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COVID-19 vaccine perceptions and uptake: results from the COVID-19 Global Rheumatology Alliance Vaccine Survey



As access to safe and effective COVID-19 vaccinations expands, vaccine hesitancy among people with rheumatic diseases has become increasingly important.^{1,2} Before widespread vaccination programmes, potential side-effects and flares after COVID-19 vaccination were frequent reasons for vaccine hesitancy among people with rheumatic disease.^{3,4} The study objective was to describe the perceptions and behaviours of people with rheumatic disease regarding COVID-19 vaccination and to identify the information sources most likely to affect their intention to be vaccinated.

The COVID-19 Global Rheumatology Alliance (C19-GRA) Vaccine Survey has been described elsewhere (appendix pp 16–93).⁵ Briefly, the survey was constructed collaboratively and iteratively with input from multiple patient partners and was launched globally in English on April 2, 2021. 11 translations were subsequently released (Italian, Hebrew, French, Punjabi, Russian, Spanish, Arabic, Traditional Chinese [Mandarin], Turkish, Simplified Chinese, Hindi). Rheumatologists and patient-facing organisations disseminated the survey on social media and the C19-GRA website. The survey was anonymous, the project was approved by Boston Children's Hospital Institutional Review Board and participants provided consent at the survey start.

analysis includes 7005 vaccinated unvaccinated respondents from 102 countries who were aged 18 years or older and provided consent, reported one or more rheumatic disease (excluding osteoarthritis and fibromyalgia), and completed the entire survey (April 2 to July 5, 2021; appendix p 2). We asked, "If one of the approved vaccines to prevent COVID-19 was available to you right now at no cost, would you agree to be vaccinated?". Respondents answering, "Yes, I have already received at least one dose", or "Yes, I will get it when it is available", were classified as willing. Those answering, "No", were classified as unwilling, and the remainder selected, "Unsure", and were classified as unsure. Vaccination willingness was also measured on a visual analogue scale from 0 to 10, with 0 indicating not willing at all and 10 very willing (appendix p 3). Vaccination perceptions were assessed using 15 statements with five-point Likert scale response options (appendix pp 6–7). Respondents also reported factors influencing vaccination willingness and ranked information sources most likely to influence their decision, such as doctors, news media, and social media (appendix pp 4–5). Results of the survey are described by means, SDs, and proportions.

Of 7005 respondents, 5548 (79.2%) had already received a COVID-19 vaccine, 883 (12.6%) were willing to be vaccinated (when a vaccine became available to them), 275 (3.9%) were unvaccinated and unsure, and 299 (4.3%) were unvaccinated and unwilling to receive a vaccine. Of the 1457 unvaccinated respondents, 883 (60.6%) were willing to receive a vaccine and 574 (39.4%) were unsure or unwilling to receive a vaccine. The mean age for all 7005 respondents was 53.2 years (SD 14.2). Of the 7005 respondents, 5367 (76.6%) reported race or ethnicity as White, 680 (9.7%) as other, 511 (7.3%) as Hispanic or Latin American, 212 (3.0%) as Asian (south or east Asian), 124 (1.8%) as Middle Eastern or North African, 93 (1.3%) as Black, and 18 (0.3%) as American Indian, Alaska Native, Aboriginal, Indigenous, or First Nations. 6023 (86.0%) respondents were female, 954 (13.6%) were male, and 28 (0.4%) were other or preferred not to say; 3619 (51.7%) resided in the WHO Region of the Americas, and 3119 (44.5%) were taking one or more disease-modifying antirheumatic drug (DMARD). Of the total respondents, 580 (8.3%) reported previous adverse reactions to other vaccines within 2 months of the vaccination and 5295 (75.6%) respondents reported receiving regular influenza vaccinations. Demographics, clinical characteristics, comorbidities, and relevant response proportions are provided in the appendix (pp 8, 12).

Almost all unsure or unwilling respondents expressed concerns about side-effects, safety, and the rapid development and use in clinical practice of COVID-19 vaccines. However, nearly half still considered themselves pro-vaccine, and many unwilling respondents displayed varying degrees of hesitancy (appendix p 3). Logistical challenges, cost, and efficacy concerns were less common. The majority of unsure (271 [98-5%] of 275) and unwilling (200 [66-9%] of 299) respondents reported that their willingness to be vaccinated could increase,

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See Online for appendix

For the C19-GRA website see www.rheum-covid.org

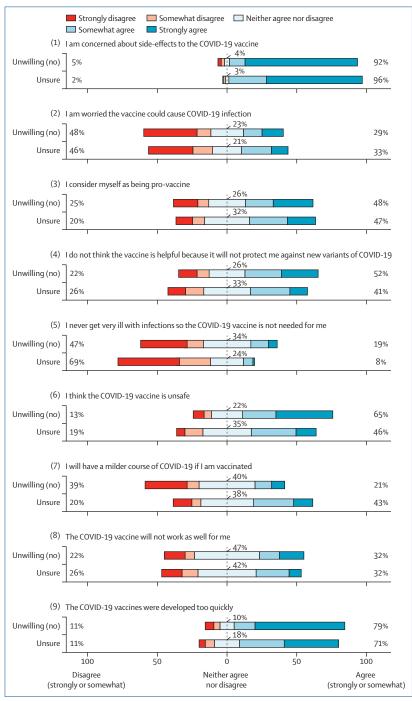


Figure 1: Vaccination perceptions among people with rheumatic diseases who were unsure of vaccination or unwilling to become vaccinated (n=574)

 $Percentages\ were\ based\ on\ the\ total\ number\ of\ people\ for\ whom\ the\ question\ was\ applicable.$

particularly with rheumatologist endorsement and more outcomes data. 562 (97.9%) of 574 respondents who were unwilling or unsure of being vaccinated ranked the top three sources of information most likely to

influence their decision for vaccination. Doctors or other health professionals were most commonly ranked in the top three among 479 (85·2%) of 562 respondents who were uncertain or unwilling respondents (appendix p 5). Patient or professional organisations were second most commonly ranked in top three sources, cited by 388 (69·0%) uncertain or unwilling respondents (appendix p 5). The news media (74 [13·2%]), political figures (17 [3·0%]), and advertisements (eight [1·4%]) were most infrequently cited in the top three sources of information most likely to influence the decision to be vaccinated (appendix p 5).

These survey results highlight the critical importance of concerns related to vaccine safety and efficacy for people with rheumatic diseases, which appear to have persisted after widespread vaccination. Vaccinerelated adverse events do occur and include both mild reactions (eq, fatique, myalgias, and headaches)² and very rare severe adverse reactions (eq. central venous thrombosis and myocarditis).^{6,7} People with rheumatic diseases might also be concerned about flares of their underlying disease, but surveys suggest that flares requiring changes to medications are uncommon.5 Many of the respondents who were unsure or unwilling also guestioned the benefits of vaccination. However, formal risk-benefit assessments have consistently found that the benefits of vaccination far outweigh potential risks,8 and rheumatology professional societies have concluded that the benefits of vaccination outweigh safety concerns for people with rheumatic diseases.9

It should be emphasised that even respondents who were unwilling to be vaccinated reported varying degrees of hesitancy, and two-thirds reported that their willingness could be increased. As with earlier surveys,3 rheumatologist endorsement was commonly a crucial factor that increased willingness to be vaccinated. Patient or professional organisations were also frequently ranked highly as credible sources of information, and information about vaccination in people like them was the second most important factor in increasing willingness to be vaccinated. Taken together, these findings suggest that advice from physicians or patient and professional organisations focusing on safety and efficacy in people with similar rheumatic diseases might be most productive to encourage vaccination. Evidence-based strategies for communicating this information should be considered,

such as affirming patient values, framing vaccination in terms of personal gain or altruistic behaviour, and providing a strong recommendation.¹⁰

Strengths of this study included participation across numerous countries and in multiple languages and a large sample of respondents with a wide array of rheumatic diseases. This study also has limitations, which include selection bias (ie, survey disseminated via patient-facing organisations and social media; non-response rate cannot be calculated), potentially limited generalisability ie, (White respondents from English-speaking countries with graduate or professional degrees were overrepresented), and response bias (ie, vaccinated people being more willing to fill out a survey about vaccination). This was a cross-sectional descriptive study, and causal inferences are not possible.

In summary, in this large international survey of people with rheumatic diseases, most people with vaccine hesitancy would consider becoming vaccinated. Data regarding the safety and efficacy of COVID-19 vaccination among people with rheumatic diseases, which is delivered by rheumatologists or patient and professional organisations, might increase vaccine uptake. These findings highlight urgent research and educational priorities to combat vaccine hesitancy in people with rheumatic diseases.

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