to work, or children who did not return to educational settings. Participants with children felt distress at viewing their child as a potential risk to their health and expressed concern about the impact on their relationship, describing feeling that they were a “bad mum” (ID19): “if he’s got a snotty nose, you sort of think, oh god, are you a danger to me. And for a five-year-old child, who you love and is your whole world, to sort of think, oh hang on, I’m a bit worried to hug and cuddle you, is just, it’s such a conflicting kind of feeling” (FG10).

**Many participants who lived on their own talked about “being lonely”** (ID22) and living with a “feeling of isolation” (ID2). The feeling of loneliness was cumulative: “I think the feeling of isolation has developed with each successive shielding period” (ID2). Those who were affected less negatively by shielding and the lockdown tended to be older, with grown-up children.

**At times, apparently opposing emotions were experienced simultaneously**, creating cognitive dissonance for our participants. Many participants’ accounts depicted a shifting dialogue between feeling protected and feeling isolated and lonely, often simultaneously: “It was, it’s going to sound weird, [shielding] was horrendous and it was good. It was horrendous because I was on my own at a time where I was about as low as I could get because I felt lonely” (ID22). A further experience of conflicting emotions is exemplified by one participant describing the receipt of supplies from a foodbank at which they had previously volunteered: “It was very odd to be the recipient of a parcel instead of helping to deliver parcels but I have to say, it was really emotional to even receive one of those, really odd. At the time I found it super-emotional, in a way, amazing support but also upsetting at the same time, it was very odd” (ID25).

## Mental health

**Many participants reported experiencing mental health problems such as anxiety and depression for the first time in their lives.** “It was like nothing I’d come across before” (FG3). Participants recognised that the lockdowns were hard for everyone from a mental health perspective. Differences for shielders compared with the general population included the degree of social isolation: “I remember being on a zoom call, being in tears and just saying, ‘I’ve had enough, I just can’t carry on working from home and I feel really alone here, and I feel just quite depressed. All I ever do is just sit here and work and I can’t really go out, I can’t see anybody’, it was really difficult, yes.” (ID4). For others, the end to shielding appeared to trigger their mental health issues: “I’ve never really suffered from mental health issues ever and I thought...when we were shielding I thought I was alright, and then it’s been the coming out of it that’s been the problem” (ID10). A minority considered suicide.

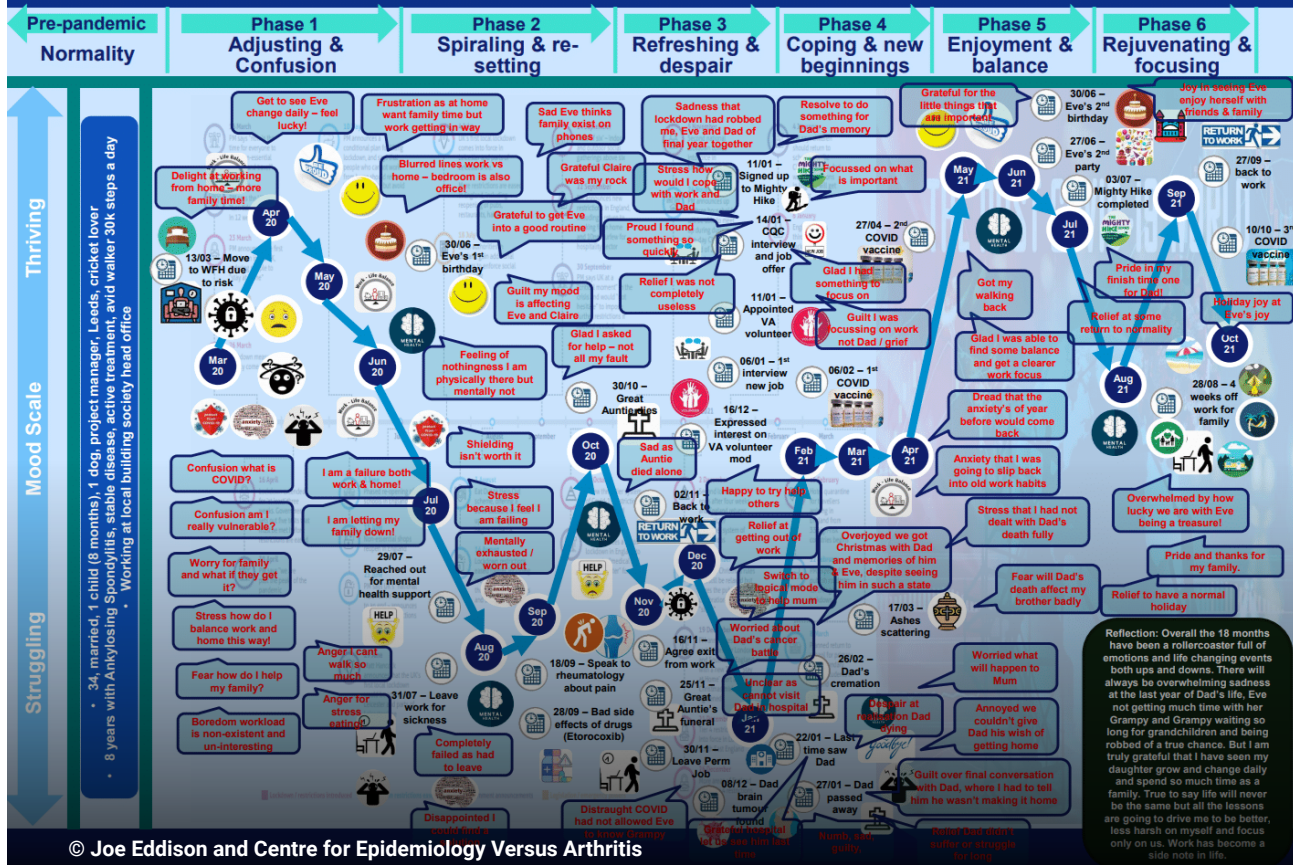
**This multitude of (sometimes) conflicting, intense and varied emotions resulted in a significant increase in ‘emotional work’ for shielders**, over and above that usually experienced during their chronic illness: “Well, it was a grief process. That’s how I call it. Because at the beginning obviously with knowing about the virus and then everything that has been happening, it went like accepting the COVID and living with it, all this process. So it’s been difficult for the mind to accept this virus is here. I was depressed, I was anxious, frustrated... So I’m not the same person before and after shielding I have to say” (ID19).



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# A personal view of my journey through lockdowns, shielding and the pandemic



## Shielding behaviour

Shielding behaviour varied, influenced by the external policy context, personal circumstances and the arising balance between **illness work**, **life work**, **biographical work** and **emotional work**. As a result, individuals took their own bespoke approaches to operationalising shielding. For example, the uncertainty around shielding notifications resulted in some contributors electing to shield before receiving formal notification: "I suppose going back to the very start of the pandemic, there was a lot of uncertainty about whether I would be told to shield or not and I really didn't know where to look or go to find out information about that. And essentially took a fairly early decision myself to work from home and effectively shield, long before I got any formal notification to" (ID15). Two participants shielded without ever receiving such a notification.

**A minority "followed the guidance completely at the beginning"** (ID23). Most, however, did not follow it to the letter, instead making individual risk assessments of each activity, particularly when the shielding period was extended. For example, the risk to physical health of meeting friends and family, or going for a walk, was offset by the benefits to mental health and physical health: "I balanced out the risks, and decided that I was willing to take that risk [of going out for a walk], purely for my own mental health, more than anything" (ID20).

There was a cyclical dimension to interaction between some themes, with emotional work resulting from shielding impacting on individuals' **shielding behaviour**, which impacted on the emotional work, and so on. Fear and anxiety impacted people's willingness to leave the house: "There was definitely an element of, like, if I step outside of this door, I'm going to die" (FG1). For some, this extended to a fear of developing agoraphobia, of becoming too used to not socialising and seeing people, describing themselves as becoming a "hermit" (FG12) and forgetting "social cues" (FG9).

During the first lockdown, participants reported that their daily lives did not differ hugely from those who did not have to shield. For a minority, shielding throughout the pandemic wasn't "that much different to the life I was already leading, because I was very unwell" (ID21). For most participants, as we saw in the biographical work theme within the perceived value to society, a major change took place when society began to open up, highlighting the differences between those who regained many freedoms, and those who were required to continue to shield, and/or those who chose to shield once formal shielding had ended.

**Participants struggled conceptually with the abrupt end to formal shielding** because it was regarded as arbitrary: “it’s still exactly the same risk, it just did not make any difference at all, it was very ironic and that was ridiculous, there should have been more of a phased one. One day you have to shield and the next day you didn’t” (ID4). Many spoke about the tensions of recognising that they would have to fit “back into the world” and “take a few more risks” (FG12), pitted against not knowing how to do that safely and appropriately. Continuous balancing of these risks used considerable time and energy, leading to a kind of decision fatigue and resulting in a significant increase in illness work: “It does kind of just take over your whole thought process, and is it safe to do this, can I do this, can I risk it. You’re constantly weighing up the pros and cons of doing anything” (FG12).

**Even once formal shielding had ended, participants described avoiding crowds,** shops and restaurants, and declining invitations or not feeling comfortable having others in their homes. Many only went out for what they deemed ‘essentials’, such as hospital appointments or to pick up medication. Some people continued to “treat everybody as if they’ve got COVID” (FG10). For others, the end to formal shielding was taken as an opportunity to regain control over their lives: “And I suppose I’ve also concluded that, really I’ve got to set my own rules on what we do and don’t do. It’s tempting to say we feel somewhat forgotten about as shielders. The guidance wasn’t great and then it was non-existent or late. And really, I’ve found it necessary to take back control of that” (ID15). A strong message from participants is summarised by the following quote: “But [shielding] is not something that came and then went, it’s something that came incredibly forcefully and the remnants of it are still very much a part of our daily lives” (FG5).

**Participants viewed vaccines very positively,** leading some to feel increasingly confident with each successive dose received: “So I definitely wasn’t gung-ho once I was double vaccinated, but it did start us thinking, okay, right, we can go and visit relatives that have been double vaccinated...” (ID15). However, despite this positivity, vaccination was not felt to be a panacea for protection from COVID-19. Most respondents were aware that their rheumatological condition and / or associated medication, might impair their ability to build effective immunity from the vaccine. There remained much uncertainty from a scientific perspective regarding the efficacy of vaccines amongst this population: “there’s a whole range, from you haven’t had a reaction whatsoever from the vaccination, all the way up to you’re probably just like a normal person in the normal population and you could be

anywhere in there. Some medications are more likely to put you down at the bad end, aren’t they, but who knows, who knows where you are? And that’s quite worrying” (FG2).

**Many reported the ongoing challenges of balancing uncertainty and risk associated with the limited scientific knowledge on vaccine efficacy:** “I still don’t know how efficacious these injections have been. I’m extremely grateful to have had them, but I don’t know whether I’ve got any protection or not. And it’s that uncertainty that makes things so, so difficult, I think” (ID2). In some cases, this **uncertainty and risk** led participants to elect to continue to take precautions as if they had no immunity, impacting their **shielding behaviour**. “I don’t know how effective the vaccines have been for me. And until more research is published in that regard, I mean, I know it’s ongoing, isn’t it? It’s being looked into at this very moment, but, until we know more definitively, I don’t feel that I can relax in that regard” (ID2).

A few expressed feeling anger and frustration with people who had refused to get vaccinated, in some cases leading them to fall out with friends and family.

**Some participants paid for private antibody testing** to alleviate their anxiety and help their mental health, as this service was not available in the NHS outside of clinical trials. One participant said knowing their antibody level “changed my life” (ID19); another that knowing they had a good antibody level gave them more confidence to start going out. These responses should be interpreted in the context that scientific knowledge around the significance of mounting an antibody response was far from clear at the time (i.e. that the presence of antibodies did not necessarily confer a good level of functional protection from COVID-19 infection and that the absence of antibodies did not necessarily imply a complete lack of protection), suggesting that participants were interpreting their antibody status in a way that would likely differ to that of a clinician.

The findings on shielding behaviour show how the different lines of illness, life, biographical and emotional work coalesced to inform people’s approach to shielding.







# RECOMMENDATIONS

## Clinical practice recommendations

1. To acknowledge and recognise individual patients' experiences of shielding and address ongoing anxiety around risk from COVID, if present.
2. To support individuals to make decisions around risk from infection including interpreting information with them according to their personal approach to risk and the evolving evidence, taking into consideration contextual factors such as family and work lives. This includes education around importance of timing and type of vaccination, testing for antibodies to vaccinations and how to interpret those responses, and timing of infusions around vaccinations, especially rituximab.
3. To continue to advocate for patients who may remain at risk from COVID-19 and other infections, not least because of reduced vaccine efficacy in this population. To support individual patients with documentation for the workplace and education settings, and more broadly to raise awareness of the need for continued caution in regard to infections in this cohort of patients.
4. To apply the principles outlined above when caring for patients at risk of infection during future pandemics.

## Policy recommendations

### Future preparedness

1. The UK Health Security Agency and public health bodies across the UK with responsibility for pandemic preparedness should develop an impact assessment framework for shielding, based on the four key areas of impact highlighted within the report. This should guide future decision making and subsequent evaluation and be produced in consultation with those who have shielded and are likely to have to shield.
2. NHS bodies across the UK must ensure that the methods of data collection, data sharing and means of generating the Shielded Patient List are maintained and improved going forward to ensure these lists can be generated at speed in future.
3. NHS bodies across the UK must embed processes which ensure more effective communication between healthcare providers and from healthcare providers to patients for future pandemics to ensure that there is consistency regarding what information is provided to people shielding.



## Public engagement

1. When national public health bodies across the UK are designing approaches and content for people who are shielding, there should be greater involvement of people with lived experience and charities at an early stage. This should form part of current pandemic planning processes.
2. Integrated Care Systems and Health Boards should map any pandemic-related information and support available from third sector organisations (for example, helplines, online resources), and ensure that local health care providers are routinely signposting this to their patients, so they have the skills and confidence to manage their health and navigate healthcare services during a future pandemic.



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## Mitigating the consequences of shielding

1. The Department for Work and Pensions should ensure that there is employment protection and enforceable access to workplace adjustments for immunocompromised or immunosuppressed people, including the duty to consider working from home wherever possible.
2. NHS bodies across the UK need to make greater provisions to ensure that people required to shield can access the essential health services they require. This includes an in-person offer, as well as online support services during a future pandemic.
3. Future mental health plans released by government health departments across the UK need to address the mental health needs of people who were required to shield, with funding allocated to support those with unmet needs resulting from the pandemic.
4. Clear information and guidance is required for people who may be advised to shield. GPs and health professionals need to be able to provide clarity and proof if required that the individual is advised to shield.



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# CONCLUSION

The findings of this research have highlighted the notable and diverse impacts the pandemic had on people who had to shield, and those who continue to do so. COVID-19 created challenges for shielders, over and above those encountered by the general population. Even today, many people who shielded from COVID-19 remain at increased risk from the impacts of the disease, and remain at risk from any future pandemics which may arise. This current and future risk means that ongoing action is required to mitigate the effects on the population of people who are at increased risk from novel infections.

The pandemic has also affected the relationships that shielders have in many aspects of their lives. This ranged from having to alter interactions with family and friends due to fear of serious illness, and, in a professional capacity, a necessary switch in working arrangements. At times, it led to a feeling of detachment from society as a whole and a feeling of abandonment. At the personal, professional and societal levels COVID-19 has severely altered people's lives, leading to a range of strong emotions, and worsening people's mental wellbeing.

These impacts also feed into how COVID-19 has altered their illness perception regarding both their underlying conditions and the wider fear of COVID-19. This is an extra burden which alters the context of managing their condition and adding to the work required to do this.

Finally, there is the longer-term effect on shielders' relationship with healthcare professionals. People who shielded felt clinicians were not wholly equipped to support them during this uncertain period. Therefore, clinicians may need support to understand people's altered perceptions of themselves, of their place in society and how they may need help from healthcare professionals in understanding their personal risk from COVID-19. This latter point is a challenge for clinicians – at the beginning of the pandemic evidence regarding both population-level and personalised risk was not already available. Currently we have much more understanding about vaccine efficacy and who remains at highest risk from COVID-19, but providing

this information to individual patients in a way that is meaningful to them, poses a challenge.

This research marks only the beginning of understanding the impact of shielding on the lives of those who had to shield. Only as time passes will we discover the longer term implications of shielding on people living with inflammatory autoimmune conditions. It is hoped this report goes some way to providing people living with autoimmune conditions with the reassurance that their voice has been heard; that it supports clinicians to understand the experiences of their patients and to advocate for them; and that it may influence policymakers when planning for future pandemics.



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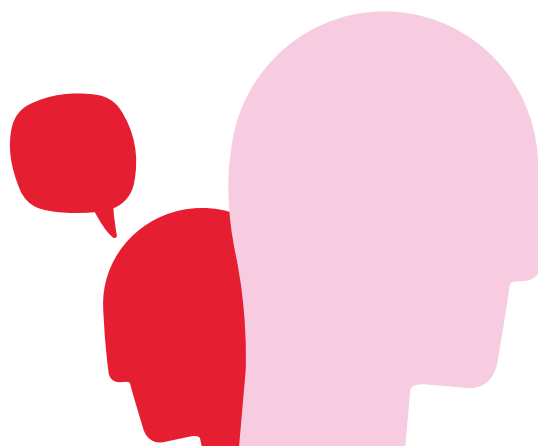
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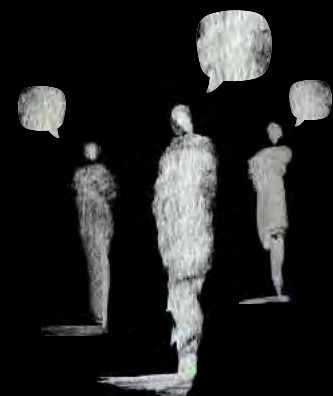
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Sharp, CA., Laidlaw, L., Fox, J. (2023) *COVID  
Shielding Voices Report*. Centre for Epidemiology,  
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