RHEUMATOLOGY

# Letters to the Editor

Rheumatology 2021;60:3474–3475
doi:10.1093/rheumatology/keab169
Advance Access Publication 16 February 2021

## Survey of adult and paediatric rheumatology patients suggests information about COVID-19 vaccination will aid uptake

**Rheumatology key message**

- Development of clear, concise, accessible information about COVID-19 vaccination for rheumatology patients will aid uptake.

Dear Editor, The coronavirus disease 2019 (COVID-19) European Patient Registry (EPR) is a longitudinal study [1] developed by parents of children and young people representing the European Network for Childhood Arthritis (ENCA), with support and involvement from individuals and organizations across Europe, including adult patients and the Paediatric Rheumatology European Association (PRES). A copy of the survey is provided in the Supplementary material, available at *Rheumatology* online. Adult patients with rheumatic, autoimmune and autoinflammatory conditions and parents of paediatric patients completed weekly surveys from April to December 2020. A total of 4336 participants from 58 countries took part in the EPR and 2.9% of each cohort have been diagnosed with COVID-19, with only 10 adults and 1 child admitted to hospital.

In December 2020, participants were asked 'When a vaccine against COVID-19 is available, will you have the vaccine when you are offered it?' They were also asked if they have had the seasonal flu vaccine and, in both cases, were invited to explain why not, if applicable, through free-text questions.

Overall, 1505 adult and 140 paediatric patients answered these questions. Of these, 87% of adults and 66% of children responded that they would have the COVID-19 vaccine. A further 11% of adults and 31% of children were unsure, leaving just 2% and 3%, respectively, who do not intend to have the vaccine when it is offered.

An analysis of reasons for not having the COVID-19 vaccine offers some insight into patient motivations. While some presented clear medical reasons for not having the vaccine (28% of adult and 28% of paediatric respondents answering this question), such as prior anaphylaxis, currently breastfeeding or direct clinical advice, others indicated a lack of information was preventing them from currently accepting the vaccine (51% adults, 22% paediatric). This lack of information included concerns about possible medication contraindications, safety and efficacy for patients with autoimmune conditions and side effects. Others misunderstood the development protocol for the vaccine or its purpose, leading to a lack of trust (18% adults, 22% paediatric).

Parents of children within the EPR also expressed concerns about suitability of the vaccine for children <16 years of age (28% of parents responding to this question), but were broadly supportive of having a vaccine once approved for their use.

We recognize that some patients have decided against having the vaccine for ethical reasons and a very small number due to conspiracy theories or misrepresentation of the dangers of COVID-19 infection. However, these represent a very small minority of patients within our cohort.

Table 1 shows the broad themes and specific concerns reported by participants, along with an estimation of the benefit of directed guidance for these patient groups.

It is important that clear information is prepared, agreed upon and shared promptly through national and international professional bodies and through clinical teams. Unlike current generic advice, this should address the specific concerns raised by rheumatology patients through the EPR. It is our opinion that clear, concise and accessible information from a trusted source will support and encourage many of these patients to make an informed choice about COVID-19 vaccination, leading to an increase in the uptake of the vaccine among these at-risk patients. The PRES website has guidelines for clinicians [2]. Ultimately it will also reduce the burden on individual rheumatology teams, as fewer patients will contact them for vaccine advice. We also urge that the stage 2/3 trials for COVID-19 vaccines among children and young people be accelerated.

*Funding*: There are no funders to report for this submission.

*Disclosure statement*: The authors declare no conflicts of interest.

## Data availability statement

Data available upon request.

## Supplementary data

Supplementary data are available at *Rheumatology* online.

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**Table 1** Themes and specific concerns raised about COVID-19 vaccination by adult patients and parents of paediatric patients with rheumatic, autoimmune and autoinflammatory conditions, along with the anticipated benefit of provision of clear, concise and accessible information from a trusted source

| Theme[a] | Specific concerns raised | Likely outcome of information provision |
|---|---|---|
| Medical<br>28% adults,<br>28% paediatric | Anaphylaxis or allergies to previous vaccines and medications<br>Currently pregnant or breastfeeding<br>Advised by doctor not to have vaccine | Due to legitimate health issues, this group is unlikely to accept vaccination |
| Information<br>51% adults,<br>22% paediatric | Lack of information on medication contraindications with immune-modifying and anti-rheumatic drugs<br>Lack of information on safety for patients with autoimmune diseases<br>Lack of long-term safety and efficacy data<br>Concern that vaccine is unsafe or untested<br>Concerns about side effects<br>Concerns about whether it will be effective with the current new strain | Clear, concise and accessible information is likely to increase vaccination uptake and reduce direct calls to rheumatology centres |
| Understanding<br>6% adults,<br>11% paediatric | Use of live viruses<br>Concerns about live bacteria<br>Questions about whether patients who have previously had COVID-19 need the vaccine<br>Misunderstanding of how vaccines work, particularly mRNA vaccines | Clear, concise and accessible information is likely to increase vaccination uptake and reduce direct calls to rheumatology centres |
| Trust<br>12% adults,<br>11% paediatric | Lack of trust in government<br>Lack of trust in vaccine development process | Unbiased information may lead some to choose to vaccinate |
| Ethical<br>1% adults,<br>0% paediatric | Ethical concerns regarding animal testing in vaccine development | Some patients may choose to receive the vaccine |
| Children<br>28% paediatric | Suitability of vaccines for children <16 years of age | When vaccines are approved and available for paediatric use, uptake is likely to be high |
| Conspiracy<br>2% adults,<br>0% paediatric | Very few cited conspiracy theories<br>Belief that COVID-19 is not severe enough to warrant vaccination | Vaccination unlikely among this group, although clear, concise information may support informed choice |

[a]Percentages indicate the proportion of free-text comments representing this topic from those adult and paediatric respondents who provided a comment. Paediatric surveys completed by parents of children <16 years of age. Percentages are indicative and not necessarily representative of all patients.

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Accepted 10 February 2021
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2 Paediatric Rheumatology European Association. Guidelines and recommendations. PRES update regarding COVID-19 vaccines in pediatric rheumatic patients. https://www.pres.eu/clinical-affairs/guidelines.html (8 March 2021, date last accessed).