

## Perceptions of risk in people with inflammatory arthritis during the COVID-19 pandemic

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## ABSTRACT

**Objectives.** People with inflammatory arthritis (IA) have an increased incidence of serious illness and mortality, placing them at risk from poor outcomes from COVID-19. This study explored patients' perceptions of risk from COVID-19 over a longitudinal period of the pandemic.

**Methods.** Fifteen adults with inflammatory arthritis attending a NHS rheumatology service, each took part in 3 semi-structured telephone interviews conducted between 16<sup>th</sup> September 2020 - 29<sup>th</sup> July 2021. Interpretive phenomenological analysis was undertaken by two researchers and two public contributors.

**Results.** Four main themes relating to perceptions of risk from COVID-19 were identified: i) Inflammatory arthritis, medications and co-morbidities, ii) Immediate social environment iii) Health policy communication, and iv) Media influence. Participants recognised that having IA increased their individual risk. Perceptions of risk and associated fear increased during the pandemic, influenced by family/friends who had had COVID-19 and health policy communications. The perceived constant use of negative messages led to many participants disengaging with the media. At the final interviews when the vaccination programme was well established, participants continued to assess the risk and benefits of engaging in activities.

**Conclusions.** This study demonstrates the breadth of factors that influenced perceptions of risk in people with an inflammatory arthritis. As health professionals we only have a small sphere of influence over some of these factors, namely health care communications. People with inflammatory arthritis appropriately knew their condition increased their infection risk, but more could be done to consider how and to what extent we involve patients in explaining risk at times of crisis.

**KEY WORDS:** RHEUMATOID ARTHRITIS, COVID-19, HEALTH COMMUNICATIONS, PERCEPTIONS OF RISK, QUALITATIVE RESEARCH.

## KEY MESSAGES

- 1) Patients were aware of their increased risk of COVID-19 related to their condition and medications.
- 2) Healthcare communication on risk needs to contain clear, plain, neutral and active language.
- 3) Involving patients in the content of healthcare communication may improve understanding and reduce psychological distress.

## LAY SUMMARY

### *What does this mean for patients?*

People with inflammatory arthritis (IA) have an increased risk of serious infection. We interviewed 15 adults with IA, three times, over 7 months during the pandemic to explore how patients interpreted their own risk to COVID-19. We found that people were fearful that COVID-19 could be fatal due to having IA. This fear was heightened by media reports of new variants, seeing family and friends with COVID-19, and receiving letters from the hospital and government confirming their increased risk. Awareness of risk remained high throughout the three interviews which may reflect the lack of evidence, at that time, regarding the exact risk to people with an IA. Our work adds to previous research that individual risk needs to be communicated in such a way that it contains information as to how risk can be reduced without inducing further distress. Patient involvement in how risk can be communicated effectively is required.

## INTRODUCTION

Patients with inflammatory arthritis (IA) have an increased risk of serious illness, infection and death due to their auto immune condition, immunosuppressant medication and related co-morbidities.<sup>[1]</sup> At the onset of the COVID-19 pandemic, these factors were considered to make patients with IA more susceptible to poorer outcomes from COVID-19.<sup>[2]</sup> In a study of 17 million adults in the United Kingdom, the risk of COVID-19 associated death for a combined group of people with RA, systemic lupus erythematosus or psoriasis was slightly higher than the general population<sup>[3]</sup> with the risk of all case deaths more prominently raised in people with rare auto immune diseases.<sup>[4]</sup> The risk of poor outcomes in people with RA with COVID-19 appears to be associated with co-morbidities, high disease activity and treatment with glucocorticoid steroids or Rituximab.<sup>[5]</sup>

On 21<sup>st</sup> March 2020 'shielding' was introduced in England for people considered to be particularly vulnerable to poor outcomes from COVID-19. Shielding involved being advised to stay at home and avoid all face-to-face contact outside their household for 12 weeks.<sup>[6]</sup> In response to government policy, the British Society for Rheumatology formulated risk stratification criteria to identify patients who required to shield, based on a combination of age, medication and co-morbidities.<sup>[2]</sup> Rheumatology departments were asked to help identify and contact those who were identified as being at increased risk of poor outcome from COVID-19 to reinforce government messaging.

People with IA have had to evaluate and assess their own risk over the various stages of the pandemic (including lockdown periods), the changes to government policy, and the introduction of the vaccination programme. This longitudinal study explored perceptions of risk during the COVID-19 pandemic in people with IA.

## METHODS

The theoretical framework for the study was interpretative phenomenology. The aim of interpretative phenomenology is to understand what the person's experience is and then uncover the meaning of the experience for the individual. This approach enables the participants, in this case people with IA, to describe their perceptions and experiences of their individual level of risk during the COVID-19 pandemic.<sup>[7]</sup> The reporting of this study was based on The Consolidated Criteria for Reporting Qualitative Health Research.<sup>[8]</sup>

### Participant Selection

Patients with inflammatory arthritis, predominantly RA, were recruited from a rheumatology department in a community hospital in Staffordshire. Eligible patients were identified from a

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rheumatology clinical database and were purposively sampled to ensure a representation of age, gender, shielding and non-shielding status. To obtain a sample size of 15 - 20 patients, 40 patients were mailed an expression of interest (EOI) letter inviting them to participate. If a positive response was received, then a consent form and participant information sheet was posted. 15 patients returned an EOI form and participated in the study. There is no definitive sample size for a qualitative study but to embrace its ideographic commitment, smaller concentrated samples are commonly utilised.<sup>[9]</sup> The rationale for the sample size was influenced by the longitudinal study design.<sup>[10]</sup>

All patients with rheumatoid arthritis were sent a letter from the rheumatology service. This contained information regarding the need to continue with current medications; a scoring grid to assess levels of individual risk (based on the BSR risk stratification criteria<sup>[2]</sup>) with actions to take if an individual was at high risk; measures to take if COVID 19 symptoms occurred; reinforcement of the government's public health advice; guidance on maintaining emotional wellbeing; web links to patient organisations.

### **Ethical Approval**

Ethical approval was granted by Camden and Kings Cross Research Ethics Committee REC reference: 20/HRA/3406. Written consent (email consent for those participants who were shielding and could not use the postal service) was obtained and reconfirmed prior to the interviews.

### **Data Collection**

Participants engaged in three semi-structured telephone interviews with the same interviewer, PC, who was not known to participants prior to the first interview. Interviews were conducted at baseline (16<sup>th</sup> September - 23<sup>rd</sup> November 2020), at 2 - 4 months (11<sup>th</sup> - 27<sup>th</sup> January 2021) and finally at 6 - 10 months (27<sup>th</sup> April - 29<sup>th</sup> July 2021). Figure 1 indicates when the interviews were performed and the prevailing restrictions at the time.

The initial topic guide was developed to examine patients' experiences of living with IA during the pandemic and reviewed by members of the study group (SR, PC, AH, ZP, SH and FM) and two patient partners (KR and MB), then further refined after two pilot interviews. As patients' perceptions of risk were identified as key areas, these themes were iteratively developed. Subsequently, the second and third interviews used the participants' previous narrative to explore perceptions of risk in relation to significant events including lockdowns, shielding and the vaccination programme (see Figure 1) during the pandemic. The topic guides are available in Supplementary Data S1-S3, available at *Rheumatology Advances in Practice* online.

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3 Demographic data including gender, age, disease duration, occupational and marital status  
4 were collected. The interviews were digitally recorded, transcribed verbatim and anonymised.  
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### 8 **Data Analysis**

9 Interpretative phenomenological analysis (IPA) was undertaken by 2 members of the research  
10 team (SR and PC). There is no single definitive approach to data analysis in IPA and to assist  
11 with validity and rigour we used an inductive method with coding and theme development  
12 directed by the content of the data as advocated by Braun and Clarke (2006).<sup>[11]</sup> Each  
13 transcript was read repeatedly to ensure familiarisation with the data and to generate initial  
14 codes to identify specific patterns of meaning. Over the course of 3 research group meetings,  
15 themes were identified from the coded data. (See Supplementary Data S4, available at  
16 *Rheumatology Advances in Practice* online, for data analysis.) The findings were shared with  
17 the two patient partners to further inform the interpretation of the data.  
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### 25 **Patient and Public Involvement (PPI)**

26 Two people with lived experience of IA (KR and MB), were involved in all stages of the  
27 research. This included the design of the study (interviews rather than focus groups),  
28 reviewing public facing information (invitation letter, patient information sheet and consent  
29 form), informing the content and piloting of the topic guides and data analysis.  
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### 35 **Results**

36 Fifteen patients participated in the 3 planned interviews, (resulting in a total of 45 interviews).  
37 14 had a diagnosis of RA and 1 had a diagnosis of Adults Still's disease. Disease duration  
38 was an average of  $22 \pm 13$  years (range 1.5 to 46 years). The sample included 9 females and  
39 6 males, with ages ranging from 46 years – 79 years. The majority of participants were retired  
40 (n=10), with one currently out of work and the remaining employed (n=4). All participants were  
41 Caucasian, and 11 of the 15 participants were married (see table 1). The interviews lasted  
42 between 23 - 60 minutes. Data saturation was achieved with no new concepts arising after  
43 the tenth participant was interviewed. Four main themes were identified which related to  
44 perceptions of risk in people with rheumatoid arthritis during the pandemic i) Inflammatory  
45 arthritis, medications and co-morbidities, ii) Immediate social environment iii) Health policy  
46 communications and iv) Media influence. The themes are discussed below with supporting  
47 illustrative quotes, relating to the three interview time points, shown in Table 2.  
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**Table 1: Participants' Characteristics**

Sex	Females 9 Males 6
Diagnosis	Rheumatoid arthritis 14 Adult Still's disease 1
Age	40-49yrs 2 50-59yrs 3 60-69yrs 3 70-79yrs 7
Medication (numbers of medications prescribed)	Conventional DMARDs 15 Biologic DMARDs 12 Glucocorticoid 4 NB Some participants were taking a combination of the above therapies
Shielding status	Shielding status 6 Non shielding status 9
Disease duration	1-10yrs 4 11-20yrs 2 21-30yrs 5 Over 31yrs 4
Occupational status	Retired 10 Working 4 Currently not working 1
Marital status	Married 11 Lives with partner 3 Single 1

**Theme 1: Inflammatory arthritis, medications and co-morbidities**

During the first two interviews, all participants referred to their increased risk of contracting COVID-19 and the likelihood of serious consequences if they contracted the virus, which they attributed to having RA and taking disease modifying anti-rheumatic drugs (DMARDs) and/or biologic therapy. For some participants the risk associated with their medications reinforced the 'serious nature' of their drug therapy. Most participants were, initially, less aware of the risks associated with taking corticosteroids.

The majority of participants recognised that having other medical conditions such as asthma or cancer increased their risk of serious outcomes if they contracted COVID-19. Concern was also expressed as to whether the vaccination would be effective with having IA. Having IA led to some participants expressing concerns about their mortality. One participant expressed resentment that having RA reduced their ability to influence the level of risk they faced. By the

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3 final interview most participants were assessing the risks of engaging in social activities after  
4 receiving drug treatments including Rituximab.  
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## 8 Theme 2: Immediate Social Environment

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10 The importance of the immediate social environment became more evident during the second  
11 interviews. As case numbers were higher, new variants were discovered and many  
12 participants personally knew of family and friends who had had COVID-19. All these factors  
13 led to increased perceptions of risk. Although for one participant, knowing someone who had  
14 recovered from COVID-19 helped to reduce their fear.  
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19 In the second and third interviews, some participants were uncomfortable when friends were  
20 deemed as taking an unnecessary risk by entering a house uninvited. Another participant  
21 based her own assessment of risk on the trust she had in the people she met, based on the  
22 understanding that they had performed a lateral flow test.  
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27 In the final interviews the significance of the virus continued to be felt when family members  
28 who were younger and fitter became seriously ill with COVID-19, re-emphasising that risk was  
29 still present. Even though the vaccination programme was active by the third interviews and  
30 lockdown had ended, most participants were still hesitant in recommencing social activities,  
31 especially if it involved younger people, as it was perceived that the latter may not have taken  
32 the pandemic seriously. Some activities such as travelling abroad or using public transport  
33 were considered too high risk to engage in, whereas visiting a garden centre or attending for  
34 health care (dentist and optician) had less risk attached to them. Some participants balanced  
35 the perceived risk of going out with the need to maintain mental wellbeing.  
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## 41 Theme 3: Health Policy Communication

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43 During the first two interviews, all participants' level of fear and the risk of contracting COVID-  
44 19 increased following correspondence from NHS England, their rheumatology department  
45 and General Practitioners. This fear led to many participants conforming to shielding  
46 requirements, whilst other participants, despite being mindful of their need for safety,  
47 introduced a modified form of shielding to protect their physical and psychological wellbeing.  
48 Some participants found it stressful to constantly assess the level of risk attached to a  
49 particular behaviour.  
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56 During the second interviews, with England entering into its third lockdown, the impact of being  
57 categorised as "Clinically Extremely Vulnerable" (CEV) increased perceptions of risk and  
58 influenced participants to adopt risk adverse behaviours. There was concern that the term  
59 CEV was complex and difficult to understand.  
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3 The development of the vaccination programme offered participants hope that by increasing  
4 immunity their risk of becoming seriously ill would be reduced. During the second interviews  
5 (when some participants had received their first vaccination), most participants reported  
6 initially feeling safer and more confident in their behaviours. At the third interview, despite all  
7 participants being vaccinated, caution was still employed around behaviour, and this would  
8 continue until more restrictions were lifted, and a greater number of the population had been  
9 vaccinated.  
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#### 15 16 Theme 4: Media Influence

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18 During the first interviews, media reports and the United Kingdom (UK) government evening  
19 briefings, including the number of daily deaths, made the risk of COVID-19 very apparent and  
20 influenced the behaviour of many participants to stay at home. During the second interviews  
21 perceptions of constant negative media messages contributed to many participants feeling  
22 low and alienated from the media. All participants expressed a desire for clearer  
23 communications and a greater focus on positive events, citing the success of the vaccination  
24 programme. Focusing more on reports that showed role models being vaccinated was  
25 regarded as one way the media could influence the further uptake of vaccines. By the final  
26 interviews the focus on 'death and destruction' in the media was slowly being supplemented  
27 with information about air travel providing some semblance of normality to some participants.  
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#### 36 **Discussion**

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38 This study explored the perceptions of risk in people with inflammatory arthritis during the  
39 coronavirus pandemic using longitudinal interviews. Perceptions of risk remained high  
40 throughout all interviews which may reflect the scarcity of evidence regarding the precise  
41 estimate of risk in this population during the duration of the study. Earlier findings from this  
42 study demonstrated that the main impact of the pandemic on wellbeing related to emotional  
43 status.<sup>[12]</sup>  
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48 Key findings were the awareness of risk participants had at the start of the pandemic due to  
49 having IA and receiving drug treatment for the condition. Perceptions of risk increased as the  
50 pandemic progressed, influenced by friends and family who had had COVID-19 and reports  
51 of new variants of the virus. Health policy communications and media reporting heightened  
52 perceptions of risk. At the final interviews when the vaccination programme was well  
53 established and most COVID-19 restrictions in England had been lifted, participants still  
54 adopted a cautious approach and continued to assess the risk and benefits of engaging in  
55 social activities.  
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3 A key strength of this study is the longitudinal design. Participants were interviewed at three  
4 time points over a period of six months during which there were significant changes in Covid-  
5 19 prevalence, mortality and health policy in the UK. This has enabled us to gain insight into  
6 patients' perception of risk over time giving us greater perspective. The involvement of  
7 research group members and 2 patient partners in coding and interpreting the data enhances  
8 the credibility of the findings. There are several limitations of the study: firstly, as the initial  
9 interviews occurred after the first lockdown in the United Kingdom, the participants' reflections  
10 at this point occurred retrospectively and secondly, the majority of the sample was not in  
11 employment and consequently the impact of work could not be fully explored. Although the  
12 participant sample in this study included a range of age at disease onset (20 - 66 years old),  
13 disease duration (1.5 - 46 years) and of gender, the sample was primarily of older individuals  
14 and solely of Caucasian ethnicity, which broadly reflects the population of people with  
15 inflammatory arthritis in North Staffordshire. Further research focusing on a more diverse  
16 sample of patients would be beneficial in understanding the wider perceptions of risk  
17 throughout the pandemic.  
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22 At the start of the pandemic our participants recognised their increased risk to COVID-19,  
23 attributed to having IA, medication use and co-morbidities. All participants were aware that RA  
24 was an autoimmune condition and medications could compromise their resistance to infection.  
25 Similar attributions were demonstrated in a survey of 550 people with a rheumatic disease  
26 who rated medications as their top concern (76.1%) in increasing the severity of COVID-19,<sup>[13]</sup>  
27 whilst patients with lupus had high levels of anxiety regarding their mortality risk to COVID-  
28 19.<sup>[14]</sup> It is not known how our participants obtained their knowledge of the risk associated with  
29 having IA and medication use. Patients commencing disease modifying anti rheumatic drugs  
30 (DMARDs) commonly attend for an information session with a rheumatology nurse or  
31 pharmacist to learn about the benefits and side effects of DMARD treatment. The information  
32 gained from these sessions may have resonated with patients at the start of the pandemic.  
33 Some participants, initially expressed surprise that corticosteroids could also increase their  
34 infection risk.  
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39 The fear of having COVID-19 increased during the second interviews due to the discovery of  
40 new variants, higher prevalence of COVID-19 in the community, and knowing friends and  
41 family who had had COVID-19. A cross-sectional study of older adults in Bangladesh which  
42 aimed to assess the perceived fear of COVID-19 and its associated factors, showed that  
43 having a close friend or family member diagnosed with COVID-19 was associated with a  
44 significant rise in fear.<sup>[15]</sup>  
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3 Receiving communication from official sources including NHS England, the rheumatology  
4 department and general practitioners clarifying risk status increased fear and heightened  
5 individual perceptions of risk in the majority of participants. Health communications that start  
6 by fostering wellbeing have the potential to promote effective and sustainable behavioural  
7 change during the pandemic and may help to reduce potential fragmentation of risk  
8 behaviour.<sup>[16]</sup> Presenting the risk attributed to having RA without offering clear options as to  
9 how to lower the risk may induce psychological distress and affect patients' understanding of  
10 their potential risk.<sup>[17, 18]</sup> Our participants found receiving written information from different  
11 official sources (rheumatology department and the government) overwhelming. This could  
12 have related to the depth of the written communication (the letter from the rheumatology  
13 department was 7 pages) and public health messages regarding how risk could be reduced  
14 may not have been easy to interpret alongside all the other information. Therefore it may be  
15 helpful to commence communications relating to a health risk, with the actions patients can  
16 take to address the risk, whilst ensuring the actions recommended are clear and easy to  
17 locate.

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28 Certainly, psychological distress was a factor entwined with participants' assessment of risk  
29 and associated fear. However, variation was present in how this was managed between  
30 participants and across time points. One particularly relevant theory can be applied to  
31 understand this variation. Terror Management Theory (TMT)<sup>[19]</sup> encapsulates cognitive  
32 processes when individuals face extreme threat of death (terror). The theory argues that the  
33 resulting anxiety is cognitively managed or buffered through shared beliefs and standards  
34 about reality, self-esteem from those beliefs, all validated by the person's close personal  
35 relationships. TMT has been applied to understand the heterogeneity of reactions to COVID-  
36 19<sup>[19]</sup> and how people balance the threat of death with the need to maintain a life that has  
37 value and meaning. This negotiation of risk versus meaningfulness may be reflected in our  
38 findings of some participants who introduced a modified form of shielding to preserve some  
39 form of social interaction, in an attempt to maintain their wellbeing. Such behaviours have  
40 been shown in other similar illness groups, for example where people with lupus left the house  
41 and sought social interaction to reduce the impact on their mental health.<sup>[14]</sup>

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51 The fear of having COVID 19, may have influenced positive vaccine behaviour as, by the time  
52 of the final interviews, all our participants had been vaccinated. This reflects the results of a  
53 Finnish survey which found that those perceiving COVID-19 as a severe disease were more  
54 likely to have the vaccine.<sup>[20]</sup> Although the vaccination programme provided hope and  
55 increased confidence, following vaccination participants still assessed the risk of engaging in  
56 specific activities.  
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3 Over the course of the pandemic participants disengaged with the media. This reduction in  
4 media consumption was also reflected in the general public.<sup>[21]</sup> Su, McDonnell, Wen et al  
5 (2021) propose that an effective media crisis communication strategy should be fact based  
6 and people-centred, including the delivery of facts that matter to the people without framing  
7 the numbers/statistics based on personal views or ulterior motives.<sup>[22]</sup> This is important as  
8 effective risk communication is crucial for understanding health threats and supporting people  
9 in making informed decisions for mitigating the risks.<sup>[23,24]</sup>

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15 There are several implications for practice arising from this study. Firstly, there is a need for  
16 patient input into the content of communications regarding risk even in a crisis, to ensure risk  
17 is communicated in such a way as to promote behaviour changes without inducing  
18 unnecessary fear or causing psychological distress. This can be addressed by providing  
19 information that uses clear, plain, neutral and active language for example, “if you take this  
20 action.”<sup>[25]</sup> Gigerenzer (2007) describes the concept of ‘collective statistical illiteracy’ referring  
21 to a large proportion of the population who lack the understanding and interpretation of  
22 numbers,<sup>[26]</sup> often used during the pandemic to convey risk. Using pictographs may be one  
23 way of helping patients make unbiased decisions regarding their individual risk.<sup>[25]</sup>

29  
30 Receiving communications from a number of different official sources, including the  
31 rheumatology service and the government increased the fear experienced and was clearly  
32 overwhelming for some participants. We do not know if patients were able to complete their  
33 assessment of risk accurately using the scoring system they were sent. If an over estimation  
34 of risk occurred in some instances this could have increased feelings of distress. Commencing  
35 written communication with positive messages on actions patients can take may assist in  
36 mitigating some of the risk. Further research is required to explore how we can communicate  
37 health messages to patients in an effective balanced manner without causing heightened  
38 feelings of distress.

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45 Secondly, information regarding corticosteroid use may not be given in the same standardised  
46 format as education on DMARDs and the need for more detailed information regarding the  
47 benefits and limitations of corticosteroids is something that health professionals should  
48 consider. Thirdly, telephone support from health professionals or ongoing peer support from  
49 trained volunteers could be utilised to address fears and support patients<sup>[27]</sup> with IA in their  
50 decision making regarding the potential risk of engaging in certain behaviours to provide some  
51 sense of control.

## Conclusion

This study demonstrates the breadth of factors that influenced perceptions of risk in people with inflammatory arthritis. As health professionals we only have a small sphere of influence over some of these factors, namely health care communications. People with inflammatory arthritis appropriately knew that their condition increased their infection risk but more could be done to consider how and to what extent we involve patients in explaining risk at times of crisis.

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### COMPETING INTERESTS

The authors have declared no conflicts of interest.

### DATA POLICY STATEMENT

The data underlying this article are available in the article and in its online supplementary material.

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**Table 2: Results**

<b>THEME 1: Having IA</b>		
<b>Interview 1 September-November 2020</b>	<b>Interview 2 January 2021</b>	<b>Interview 3 April-July 2021</b>
"I do know I have to be careful with my immune system I've always known that because it's an immune condition Rheumatoid Arthritis is." (Female aged 61 years).	"I know I've had the biologics and it's reduced my immune system so I do I feel as though because of the meds and everything that I'm on I've got not resistant if something was to come my way, I wouldn't be able to fight it." (Female aged 57 years).	"I mean they ask me to go out bowling on Thursday night, well one I'd just had my infusion (Rituxamib) on the Wednesday so by rights I should be being a bit careful and shielding." (Male aged 55 years).
"I never actually thought I could be at more risk because of the Steroids. (Male aged 55 years).	"It means that if we contact Covid in any sort of way within a week we would probably be in hospital in intensive care and we would die because of the drugs we're on." (Female aged 73 years).	"Well I had to shield again because of the Steroid injection so I won't be able to go out." (Female aged 57 years).
"A certain resentment really at the condition that I'd got, could make me more prone to not only catching the virus but having potentially a worse result after catching the virus. I felt a little bit of resentment that despite my best efforts something might get me that was totally out of my control". (Male aged 55 years).	"It's made me realise that it's the medication because its Immunosuppressant it's made me realise that the medication I'm on is a serious one." (Female aged 78 years).	"I've been put on Steroids, but I think they're very reluctant to put people on Steroids because of the risk of infection so it heightens your risk, so I could be completely wrong about that." (Female 61 years).
"I shouldn't be frightened but something as small as Covid I recognise is going to kill me so I am nervous I don't want to die yet." (Male aged 71 years).	"So I do very much consider myself to be extremely vulnerable. Now that's a combination of having been ill and medication and Rheumatoid Arthritis all rolled in together." (Male aged 71 years).	"Yes. I know people say oh you get the vaccination but you never know if it's actually going to work with you do you, especially me having the arthritis stuff they were never sure whether it would work or not anyway." (Male aged 66 years).
As soon as I heard that people develop breathing difficulties, I was only a few months off the pneumonia knew that if I caught this Covid I would be dead, I would not survive it." (Male aged 71 years).	"I saw the haematologist and she said whatever you do don't get ill and so that's always praying on my mind, I think if I get ill it's going to be bad." (Male aged 71 years).	You've had the vaccine but you can still catch it and nobody knows for people like me who are immunosuppressive or have got any other sort of problem they don't know if you catch it is it still going to be bad or not." (Female aged 71 years).
"So I knew I had to be sort of extra careful because I've got a bit of asthma as well." (Female aged 71 years).		



**THEME 2: Immediate Social Environment**

Interview 1 September-November 2020	Interview 2 January 2021	Interview 3 April-July 2021
	"We know people or of people who've had it and that's led us to think that this is getting more serious, you know this latest one is worse." (Female aged 75 years).	"No I am very wary my cousin got Covid and ended up in hospital and her husband who was very very fit, he got it and he almost died. It was a serious wake up call so yes we have been ultra careful because of that and we're probably going to be the last couple in England who will be out and about." (Female aged 75 years).
	"I think I'm a lot more frightened of the virus than I was. I think obviously the numbers going up, I think because I personally know a lot more people, I think it was a bit more remote certainly during the first lockdown." (Female aged 61 years).	"I think I still would prefer not to mix with lots of people at the club because the ones who are going back are younger people who probably haven't been terribly careful because they don't feel threatened." (Female aged 67 years).
	"A neighbour had got it, he's on the ventilator now so it does bring it home doesn't it? Whereas before it was just something in the paper and now its people that you know or relatives or whatever." (Male aged 66 years).	"Normally we go away each year with friends and sometimes we travel together to France you see in the same vehicle but, I can't imagine wanting to do that." (Female aged 57 years).
	"I think (the fear has reduced) as well because my daughter's friend had it and he's ok." (Male aged 54 years).	"I used to use the buses a lot but I haven't been on a bus and I don't think I'd be on one yet." (Female aged 73 years).
	"A very close friend just walked straight into the house. I think she realised that we were uncomfortable I'm not a great risk taker really." (Female aged 61 years).	Well, I am still extraordinarily careful. I've been to some Garden Centres." (Male aged 71 years).
	"The risk has changed because of the new variants that are 70% more transmittable it's put me on the back foot more so than it did before." (Male aged 72 years).	"I just got to the point of thinking well if I trust the people I'm going to see and if they've had negative tests before I see them then I want to exercise my choice." (Female aged 78 years).
	"I think it will probably be gently gently with us when more people have been vaccinated maybe we might go out with a couple of friends and have a meal. Certainly not interested on going on a plane yet or a cruise definitely, definitely not yet not for quite a while." (Female aged 75 years).	"We've been to the dentist, and opticians, but as for socialising, no we haven't started doing anything like that yet. We don't want to go out for meals yet, we don't feel that the time is right yet." (Female aged 79 years)).
		"It's a question of striking a balance between mental wellbeing and protecting myself physically and I just thought well I'm doing the best I can I don't think I'm putting myself at risk and I need to go out and do things." (Female aged 67 years).

**THEME 3: Formal Health Policy Communication****Interview 1 September-November 2020**

“Then had a letter from the hospital and it explained in details the significant risks that were present and how certain drugs just increase the risks and combination of drugs pushed it even further, and so we recognised that we were both in a very high risk category.”  
(Male aged 72 years).

“I got a letter from the NHS saying I’m very vulnerable so I then took it far more seriously and then I got bombarded with texts and letters from the NHS and my GP and it frightened the life out of me.”  
(Female aged 75 years).

“I had a letter from The Haywood and it did state that I was vulnerable and should be careful and it gave a check list of things to tick off and then it said if you have one tick you’re low if you have two tick’s you’re medium if you have three ticks you’re high vulnerability, and I kind of thought well yes ok I understand that but I’m not going to stay in and avoid life for the next 6 months or the next year.” (Female aged 67 years).

“I knew it was too risky to go out so I didn’t. I stopped doing absolutely everything.” (Female aged 61 years).

“I did a kind of modified shielding in that I didn’t completely isolate. I was still going out and about but I wasn’t going to crowded places, I stopped doing the shopping, I was very selective about where I went and that I think was a protective factor in terms of physical and psychological health.” (Male aged 47 years).

**Interview 2 January 2021**

“The risk has changed because I’m clinically extremely vulnerable it’s put me on the back foot, more so than it did before.” (Male aged 72 years).

“I don’t think clinically extremely vulnerable is sufficient for the layman generally speaking. It needs to have short sharp punchy words like ‘high risk, very high risk’ you know so I feel that people would be a bit more understanding.” (Male aged 72 years).

“Now you’re thinking yes it’s a nice day but if I go here what risk am I taking so you’re brain’s working overtime all the time thinking of what ifs and is it safe.”  
(Male aged 66 years).

“The vaccine has delivered a layer of confidence, without that I would not be leaving the house.”  
(Male aged 71 years).

“I’ve had four letters now from Matt Hancock telling me I’m clinically extremely vulnerable and I didn’t really like it but I’ve decided to use it to my advantage, if it means that I will get vaccinated earlier because of having that label.”  
(Female aged 67 years).

**Interview 3 April-July 2022**

“That affected me (being classified as CEV) and made me very risk adverse.”  
(Female aged 67 years).

“I think in some cases it’s almost I get to a point where I’m feeling overwhelmed with being shut off and isolated so then I sit down and talk to myself and say right what’s the risk and how far are you at risk if you do this and how much will it matter if you don’t do it, and then I just say right this is what I’m going to do this is what I’m happy with doing.”  
(Female aged 67 years).

“Doesn’t feel any safer with having both vaccines I think it’s only going to take time I think it’s just got to be a natural progression of numbers being down, feeling a little bit more relaxed with everything, I think it’s just time.”  
(Female aged 57 years).

“After the vaccine I was much more confident to take a risk and go out, using all the measures what is it hands, face, space all of that, doing and those things but do you know I wouldn’t have even done them without the vaccines.” (Male aged 71 years).

“I think we’ve become very risk adverse haven’t we and we’ve kind of changed as a nation really, people are so frightened, you know, I think everybody takes risks at some point don’t they.”  
(Female, aged 61 years).

**THEME 4: Media Influence**

Interview 1 September-November 2020	Interview 2 January 2021	Interview 3 April-July 2021
<p>“On the news and hearing on the television about large numbers of people dying, it really did bring it home that something very profound was happening.” (Male aged 71 years).</p>	<p>“Well it’s all been negative, negative, negative all of the time there should have been far more positive messages that if you do this, this will be the outcome.” (Male aged 72 years).</p>	<p>“Well I stopped watching the news, I read the newspaper and that’s about it, I don’t watch any news anymore because I found it was just too depressing.” (Male aged 66 years).</p>
<p>“But as soon as the world was aware of it news bulletins were gearing everybody to expect a tsunami of illness crashing onto the shore.” (Male aged 72 years).</p>	<p>“It hasn’t changed my behaviour, I basically don’t look at the news any more on the television cos I feel that that’s just basically negative all the time.” (Male aged 65 years).</p>	<p>“Everything seems to be doom and gloom even though we’re getting more and more people vaccinated and there’s still doom and gloom on the telly.” (Male aged 65 years).</p>
<p>“The papers were very doomsday kind of thing weren’t they they’d go from one extreme to the other.” (Male aged 65 years).</p>	<p>“I try not to watch it because one day they’ll say one thing and then the next day they say something else.” (Male aged 66 years).</p>	<p>“I have to keep checking when can I do this and you know ‘cos it’s different for every country as well isn’t it like Scotland and Wales are slightly different. So I would say stop telling us the rules in Scotland and Wales because then I get really confused.” (Female aged 61 years).</p>
<p>“Watching on the news, seeing television programmes, hearing on the radio the numbers of people dying from Covid especially when you have a weakness, is horrifying and I would not venture out.” (Male aged 71 years).</p>	<p>“I actually think the media are just as responsible as the people who don’t adhere to the guidelines because they’re so negative, the media has made it confusing for people.” (Female aged 71 years).</p>	<p>“I don’t think even my husband is watching the news so much now.” (Female aged 67 years).</p>
	<p>“The way the media has portrayed the vaccine has been good because they have highlighted people getting it and talked about the Queen getting it and it does influence people you know seeing all these people lining up to get the vaccine.” (Female aged 61 years).</p>	<p>“It’s all about whether people can fly to Spain on holiday and it does feel like the death and destruction headlines have been replaced with back to normal just griping at everyone, which feels better.” (Female aged 46 years).</p>

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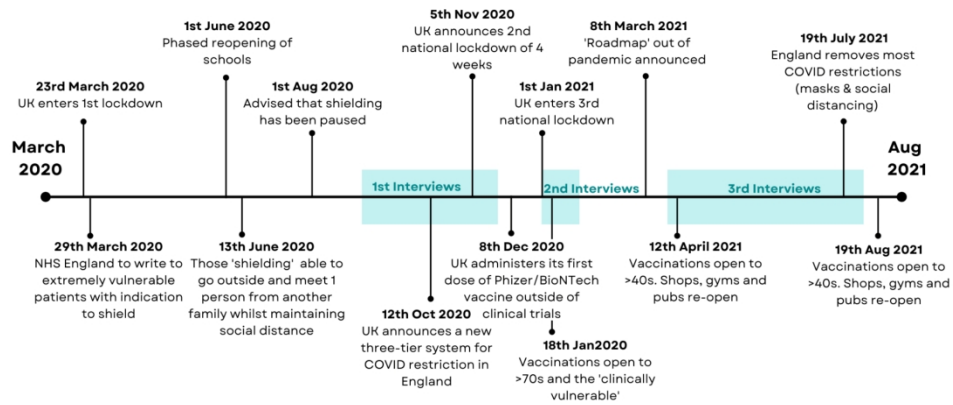


Figure 1. Timeline of events in the UK pandemic response in relation to the study interviews.  
 Key: The Tier system involved a series of regional public health restrictions based on the incidence of COVID 19 within the locality.

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