

BMJ Open Qualitative interview study of rheumatology patients' experiences of COVID-19 shielding to explore the physical and psychological impact and identify associated support needs

Christine A Silverthorne ^{1,2}, Bethan Jones,^{1,2} Mel Brooke,³ Laura C Coates ⁴, Jen Orme,^{1,2} Joanna C Robson,^{1,2} William Tillett,^{3,5} Emma Dures ^{1,2}

To cite: Silverthorne CA, Jones B, Brooke M, *et al*. Qualitative interview study of rheumatology patients' experiences of COVID-19 shielding to explore the physical and psychological impact and identify associated support needs. *BMJ Open* 2024;**14**:e075871. doi:10.1136/bmjopen-2023-075871

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<https://doi.org/10.1136/bmjopen-2023-075871>).

Received 22 May 2023
Accepted 07 March 2024



© Author(s) (or their employer(s)) 2024. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

¹Academic Rheumatology, Bristol Royal Infirmary, Bristol, UK

²University of the West of England, Bristol, UK

³Royal United Hospitals, Bath, UK

⁴Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford, Oxford, UK

⁵University of Bath, Bath, UK

Correspondence to

Christine A Silverthorne;
chris.silverthorne@uwe.ac.uk

ABSTRACT

Objective Many clinically extremely vulnerable rheumatology patients have only recently ceased shielding from COVID-19, while some continue to minimise in-person contact. The objective of this study was to understand the impact of shielding and associated support needs in patients with rheumatic conditions and to understand how rheumatology teams can meet these needs both currently and in future pandemics.

Design, participants and setting The study was conducted in the Southwest of England using a case-study design. The participants were 15 patients with rheumatic conditions who were advised to shield and/or chose to shield at any time during the COVID-19 pandemic.

Methods Qualitative data collected via telephone and online semi-structured interviews and analysed using reflexive thematic analysis.

Results Fifteen interviews were conducted. Three main themes represent the data:

'Just shove them over there in the corner' captures changes in patients' self-perception. They felt different to most other people, vulnerable and left behind. The initial sense of shock was followed by a sense of loss as changes became long term.

'A long and lonely road' captures patients' psychological isolation due to a perceived lack of understanding and support. This included having to prove their health status and justify their shielding behaviours, which impacted their relationships. At times, they felt abandoned by their healthcare providers.

'You can't just flip a switch' captures the difficulty of getting back to pre-pandemic normal after shielding. Patients did not recognise themselves physically and mentally. They wanted to collaborate with health professionals and identified the need for specific guidance to support their recovery.

Conclusion Patients are dealing with lasting physical and mental effects from shielding and consequences of delayed healthcare. Health professionals need time and resources to ask about patients' well-being, identify their health needs and refer/signpost to appropriate sources of support.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study captured the views of participants as they had recently stopped shielding or were ceasing to shield and so gained an insight into their thoughts and behaviours at this particular point in time.
- ⇒ The study explored participants' support needs with regards to both their physical and mental health.
- ⇒ Data were collected and analysed by two insider researchers, which may have allowed for a greater rapport with participants, resulting in richer, more detailed data due to their shared experiences, knowledge and understanding.
- ⇒ The research findings were informed by discussions with coauthors with multidisciplinary backgrounds, including medicine, psychology and lived experience of shielding.
- ⇒ Participants were from a limited geographical area (Southwest of England).

INTRODUCTION

During the COVID-19 pandemic, approximately 4 million people in the UK were classified as clinically extremely vulnerable (CEV) and advised to 'shield'.¹ To be considered as CEV, individuals need to have a weakened immune system due to a particular health condition or taking medication that suppresses their immune system and who therefore may have a reduced ability to fight infections and other diseases, including COVID-19. This therefore included patients with rheumatic conditions, at risk of severe harm from the virus due to being immunosuppressed. Shielding required people to strictly isolate for long periods, with shielding advice remaining in place throughout 2020. At various times during 2020 and 2021, people shielding were advised that they should not leave their homes, and to physically distance themselves from others in their

household, eat separately and sleep and wash in separate spaces where possible. Additionally, many patients with rheumatic conditions who were not formally identified as CEV took shielding precautions to protect themselves during the pandemic.²

Existing research has demonstrated that many patients with rheumatic conditions found the process of shielding had a negative impact on their well-being and increased their levels of anxiety and depression, reduced their physical activity and fitness levels, and led to feelings of isolation.^{3,4} Research has also indicated that the psychological, social and practical impact of COVID-19 is expected to continue for several years.^{5,6} For CEV patients, shielding meant that many of them experienced a continued state of distress on top of the challenges they already faced by living with a health condition. Indeed, CEV patients were found to be significantly more likely to reach the threshold for health anxiety or generalised anxiety than those who were not classed as CEV.⁷ Similarly, patients with pre-existing physical health conditions were found to have a larger increase in distress during the first wave of COVID-19 as compared with the general population.⁸

In addition, during the height of the pandemic, CEV patients also had to cope with disruptions to the provision of their rheumatology care, partly due to the redeployment of rheumatology health professionals to the COVID-19 front line⁹ as well as rheumatology health professional own sickness.¹⁰ This disruption included cancellations and delays to appointments, difficulty accessing medication and a reduction in the monitoring of symptoms, all of which increased the risk of long-term damage, for example, as a consequence of not quickly treating disease flares.¹¹ Further, high levels of stress and negative changes to diet or physical activity can exacerbate some long-term health conditions.¹²

The aim of the current study is to understand the experience and impact of shielding in patients with rheumatic conditions and to explore their support needs. Also, it aims to understand how rheumatology teams can meet these needs both during and after times of isolation, for example, when patients are experiencing health-related setbacks that can occur with rheumatic conditions or should any future pandemics occur.

METHODS

Study design

A qualitative design was used with data collected using one-to-one, semi-structured, telephone or online interviews. Semi-structured interviews can generate insights into the thoughts and feelings of participants.¹³ In the semi-structured format, participants are asked the same core questions, but there is flexibility to probe more deeply and develop new lines of enquiry based on their responses. The core questions in the interviews were based on the study objectives. The interview schedule was designed by the research team (comprising psychology researchers, rheumatology consultants,

Box 1 Interview schedule

Section 1: experience and impact of shielding

- ⇒ Shielding behaviours and practices
- ⇒ Physical and psychological effects
- ⇒ Impact on healthcare and access to healthcare services

Section 2: how shielding experience informed behaviours as restrictions were lifted

- ⇒ Returning to pre-pandemic activities
- ⇒ Thoughts and feelings about what felt safe to do/not do

Section 3: shielding support

- ⇒ Support received during shielding and current support needs
- ⇒ Lessons learnt and support for patients in the future

insider researchers and a patient research partner with lived experience of shielding) and in collaboration with regional rheumatology patient groups. See [box 1](#) for interview schedule.

Sampling and recruitment

This study was conducted in the Southwest of England. Participants were patients with rheumatic conditions who were advised to shield and/or chose to shield at any time during the COVID-19 pandemic. Potential participants were informed about the research and invited to take part via a flyer to the regional branches of relevant rheumatology patient groups including the National Rheumatoid Arthritis Society (NRAS) and the National Axial Spondyloarthritis Society. In addition, social media posts were sent to social media networks related to CEV people to advertise the study. Potential participants who were interested in taking part contacted the lead author for further information and to arrange a telephone or online interview. The concept of ‘information power’¹⁴ was used to inform the sample size. This is based on the idea that the more information the sample holds relevant to the research, the lower the number of participants needed. In this study, the researchers felt that the study objectives were met after collecting data from 15 participants.

Data collection

Interviews were conducted over the telephone or online via video call. Before the start of the interviews, the participants signed a consent form and provided demographic data (rheumatic condition, disease duration, disease medication, gender, age and ethnicity). The lead author and one other member of the research team conducted the interviews. Both interviewers had shielded during the COVID-19 pandemic and disclosed this to participants. At the time the interviews were conducted, all official government guidance to shield had ended. Interviews were audio recorded, transcribed by a professional transcription service, checked for accuracy against the original audio files and anonymised by changing the names of people and places.

Reflexive thematic analysis was used to analyse the data.¹⁵ The aim of this type of analysis is to identify patterns in the data to describe participants’ views and experiences.

This involves becoming familiar with the data, attaching codes to the transcripts to describe the content, generating initial themes, reviewing and developing themes and then refining, defining and naming the themes. It is an iterative process that involves moving between the entire data set and the coded extracts of data. This approach was taken as it is appropriate for research that is not based on pre-existing theory about the phenomena being studied. It was also suitable for highlighting both similarities and differences in the experiences and views of the participants.

The lead author read all 15 transcripts and coded sections of text that related to the research question. Related clusters of coded text formed subthemes, which were grouped together to form a smaller number of higher order themes that described broad elements in the dataset. Two anonymised transcripts were both reviewed independently by two other members of the study team and then discussed to ensure that the findings were informed by multiple viewpoints.¹⁶ The final analysis was based on the integrated interpretations of four team members, including the two researchers who had collected the data and two other team members. The themes and subthemes were also discussed with other team members, including the patient research partner who felt that they reflected their own experience of shielding as well as those expressed in their local patient networks.

Patient and public involvement

The study team, including a patient partner, collaborated with regional rheumatology patient groups in the Southwest of England to develop the research question and study design and to acquire funding. Regional patient groups supported study recruitment by advertising the study to their members. A lay summary of the study findings has been distributed to rheumatology patient groups across the UK via their social media platforms and electronic newsletters, including on the NRAS website (published on 9 March 2023).

RESULTS

A total of 15 interviews were conducted with patients with rheumatic conditions living in the Southwest of England with experience of shielding during the COVID-19 pandemic. Rheumatic conditions included rheumatoid arthritis, psoriatic arthritis, systemic lupus erythematosus, ankylosing spondylitis, axial spondylopathy, osteoarthritis, undifferentiated connective tissue disease, fibromyalgia, Antineutrophil cytoplasmic antibody (ANCA) vasculitis and Sjogren's syndrome. Treatments included biologic medicines (adalimumab, upadacitinib, abatacept, ixekizumab and rituximab) and non-biologic medicines (methotrexate, hydroxychloroquine, leflunomide, sulfasalazine and mycophenolate) as well as prednisolone, amitriptyline and paracetamol. Thirteen of the participants were taking immunosuppressant medicine

Table 1 Themes and subthemes

Main theme	Subtheme
'Just shove them over there in the corner'—feeling different to others and left behind.	'Fast tracked to the more critical'—feelings of vulnerability and a change in self-perception. 'A real sense of loss'—living with long-term changes.
'A long and lonely road'—psychological isolation heightened by a lack of understanding and empathy.	'You have to prove yourself all the time'—having to justify shielding behaviours. 'Nobody's checking up on me'—feeling abandoned.
'You can't just flip a switch'—the difficulty of getting back to normal after shielding.	'I didn't recognise myself'—the struggle to stay physically and mentally well. 'Work through it together'—the need for a collaborative approach to recovery.

and so met the criteria for being CEV, while two participants did not strictly meet the criteria for being CEV but still chose to shield.

Interviews ranged from 31 to 81 min in length (median: 60 min). Online supplemental table S1 presents participant demographics. Three main themes with subthemes capture the patterns across the data (table 1). The themes and subthemes have been labelled using participants' own words and are evidenced using data extracts. Additional data extracts are provided in online supplemental tables S2-S4.

Theme: 'Just shove them over there in the corner'—feeling different to others and left behind

The participants described the effects that being labelled as 'vulnerable' had on their lives and how it affected their thoughts, feelings and behaviours. Participants talked about how this label, combined with the experience of shielding, had led in some cases to a sense of exclusion and long-term changes in their lives.

Subtheme: 'Fast tracked to the more critical'—feelings of vulnerability and a change in self-perception

Participants talked about how being identified as CEV had made them feel vulnerable, often for the first time, and for some this experience had changed how they saw themselves. Many were worried about a COVID-19 infection leaving them with further health complications and some were afraid of dying. Participants felt acutely aware of being different to others who were not classed as CEV and deemed at high risk of adverse outcomes from COVID-19, including feeling less powerful and less important.

'I suppose what it did was exaggerated my condition...suddenly, I wasn't just a person with psoriatic arthritis, I was an elderly extremely vulnerable person which is not what I saw myself as before Covid...I

suppose it changed my perception of myself as well' (Interview 14)

'...the feeling that I was being infantilised and my power, what little power I had as someone with lupus, anyway, was sort of taken away' (Interview 7)

Subtheme: 'A real sense of loss'—living with long-term changes

Many participants had still not returned to pre-pandemic activities, including exercise, social activities and attending church. Many expressed sadness and resentment at how others had been able to return to life as normal while they were still living with changes and loss. For some, there were real fears about still being unprotected and not having made sufficient antibodies from the vaccines. Others felt they had lost the ability to mix in social situations or had become accustomed to staying in the home and noticed that they went out far less than they had before.

'...the impact for me, has been a real sense of loss... and I think it's ongoing, living with loss. I feel my life has changed, and its definite sadness that comes with that because things just do feel harder' (Interview 4)

'...for me, the going into shielding was not such a big step from my normal life but the coming out of shielding has felt much, much harder and the more that life gets back to so-called normal for other people, the more I feel my abnormality' (Interview 7)

Theme: 'It's a long and lonely road'—psychological isolation heightened by a lack of understanding and empathy

Participants talked about how they wished others had shown more understanding and empathy for their situation. They described some of the challenges of living with an often invisible health condition and feeling pressured to tell others about their health status to justify why they were shielding. They also talked about the support they had received from their rheumatology team with some finding greater help than others.

Subtheme: 'You have to prove yourself all the time'—having to justify shielding behaviours

Participants often felt they needed to prove themselves to others and justify why they needed to shield. Some felt uncomfortable at disclosing and discussing their rheumatic condition with others, sometimes for the first time. People challenging the participants' shielding decisions and behaviour strained their relationships, including those with family, friends, employers and their children's school/nursery.

'...it's denying your existence, almost...it's almost like you have to prove actually this is real, actually there is a concern for my life, and it's almost like you're having to prove it, and that's...well, it's exhausting... It's just a battle, it feels like you have to prove yourself all the time, and that's just exhausting' (Interview 11)

'There was this thing that with arthritis it's not a life-threatening condition and then suddenly it

became this really big thing that I started having to tell everyone about which felt quite uncomfortable' (Interview 15)

Subtheme: 'Nobody's checking up on me'—feeling abandoned

The participants had varied experiences of the support they received from their rheumatology teams during their time shielding, with some feeling the specialist nurses offered a valuable source of help. However, others described feeling abandoned and felt they had to manage any healthcare issues for themselves.

'I feel a little bit abandoned by my team at [hospital]... they must've been overloaded but I have felt a bit abandoned' (Interview 12)

'I would have appreciated a bit of how are you managing with it? Or how are you coping with it? Or something but there was nothing' (Interview 11)

'...what has become much more difficult is the nurse helpline because they're just so busy.' (Interview 10)

Theme: 'You can't just flip a switch'—the difficulty of getting back to normal after shielding

Participants described the physical and mental impact of shielding, which for many was still an ongoing concern. They talked about how they often felt quite alone in dealing with the negative effects of shielding and how they would have valued receiving more specific guidance and support from rheumatology. They also talked about the benefits of peer support.

Subtheme: 'I didn't recognise myself'—the struggle to stay physically and mentally well

Most of the participants had experienced a negative impact on their physical health following shielding, including loss of strength and stamina and a gain in weight. Some had made a conscious decision to continue with exercise and been able to incorporate physical activity into their daily lives while shielding. Participants described how factors such as having access to a garden or safe open space, a supportive partner, owning a dog, not being employed, and having no childcare responsibilities made continuing with exercise easier.

'...my mobility really deteriorated, and my weight went up a lot' (Interview 5)

'...you can't just flip a switch and overnight go back to where you were before and so, I did find it really difficult and to a certain extent, quite disheartening to see how much I'd lost in the time that I'd been shielding.' (Interview 8)

'I struggled there because I wasn't doing them [physiotherapy exercises] with anybody, so my motivation had hit the floor' (Interview 6)

Shielding, and ceasing to shield, had a negative impact on the mental health of many participants with some describing how they were still living with a lasting anxiety and with decreased confidence about being back out

in the wider world. Participants described their need to have had someone to talk to during shielding and how they had been reluctant to talk to friends and family as they were worried about being seen differently by them, worried that they would be seen as ‘weak’ and ‘less independent.’ Several factors influenced the degree of stress experienced, including the level of support participants received from partners, family, friends and employers.

‘I didn’t want to talk to my friends about it [anxiety], because I didn’t want them to see me as that person... they’ve always seen me as that strong, independent go-getting person, and I didn’t want them to see me as being weak and pathetic’ (Interview 3)

‘...it’s a psychological thing, it’s the mental impact, that’s what’s gone, I mean my sense of confidence’ (Interview 2)

‘I’m somewhat losing confidence or losing familiarity with being out in the outside world and with that loss of familiarity things just are a bit less normal for me mentally’ (Interview 13)

Subtheme: ‘Work through it together’—the need for a collaborative approach to recovery

Participants expressed how they would have valued, and would still value, receiving specific guidance and support from rheumatology health professionals, including information and guidelines on areas such as diet, exercise and medication, as well as support for their mental health and being asked about how they were coping. Several participants described how they were constantly making risk assessments of what was safe or not safe to do, how stressful this was for them and how they would have valued help with this decision-making.

‘Ideally, they’d ask about your mental health, they’d ask about the whole picture not just your physical joint pains, and they’d talk to you about the impact of Covid, and how you were managing it, and help you work through it together, and not send you things out in the post and then leave you to deal with the aftereffects of that.’ (Interview 11)

Several participants talked about the benefits of being able to talk to others with a rheumatic health condition who were going through similar experiences to themselves. Some had developed an online support network, for example, through Facebook, to help them manage while shielding. However, not everyone was aware of these online support groups, and some expressed a preference for face-to-face, one-to-one or telephone support.

‘I think to have like a peer support group and then a phone line for people and also some one-to-one support would be really good’ (Interview 15)

The participants’ experiences highlighted the benefits of online treatments, for example, physiotherapy, and online classes, for example, yoga and art. This shows the value of continuing to offer flexibility between online and

face-to-face sessions. Shielding also enabled some participants to take a break from some of the pre-pandemic pressure of life and they found relief from not having to do all the things they were doing alongside living with a rheumatic condition. For some, it was an opportunity to assess what was most important to them in life.

‘I know some people really struggled with not doing face to face, but I think a lot can be done over the phone, or with something like physio, can be done on Zoom’ (Interview 5)

‘it was quite nice not having all the pressures of having to do all the stuff I was doing.’ (Interview 11)

DISCUSSION

This study set out to explore the experience and impact of shielding in patients with rheumatic conditions and specifically to understand their support needs both during and after shielding. The study also aimed to identify how rheumatology teams can support patients better in future times of isolation such as health-related setbacks. The findings indicate that for many participants shielding was the first time they had seen themselves as ‘vulnerable’, which for some led to a change in self-perception. Participants said they felt different and often less important than those not shielding and talked about feeling left behind when others returned to their normal lives. Some participants described feeling abandoned by their rheumatology team and how, as a result of shielding, they were living with long-term changes to both their physical and mental health as well as to their work and social activities. Participants also described how shielding had impacted their relationships and how they had felt, and often still felt, the need to justify their shielding behaviours.

The findings are consistent with those found in another study¹⁷ where the self-management abilities of patients with inflammatory arthritis were impacted by shielding and that for the majority of participants their physical activity levels decreased and their diet had got worse. They are also consistent with the findings from a recent systematic review⁸ where participants with a pre-existing physical health condition tended to show a larger increase in mental health symptoms (depression, anxiety, well-being) than the general population during the first lockdown in March 2020, and with those from a rapid review of survey data where people with long-term health and care needs experienced a negative effect on their well-being (including increased anxiety and loneliness) during the first wave of COVID-19.¹⁸ The findings are also similar to those of a recent qualitative study in which participants felt that being labelled as vulnerable exposed their disease status more widely than they would have liked and/or classed them as a separate entity of lesser value compared with the rest of the population.⁴

Current guidance recommends that health professionals should consider psychological well-being when treating physical symptoms.¹⁹ This study has shown how



participants' need for psychological support was amplified during shielding and yet they often received less psychological support than they had before. Participants indicated they would have valued some reassurance about their shielding behaviours as well as having a clear, supportive point of contact for their concerns about medication, disease flares and symptoms and dealing with depression and anxiety. Studies have shown the need for greater access to mental health support in rheumatology^{20–24} and this has proved to be even more critical during and after times of isolation. Rheumatology professionals should be encouraged to ask about their patients' mental well-being and should feel confident there are appropriate services or referral pathways in place when required.²⁵ Participants with access to nurse-led rheumatology helplines found these supportive indicating the value of expanding this source of help to all patients.

The study findings that participants often felt abandoned by their rheumatology team are of concern as research indicates that patients are more likely to adhere to treatment and to be satisfied with their care if they feel that health professionals are respectful, interested, supportive and understanding.²⁶ The redeployment and sickness of rheumatology health professionals during the pandemic meant that inadequate time and resources were available to give this level of support to patients.¹⁰ Abandonment (due to a lack of clear information about levels of risk and changes to care plans) was also a major finding in a recent survey from the Rare Autoimmune Rheumatic Disease Alliance.²⁷ In another study, previously responsive rheumatology departments were reported to have not responded effectively (or at all) to repeated requests for medical advice and help, which was felt to have contributed to physical deterioration and a sense of abandonment.¹¹ Patients with rheumatic conditions can experience permanent joint damage if their disease is not optimally managed and unchecked inflammation may also affect other parts of the body, including the heart, eyes, lungs and vascular system.²⁸ It is important to ensure that the patient–healthcare relationship is not similarly affected by any future periods of patient isolation to mitigate the subsequent risk of deterioration in patient health. This also emphasises the need to address the mental health of the health professionals who were under immense pressure during the pandemic.

Support and understanding from family, friends and employers were mentioned by participants as an important factor in helping them to cope with both shielding and ceasing to shield. This is consistent with other research findings that social support was an influencing factor in the effect of shielding on mental health.²³ The current study also highlighted the specific power of peer support and the benefits of talking to others in a similar situation. Some participants had found online support groups helpful, but others were not aware of them or stated a preference for meeting others face to face, indicating the need for flexibility in support offered. Checking patients' support needs and

sign posting and raising awareness of relevant rheumatology support groups and, where possible, introducing, or re-establishing face-to-face support groups should be a priority for patient care.

Several participants had perceived a lack of respect and empathy from others, including friends, employers, schools and the general public indicating the need for greater awareness of the issues faced by CEV people, including those with hidden disabilities. This was particularly true when coming out of shielding and participants felt that it was difficult for them to go back to normal. It is consistent with other research findings where participants felt like they'd 'been thrown to the wolves' and were less valued than 'healthy' members of the population.²⁹ CEV people cannot shield effectively without the understanding and cooperation of those around them, emphasising the need for better policies and legislation relating to CEV people.

This study has found that life has not returned to normal for many participants despite the end of shielding restrictions. This is consistent with the findings of a review into the psychological impact of quarantine which suggested negative psychological effects including depression and stress can be wide-ranging, substantial and detected months or years later.³⁰ It has highlighted how many still need support to effectively manage their physical and mental health as they cease shielding or continue to shield. The study also indicates the value of providing rheumatology-specific guidelines and sources of information relating to diet, exercise, medication, relaxation skills and employment rights, all of which could be made available online for times of isolation. The study also highlights the importance of providing methods, such as helplines and support groups, to enable people to get advice and talk to others going through similar experiences. Participants' experiences of vulnerability, changes to self-perception and difficulties in conveying their feelings and behaviours to others indicate an additional need for a psychologically informed approach to help with building self-confidence, developing coping strategies and help with acceptance and communicating about their rheumatic condition. Providing patients with the support they need during times of isolation and ensuring they do not feel forgotten will both help minimise their physical and mental distress at the time and prevent the need for more invasive and costly healthcare and treatments in future, saving both patient distress and National Health Service resources.

Future research should investigate the ongoing physical and mental impact of shielding on patients with rheumatic conditions to ensure they receive appropriate treatment and support. The financial and employment impact could also be studied due to changes in employment, work patterns and job losses either as a consequence of shielding or due to deterioration in health. The impact on patients' partners and family would also be a beneficial area of future study.

Strengths and limitations

A strength of this study is that it captured the views of participants as they had recently stopped shielding or were ceasing to shield and so gained an insight into their thoughts and behaviours at this particular point in time. It looked at what activities and behaviours participants felt were safe for them to do and explored the support they needed to help with this decision-making, as well as looking at their support needs with regards to their physical and mental health. The data were collected and analysed by two ‘insider researchers’ (ie, the researchers shared group membership with the participants as they also had personal experience of shielding due to being classified as CEV), which may have allowed for a greater rapport with participants, resulting in richer, more detailed data due to their shared experiences, knowledge and understanding.³¹ The research findings were informed by discussions with coauthors with multidisciplinary backgrounds, including medicine, psychology and lived experience of shielding, to ensure an all-round perspective was obtained. A further strength of this study is that the participants had a range of rheumatic conditions with a range of disease duration.

A limitation of this study is that there was a lack of ethnic diversity as participants were all from a white ethnic background. In addition, participants were from a limited geographical area (Southwest of England), but the data obtained reflect those found in other similar studies.

CONCLUSIONS

Shielding led to some patients feeling ‘forgotten’ and many found it difficult to talk about their experiences and the challenges they faced to other people. Many are still dealing with lasting physical and mental effects both from the experience of shielding and as a consequence of delays to their healthcare and treatment. For many, the COVID-19 pandemic is over, but 3 years on some individuals with rheumatic disease have only recently ceased shielding, while some continue to shield. Health professionals must be given the time and resources to ask about patients’ well-being and support needs and be able to ensure their patients can be signposted and referred to timely and appropriate sources of psychological support. Rheumatology-specific guidelines would benefit patients during any future pandemics. It would also be helpful to involve CEV people in the plans for any future need for them to isolate, whether for health-related setbacks or for a future pandemic.

X Laura C Coates @drlauracoates

Contributors Conception/study design: CAS, BJ, MB and ED. Development of topic guide: all authors. Access to participants/acquisition of data: CAS, BJ, JO and ED. Conducting the interviews: CAS and BJ. Analysis and interpretation of the data: CAS with support from BJ and ED. Project management: ED. Manuscript drafting: CAS. Manuscript revision and approval: all authors. ED, guarantor.

Funding The project was funded by the Bath Institute for Rheumatic Diseases (BIRD).

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval The study was approved by the Health and Applied Sciences Faculty Research Ethics Committee of the University of the West of England (reference: HAS.21.12.047). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iDs

Christine A Silverthorne <http://orcid.org/0000-0001-8145-2305>

Laura C Coates <http://orcid.org/0000-0002-4756-663X>

Emma Dures <http://orcid.org/0000-0002-6674-8607>

REFERENCES

- ONS. 2020. Available: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronavirusandclinicallyextremelyvulnerablepeopleinengland/22februaryto27february2021#reasons-for-clinically-extremely-vulnerable-people-leaving-their-homes>
- Versus arthritis. 2020 Available: <https://www.versusarthritis.org/news/2020/july/new-research-reveals-shielding-experiences-of-millions-with-arthritis/>
- Versus arthritis. 2020. Available: <https://committees.parliament.uk/writtenevidence/18230/pdf/>
- Sloan M, Gordon C, Lever E, *et al*. COVID-19 and shielding: experiences of UK patients with lupus and related diseases. *Rheumatol Adv Pract* 2021;5:rkab003.
- Anderson. 2021. Available: [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)00232-4/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)00232-4/fulltext)
- Oyebode O, Ramsay SE, Brayne C. Public health research in the UK to understand and mitigate the impact of COVID-19 and COVID-19 response measures. *J Epidemiol Community Health* 2021;75:209–12.
- Rettie H, Daniels J. Coping and tolerance of uncertainty: predictors and mediators of mental health during the COVID-19 pandemic. *Am Psychol* 2021;76:427–37.
- Robinson E, Sutin AR, Daly M, *et al*. A systematic review and meta-analysis of longitudinal cohort studies comparing mental health before versus during the COVID-19 pandemic in 2020. *J Affect Disord* 2022;296:567–76.
- Dacre J. *Virtual Rheumatology During COVID-19: A Personal Perspective*. 2020:7.429–31. Available: <https://doi.org/10.6084/m9.figshare.12657380>
- Nune A, Iyengar K, Ahmed A, *et al*. Challenges in delivering rheumatology care during COVID-19 pandemic. *Clin Rheumatol* 2020;39:2817–21.
- Sloan M, Gordon C, Harwood R, *et al*. The impact of the COVID-19 pandemic on the medical care and health-care behaviour of patients with lupus and other systemic autoimmune diseases: A mixed methods longitudinal study. *Rheumatol Adv Pract* 2021;5:rkaa072.



- 12 Hartmann-Boyce J, Mahtani KR. Supporting people with long-term conditions (LTCS) during National emergencies. Centre for Evidence Based Medicine Review; 2020. Available: www.cebm.net/covid-19/supporting-people-withlong-term-conditions-ltcs-during-national-emergencies [Accessed 7 Jul 2021].
- 13 DeJonckheere M, Vaughn LM. Semistructured interviewing in primary care research: A balance of relationship and rigour. *Fam Med Community Health* 2019;7:e000057.
- 14 Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res* 2015;26:1753–60.
- 15 Braun V, Clarke V. Conceptual and design thinking for thematic analysis. *Qualitative Psychology* 2021. Available: Advance online publication
- 16 Clarke V, Braun V. Thematic analysis. *The Journal of Positive Psychology* 2017;12:297–8.
- 17 Caton E, Chaplin H, Carpenter L, et al. The impact of COVID-19 on self-management Behaviours and Healthcare access for people with inflammatory arthritis. *BMC Rheumatol* 2021;5:58.
- 18 National Voices. WHAT WE KNOW NOW: WHAT people with health and care needs experienced during the first wave of COVID-19 A rapid review of data from over 66,000 responses to National Voices members' surveys, 2020. Available: https://www.nationalvoices.org.uk/sites/default/files/public/news/download/what_we_know_now_1.pdf [Accessed 2 Nov 2023].
- 19 Mental Health Foundation. Physical health and mental health, 2019. Available: <https://www.mentalhealth.org.uk/a-to-z/p/physical-health-and-mental-health> [Accessed 4 Feb 2022].
- 20 Dures E, Almeida C, Caesley J, et al. A survey of psychological support provision for people with inflammatory arthritis in secondary care in England. *Musculoskeletal Care* 2014;12:173–81.
- 21 Dures E, Almeida C, Caesley J, et al. Patient preferences for psychological support in inflammatory arthritis: A Multicentre survey. *Ann Rheum Dis* 2016;75:142–7.
- 22 Dures E, Fraser I, Almeida C, et al. Patients' perspectives on the psychological impact of inflammatory arthritis and meeting the associated support needs: open-ended responses in a multi-centre survey. *Musculoskeletal Care* 2017;15:175–85.
- 23 National Rheumatoid Arthritis Society. RA and mental health. 2022. Available: <https://www.nras.org.uk> [Accessed 20 Jun 2022].
- 24 British Society for Rheumatology. Rheumatology workforce: A crisis in numbers. Workforce Policy Report; 2021.
- 25 Fisher A, Roberts A, McKinlay AR, et al. The impact of the COVID-19 pandemic on mental health and well-being of people living with a long-term physical health condition: a qualitative study. *BMC Public Health* 2021;21:1801.
- 26 Miller WR, Rollnick S. Motivational Interviewing: Preparing People to Change Addictive Behavior. New York: Guilford, 1991.
- 27 RAIRDA. Chronic crisis: the impact of COVID-19 on people with rare autoimmune rheumatic diseases - RAIRDA. 2020.
- 28 National Rheumatoid Arthritis Society. Accessing care during the pandemic survey. 2022. Available: <https://nras.org.uk/resource/accessing-care-during-the-pandemic-report/> [Accessed 11 Feb 2023].
- 29 Fox J, Laidlaw L, Dixon WG, et al. P066 COVID voices: Co-produced research to explore the shielding experiences of people with inflammatory musculoskeletal disease. *Rheumatology* 2022;61.
- 30 Brooks SK, Webster RK, Smith LE, et al. The psychological impact of quarantine and how to reduce it: Rapid review of the evidence. *The Lancet* 2020;912–20. Available: [https://doi.org/10.1016/S0140-6736\(20\)30460-8](https://doi.org/10.1016/S0140-6736(20)30460-8)
- 31 Hayfield N, Huxley C. Insider and outsider perspectives: reflections on researcher identities in research with Lesbian and Bisexual women. *Qualitative Research in Psychology* 2015;12:91–106.

Supplementary Table 1: patient demographics

Interview number	Rheumatic condition	Disease duration (years)	Current rheumatic medication	Gender	Age range (years)	Ethnicity
1	AS	More than 10	Adalimumab	Male	30 to 39	White British
2	SLE	More than 10	Methotrexate Hydroxychloroquine Amitriptyline Paracetamol	Male	60 to 69	White British
3	SLE	More than 10	Hydroxychloroquine Mycophenolate	Female	50 to 59	White British
4	ANCA Vasculitis	Less than 5	Prednisolone Methotrexate Hydroxychloroquine <i>due to start Rituximab</i>	Female	50 to 59	British
5	PsA	More than 10	Leflunomide Upadacitinib	Female	50 to 59	White British
6	RA	More than 10	Abatacept Methotrexate Prednisolone	Female	60 to 69	White British
7	SLE / Sjogren's / FMS	Less than 5	Mycophenolate Hydroxychloroquine	Female	60 to 69	White British
8	PsA	More than 10	Ixekizumab Methotrexate	Female	40 to 49	White British
9	SLE	More than 10	Hydroxychloroquine	Female	60 to 69	British
10	RA	Less than 5	Abatacept Methotrexate	Female	60 to 69	White Irish
11	SLE	5 to 10	Rituximab Methotrexate Prednisolone Hydroxychloroquine Amitriptyline	Female	40 to 49	White British
12	RA PsA	More than 10	Adalimumab	Female	70 to 79	White British
13	RA	5 to 10	Sulfasalazine Methotrexate	Male	70 to 79	White British
14	PsA	5 to 10	Paracetamol	Female	70 to 79	White British
15	PsA	5 to 10	Sulfasalazine Methotrexate Prednisolone	Female	40 to 49	White British

Abbreviations for Supplementary Table 1

PsA – psoriatic arthritis / SLE – systemic lupus erythematosus / AS – Ankylosing Spondylitis / axSpA – axial spondylopathy / OA – osteoarthritis / RA – rheumatoid arthritis / UCTD – undifferentiated connective tissue disease / CAD – cardiac artery disease / CFS – chronic fatigue syndrome / FMS – Fibromyalgia

Supplementary Table 2: data extracts evidencing theme 1 sub-themes (number in brackets refers to patient interview number)

Theme 1: 'Just shove them over there in the corner'
<p>(i) 'Fast tracked to the more critical'</p> <p><i>'I just felt that I was grouped in with people that are seriously ill, and are probably, say a terminal illness, etc.'</i> (Interview 3)</p> <p><i>'I think the hard thing in COVID was I felt like I got fast tracked to the more critical. So, suddenly, I'm in the clinically extremely vulnerable group...that's quite a big mental leap...Suddenly, I'm looking at myself differently, feeling much more vulnerable'</i> (Interview 4)</p> <p><i>'I think that I'm much more vulnerable now than I've ever been and possibly will never gain that back'</i> (Interview 2)</p> <p><i>'But I'm vulnerable, apparently. I don't know whether I am, I don't feel like I am'</i> (Interview 12)</p> <p><i>'I just didn't want another health condition'</i> (Interview 6)</p> <p><i>'What I am worried more about is long Covid combined with the conditions that I already have'</i> (Interview 1)</p> <p><i>'I don't really want to be different'</i> (Interview 4)</p> <p><i>'Don't worry about them, just shove them over there in the corner'</i> (Interview 3)</p>
<p>(ii) 'A real sense of loss'</p> <p><i>'I haven't gone back to the gym, haven't gone back to dancing and I don't intend to because every time there's a dance there's a cluster of infections.'</i> (Interview 12)</p> <p><i>'I haven't really gone back to it [swimming] because I still have that fear, and I certainly wouldn't not go in the steam room or the sauna, still I wouldn't do that.'</i> (Interview 14)</p> <p><i>'I haven't been back to church which actually was quite a big part of my life but I'm just not going in because I know there are people there who aren't very careful'</i> (Interview 10)</p> <p><i>'The hard, the really hard thing was when people could go back to their lives, able bodied and full of energy and I realised that even when I got out of shielding I wouldn't get out of lupus, and I think those were the transition points that were really hard for me.'</i> (Interview 7)</p> <p><i>'I had this real sense of being on the hard shoulder of life, with my hazard lights on...and people just saying we're done with it now and barely even looking back at you.'</i> (Interview 4)</p>

'it's quite isolating when everyone else goes back, and they're all enjoying life, and you're still not ... you're not, and you're not able to go back to that, and there's no light at the end of the tunnel' (Interview 11)

'I do resent the fact that other people can just do what they like' (Interview 4)

'I still feel quite dislocated from life' (Interview 4)

'I think my main issue currently is that the world has gone back to normal, and actually it's very difficult for a lot of people who have been shielding to go back to normal. Although, the rates are lower, and we've had immunisations, it doesn't mean that we're protected, because of the way our immune systems work.' (Interview 5)

'it sort of becomes the norm, to the point where you're now thinking you're not exactly institutionalised in the house, but it definitely becomes noticeable when you go out, you're not going out as much as you used to. So, it appears to be more the exception' Interview (13)

Supplementary Table 3: data extracts evidencing theme 2 sub-themes (number in brackets refers to patient interview number)

Theme 2: 'A long and lonely road'
<p>(i) 'You have to prove yourself all the time'</p> <p><i>'It's a long and lonely road and it's amazing how quickly friends forget that you're there, because even my close friends in Bristol don't see me that much, hardly ever.'</i> (Interview 6)</p> <p><i>'some of my university friends went really anti-vax and I can't talk to them anymore, I just can't.'</i> (Interview 15)</p> <p><i>'I felt management just weren't really prepared to make adjustments for me...HR came in as well and they all sat in a meeting and let me cry my way through it, while they said, I could only come back if I was prepared to not wear a mask or not social distance'</i> (Interview 4)</p> <p><i>'I also had to be very pushy about my son who was at school having the vaccine early, there was a lot of misinformation about that, and I was saying this is mad, you're saying that I have to be in a cotton wool ball but my son who's coming in and out of my domain every day, doesn't, it was just mad.'</i> (Interview 7)</p> <p><i>'maybe it's one of those hidden disability things...it's hard for people to understand the issues around shielding or to even believe that you're on medication that makes you vulnerable'</i> (Interview 4)</p> <p><i>'I just wish people would be more mindful of clinically vulnerable people and being more respectful, if somebody is wearing a mask, that it's because they need to wear a mask, not because they're just being ridiculous and paranoid.'</i> (Interview 5)</p> <p><i>'I've found that quite hard, the lack of empathy from people quite stark really if I'm honest.'</i> (Interview 15)</p> <p><i>'we're back to every man for himself again now.'</i> (Interview 5)</p>
<p>(ii) 'Nobody's checking up on me'</p> <p><i>'I didn't have any problems with the Lupus, it wouldn't have been very good if I'd have to say I've got this swollen wrist or, having trouble, but I felt well enough to say no, I'm okay.'</i> (Interview 9)</p> <p><i>'actually I felt a bit abandoned at that point'</i> (Interview 10) [when needed advice on whether to continue with biologic injection when feeling ill]</p> <p><i>'I didn't really feel very supported [by rheumatology]...it felt very much like you're on your own in this, and you've just got to work your way out'</i> (Interview 11)</p> <p><i>'Rheumatology does not have psychological support; they don't have that built into their structure'</i> (Interview 2)</p>

'I think there was a lack of understanding of how vulnerable, we as patients, felt...there was a real lack of communication...it was very difficult to get people to respond to you...I think just an empathetic, efficient medical response to medical questions is really what you want.'
(Interview 4)

'I'd like to see them have more staff so they can support their patients better. Because actually what we've been through for the last few years, has been really, really difficult and I think they've only got enough capacity to deal with emergencies' (Interview 11)

'This was the big disappointment actually, all the healthcare teams...so the lack of continuity' (Interview 12)

'it's continuity and follow through, there's no follow through, nobody's checking up on me, nobody's checking up on me' (Interview 12)

Supplementary Table 4: data extracts evidencing theme 3 sub-themes (number in brackets refers to patient interview number)

Theme 3: 'You can't just flip a switch'
<p>(i) 'I didn't recognise myself'</p> <p><i>'one of the consequences [of shielding] is that I have become even more deconditioned than I was before, and I have become much fatter than I was before.'</i> (Interview 6)</p> <p><i>'I'm using a walking stick all the time now'</i> (Interview 5)</p> <p><i>'I think I've become a lot more static. I think I've probably lost muscle as a result of that. I know I've put on some weight as a result of that and that's simply because my general day-to-day level of activity dropped enormously.'</i> (Interview 13)</p> <p><i>'I think it is only the vast reduction in the amount of activity that I've now become a couch potato'</i> (Interview 13)</p> <p><i>'actually taking exercise requires a decision to go out and do it whereas without shielding you'd just be out and about a lot more as part of general life.'</i> (Interview 13)</p> <p><i>'I found it really difficult to walk very far to start with, again, that deconditioning of being at home and not doing anywhere near as much.'</i> (Interview 8)</p> <p><i>'the whole shielding thing was a very frightening, worrying time that has left me with an anxiety about the effect of well I suppose various things. With my condition, I am now aware of the fact I'm more vulnerable to things than I probably realised before'</i> (Interview 14)</p> <p><i>'my mental health had a real dip, and I've never experienced anything like that before...anxiety suddenly hit me I didn't recognise myself, just couldn't cope with things...I just thought I was suddenly losing my mind, and I just had to take a complete step back from everything...It was like everything, all my sensations were on overload...'</i> (Interview 11)</p> <p><i>'Well, I think there was just this constant feeling of fear'</i> (Interview 14)</p> <p><i>'I thought the situation was a lot worse than probably everybody around me did and no one else realised the panic in me.'</i> (Interview 14)</p> <p><i>'I think I'm far more anxious than I was, I think I'm far more sensitive to my interactions with people'</i> (Interview 15)</p> <p><i>'emotionally I need to start getting back to interacting with people more. I do find that I tend to arrange things and then back out at the last minute quite a bit now'</i> (Interview 15)</p> <p><i>'It became like I just need to talk to someone you know?'</i> (Interview 12)</p> <p><i>'I knew that I was high risk and I kept thinking if something happens to me I'm going to leave my children without a mother, and I found it absolutely terrifying to be honest'</i> (Interview 15)</p>

(ii) 'Work through it together'

'so just sort of simple guidelines on exercise, on diet, maybe on mental health for some people' (Interview 7)

'...a lot more education and understanding in what your medication is doing to your body.' (Interview 1)

'I think we probably needed a bit more guidance on how to manage the risks, particularly as they were lifting restrictions...I think knowing sort of what the rights were and what mitigations they could put in place' (Interview 15)

'I wished that the rheumatology department had taken a line on it and said okay, these are the parameters we think you should operate between.' (Interview 7)

'I guess it's just information and it's information and support and just allowing safe space and just recognising that there's going to be a psychological trauma with what we've been through because what was once an inconvenient, bloody annoying condition, has become a life threatening one. Like, for almost two years everything has been a risk assessment' (Interview 15)

'We're dealing with our lives being at risk, all the time, and the stress and the impact of that all the time, and I'm sure that has a physical impact and a mental health aspect to it.' (Interview 11)

'I think more communication just to reassure people that no, we haven't forgotten about you...' (Interview 13)

'Until you've had a kind of chronic illness you don't really get a chronic illness; you don't get what it's about.' (Interview 7)

'I would say the shielding groups that I joined, the Psoriatic Arthritis, Facebook group, were probably the best source of information' (Interview 5)

'it would be nice to maybe have some kind of group or something with people who are shielding, and I suppose it would be even nicer for me if I had somebody with my own condition'... 'sometimes, what we'd like to just spend a little bit of time in person, talking to others who feel similar. I just don't really have that.' (Interview 4)

'so, I did more yoga than I've ever done. I still now do yoga online now, they kept it up as a hybrid thing and I realised the reason I could do it is because I could just roll out of bed and start the yoga, whereas before I had to get out of bed and get up and drive somewhere and then do yoga, many days I just hadn't got that energy. So, that was a plus thing in terms of my physical health' (Interview 7)