

## The impact of COVID-19 self-isolation measures on people with inflammatory arthritis: Interim briefing report for health professionals

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### Study aims, sample and methods

**Aim:** to understand the impact measures designed to restrict the spread of the COVID-19, such as shielding, had on people with inflammatory arthritis, including on their wellbeing and access healthcare support

**Sample:** People registered on Norfolk Arthritis Register (NOAR), a large population-based cohort of patients identified as having inflammatory arthritis.

**Method:**

- An online survey sent to all registered on NOAR. Questions investigated use of healthcare services, disease activity, perceived isolation, loneliness and wellbeing. The first wave of the survey was completed by 264 respondents between 28/4/20 – 27/5/20. Subsequent waves, conducted at four weekly intervals, will close 30<sup>th</sup> July 2020.
- Semi-structured telephone interviews were undertaken with a sub-sample of survey respondents. Questions explored impacts on exercise, pain, fatigue, wellbeing, employment, managing daily activities, social support and access to healthcare. 26 interviews were completed between 27/5/20-19/6/20. The sample were selected to reflect a range of diseases, medications, and age groups. Follow-up interviews are planned with all participants. (Female 17 (65%); mean age 60 years, range 29-83 years)

### What are the impacts on health and access to healthcare?

Early findings from the first wave of the survey and emerging themes from interviews are summarised below:

**Symptoms:**

- Symptoms had increased for 102 (39%) of survey respondents and energy levels had decreased for 103 (42%). Some interview participants felt that increased symptoms including pain and stiffness were because of reduced activity and exercise: *"I haven't had a flare for a long time I think this one is because of I can't exercise"*. Others spoke of increased demands and pressures associated with caring responsibilities and working at home - *"I overdid it...it got too much and I did work myself up into a big flare."* Similarly, perceived increased fatigue was sometimes attributed to inactivity (*"I am just sitting here"*), or managing multiple roles within the home. Anxiety also impacted on energy levels or a sense of stagnation: *"my body is shutting down."*

### Interpretations of shielding and social distancing

- A few respondents, realising the implications of immunosuppressant medications, had reduced social contact before being advised to shield. The shielding letter received by patients was generic, and some remained unclear about the specifics of why they needed to shield. All were making personal judgements about how to follow guidelines, balancing their perceived risk against the need to maintain their health and wellbeing: *"Decision making has been really tough, knowing what to do"*. Some continued to venture out for walks, while others followed shielding in a very strict way, using separate bedrooms and bathrooms from their family.

## Accessing health care

- 51 (20%) of survey respondents reported having accessed health care either in person or on the telephone including Rheumatology department, GP, Practice Nurse, Pharmacist, NHS 111, A&E.
- **Seeking health advice:** Many of those interviewed described ‘holding on’ to concerns and anxieties about their condition: *“You don’t want to put pressure on the system for something that can wait.”* Health concerns cited included increases in fatigue, increased pain, new symptoms or side effects of medications.
- **Postponed appointments:** Some expressed relief about not having to go to hospital for appointments, feeling anxious about increased risk. However, routine appointments with rheumatology were very much valued, and missing them creating anxiety and a sense of detachment from healthcare support for some. This could also compound delayed advice seeking: *“I would have brought it up [at postponed appointment] and it would have been good to discuss those things, and you do worry.”*
- **Telephone appointments:** While some preferred to have telephone appointments, feeling this to be safer during the pandemic, many said that these did not substitute entirely for face to face contact. They noted being unable to communicate via body language, expression, or, as one participant put it feeling less able to be *“in the zone”* to talk about their condition. Another pointed out that they *“didn’t want to raise small concerns in telephone call”* and that it was *“difficult to raise emotional things”*. One person described a physiotherapy telephone appointment. While they acknowledged this had been helpful, they also said *“[I] need human intervention for my body”*.
- **Helpline:** People agreed the rheumatology telephone support was good, and a small number of people had phoned to clarify shielding options. However although they spoke highly of the helpline support, they were hesitant to use it, for fear of burdening the service. Others were uncertain about whether the service even remained available: *“I know those nurses are probably deployed somewhere else, but it would have been nice to know that the helpline was still open.”*
- **Blood tests:** Some had concerns about new procedures at GP surgeries and this meant they had delayed seeking appointments for routine blood tests. Generally most reported that routine bloods were being successfully managed by GP surgeries with initial concerns about risk of infection alleviated at first visits. A few had delayed or missed blood monitoring due to concerns about how GPs were managing infection risk

## Medication

- **Management of medication:** the majority of people had no concerns about their current medication regimes, although all were aware of increased clinical vulnerability *“I don’t think I am vulnerable but medications tell me I am.”* A few had reduced dosages and one person had hoped to start biologics but cancelled appointments meant these actions had not happened, leading to worries about how long they would have to wait before a treatment plan could be restarted. One participant had started new medication for the first time during lockdown and despite experiencing adverse reactions, did not seek help and tried to cope alone.
- **Access to medication:** Participants reported medications being delivered by local pharmacies, or friends or family collecting prescriptions, and biologics delivery continuing as normal. However, not all were aware that they could get medication delivered, and one person who was shielding had continued to queue at the pharmacist, only recently becoming aware that he could arrange delivery instead.

### Physical activity

- Physical activity levels had decreased for 144 (59%) of survey respondents. Interviews also revealed that although some were trying to exercise at home, (e.g. using a treadmill, exercise DVD or online classes), others were taking very little exercise. People weighed up risks and some took walks if they felt they were unlikely to meet others. However fear of catching COVID-19 meant many were much more sedentary and not leaving the house at all.

### Wellbeing

- Descriptions of low mood, isolation, boredom, feeling “*fed up with life*” were common in the interviews. However, others were appreciating being at home with family or slower pace of activity. Many felt vulnerable and anxious, and also reported a sense of being left behind and forgotten about as life resumed for others. Many expressed worries about the future - “*Will I ever get out?*” - and some explained they would continue staying at home even if shielding guidelines were relaxed. A few said only a vaccine would make them safe.

### Household tasks and shopping

- Some participants who were shielding discussed no longer having access to assistance with household tasks, e.g. not having cleaners visit, other family members temporarily moving out of the house in an effort to reduce risk of exposure to the virus, or reluctance to call on neighbours to help with emergency tasks round the house. Some explained this had adversely impacted on their physical or mental health. A few spoke of pacing household activities but had not received professional advice on this. Strategies for food shopping included online supermarkets, family or friends shopping on their behalf or going in person to food shops at quiet times. All those interviewed had used online grocery shopping, some reported difficulties accessing a slot, and for one or two the inability to access food shopping slots was a major concern.

### Working from home

- Several interviewees explained they were working from home in physical work environments which were far from ideal for the maintenance of good joint health, for example using a dining room chair and laptop. This supports findings from Working at Home Wellbeing study<sup>2</sup>. Many thought they would be home working for some time. Levels of support and provision of equipment from employers was variable.

### Sources of support

- Interview participants had turned to a variety of avenues of support: e.g. online arthritis forums, or work-based counsellors. Some had received food parcels from the council and help from friends and neighbours. One participant however felt this community support is dwindling as friends return to work and she is slipping from their mind. Some had not accessed support and felt isolated and many felt guilty about relying on others to help.

## What could health professionals do?

Interim points from interviews that might help health professionals in interactions with patients:

- This patient group have shown great resilience, but many highlighted challenges or stresses associated with the COVID-19 pandemic. In some this was accompanied by worsening symptoms. A few however described it offering a period of 'respite' during which they have been better able to cope with their condition.
- The level of adherence to shielding guidance varies considerably. Avoiding exposure to the virus was weighed against other priorities, such as maintaining mental wellbeing by going for a walk. Some may require additional support or reassurance in making decisions about competing risks. Those in the 'moderate risk' group also have a personal onus of decision-making and risk assessment *"to self-isolate or maintain social distance at their discretion"*<sup>3</sup>
- For some, these decisions needed to be taken in the context of family life, managing dilemmas about protecting their own health against family wellbeing (e.g. should children return to school?). Easing of shielding increased concerns about risk and when it will be safe to do more outside the home. This complexity needs to be acknowledged in the context of changing guidance.
- Some patients may require further explanation or information about why they are at greater risk or need to shield.
- Health professionals should remain vigilant that lack of contact or failure to report symptoms might not mean that all is well. Health concerns may not be reported due to postponed appointments and because many do not want to trouble health services at this time.
- Support needs to be maintained and widely publicised. Communicate to patients that advice from the rheumatology helpline or GPs is still available.
- Support may need to be especially targeted at particular groups, for example, those waiting to reduce treatment regimens or hoping to start new regimens. Challenges may also be more pronounced for recently diagnosed who may still be coming to terms with their condition and adjusting to medications that work for them. Time may be needed to explain clinical decisions and risks.
- Support and advice people had received from health professionals was highly rated by many. Some feel reassured that they did not currently have to attend face-to-face appointments, and risk being exposed to the virus. However, there was also a sense of detachment and isolation from healthcare support. Some said that remote telephone appointments were not able to replicate in-person consultations, and they were not able to discuss their condition as readily over the phone. A choice in consultation style may be appreciated - telephone consultations should be patient choice, rather than the norm.
- Pacing information might be need if normal routines have been disrupted and fatigue increases, along with assessment of Instrumental Activities of Daily Living (IADLs).
- Enquire about the home working environments. A priority point if home working continues is the potential need for employers to offer virtual assessment of home working spaces.
- Provide advice about staying physically active while at home.
- Be mindful of potential changes to mental health within the context of COVID-19, including heightened anxiety or low mood.

**We would welcome your feedback**

This Interim Research Briefing reports early findings and key emerging themes. We would be very interested to hear your thoughts as clinical practitioners about the impact of COVID-19 on rheumatology patients and the support you have been able to offer at this time. Your feedback can help shape our topic guide for follow-up interviews, and inform analysis of the data we have already collected.

Please email: [P.belderson@uea.ac.uk](mailto:P.belderson@uea.ac.uk)

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<http://www.uea.ac.uk/noar>

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