

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)**

<b>Theme 1: 'Just shove them over there in the corner'</b>
<p><b>(i) 'Fast tracked to the more critical'</b></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><b>(ii) 'A real sense of loss'</b></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)**

<b>Theme 2: 'A long and lonely road'</b>
<p><b>(i) 'You have to prove yourself all the time'</b></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><b>(ii) 'Nobody's checking up on me'</b></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)**

<b>Theme 3: 'You can't just flip a switch'</b>
<p><b>(i) 'I didn't recognise myself'</b></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)*