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BRIEF REPORT

Engaging Multistakeholder Perspectives to Identify Patient-Centered Research Priorities Regarding Vaccine Uptake Among Adults With Autoimmune Conditions

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Objective. The study objective was to prioritize topics for future patient-centered research to increase uptake of common vaccines, such as for pneumococcal pneumonia, influenza, herpes zoster, human papillomavirus, and severe acute respiratory syndrome coronavirus 2, among adults living with autoimmune conditions.

Methods. A steering committee (SC) was formed that included clinicians, patients, patient advocates, and researchers associated with rheumatic diseases (psoriatic arthritis, rheumatoid arthritis, vasculitis), inflammatory bowel disease, and multiple sclerosis. Through a scoping review and discussions, SC members identified research topics regarding vaccine uptake and/or hesitancy for prioritization. A larger multistakeholder alliance that included patients and patient advocates, clinicians, researchers, policy makers, regulators, and vaccine manufacturers conducted a modified Delphi exercise online with three rating rounds and one ranking round. Frequency analysis and comparisons across stakeholder groups were conducted. A weighted ranking score was generated for each item in the ranking round for final prioritization.

Results. Through the Delphi process, 33 research topics were identified, of which 13 topics were rated as critical by more than 70% of all stakeholders (n = 31). The two highest ranked critical topics per the full stakeholder group were "How well a vaccine works for adults with autoimmune conditions" and "How beliefs about vaccine safety affect vaccine uptake."

Conclusion. A multistakeholder group identified key topics as critically important priorities for future research to decrease vaccine hesitancy and improve uptake of vaccines for adults with autoimmune conditions.

INTRODUCTION

People living with autoimmune diseases (eg, rheumatoid arthritis or systemic lupus erythematosus) have nearly twice the risk of acquiring severe, vaccine-preventable infections, as well as a higher risk of serious infection-related complications, making vaccination a high priority in this group ([1]). Despite these risks, vaccine uptake remains relatively low in this group.

Many factors influence patients' decisions about vaccination, including beliefs and knowledge of vaccines, age, risk status, and advice from physicians ([2],[3]). Adequate knowledge of vaccination is frequently associated with optimal vaccination; however, such

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SIGNIFICANCE & INNOVATIONS

- This study brought together a multistakeholder panel from the autoimmune health community to prioritize topics related to vaccine uptake for adults with autoimmune conditions by using a well-established methodology that allows for the identification of areas of consensus and disagreement across stakeholder groups. Decision to vaccinate is a multifaceted process that is the result of a complex series of attitudes and decision-making actions involving a range of stakeholders; therefore, multistakeholder considerations are integral to prioritize topics.
- Safety and efficacy of vaccines for adults living with autoimmune conditions emerged as the highest priority topic across all stakeholder groups, with concerns that range from whether certain vaccines could cause an exacerbation of autoimmune disease to the degree to which autoimmune diseases or use of immunomodulatory therapies may blunt vaccine response.
- Generating high-quality vaccine safety and efficacy data in patients with autoimmune disease and ensuring effective messaging to patients living with autoimmune conditions is critical to improving vaccine uptake and improving the health of patients.

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knowledge remains low or average among patients with autoimmune diseases (4,5). Many studies report that participants are unaware that vaccination is needed or feel that vaccination is unnecessary (6,7).

The current US health care landscape also poses unique barriers and facilitators, including unfettered access to (mis)information available on the internet (8), fading memory of infections often perceived of as rare, growing confidence in medical knowledge in populations without medical training, a lack of consensus among health care providers around vaccine scheduling and adjusting immunomodulating therapies (many of which are new therapeutics) (9), and an erosion of trust in public health agencies and institutions (10), as well as toward the pharmaceutical industry. Disparities in health care access determined by race and ethnicity and geographic area of residence for communities across the country remain a key influencer of vaccine uptake. Additionally, different cultural beliefs, especially among communities of color, for whom there are medical and historical legacies of betrayal and violence, make it essential to examine the current health care landscape when evaluating vaccine uptake. Through a general literature review that informed iterative and dynamic discussions with multiple stakeholders we gathered key insights into perceived and real barriers and facilitators, including the role of stakeholders in the real world. The objective of this project was to engage stakeholders (eg, providers, public policy representatives, policy advocates from the nongovernmental sector, vaccine manufacturers, academic and community pharmacists, and

researchers) to reach consensus on an agenda of high-priority topics for future patient-centered outcomes research (PCOR) and comparative effectiveness research (CER) on informed decision-making and optimizing uptake of crucial adult vaccines (eg, pneumococcal pneumonia, influenza, herpes zoster, human papillomavirus, and severe acute respiratory syndrome coronavirus 2) in persons living with autoimmune conditions (2). This project was national (US) in scope, and the context of country-specific factors (eg, ethnic and racial issues, communication and messaging preferences, sociogeographic factors, and availability of national guidelines and consensus recommendations) was considered.

Understanding potential facilitators and barriers to uptake of relevant vaccines is critically important to support informed patient health care decision-making. Vaccine hesitancy, defined as a "delay in acceptance or refusal of vaccination despite availability of vaccination services," remains problematic, and suboptimal uptake by adults with autoimmune conditions may be better understood by viewing vaccination as a behavioral action resulting from a complex set of systems influenced by people's attitudes, health conditions, policies, and permissions (11,12).

Understanding stakeholder perspectives regarding the factors that influence vaccine uptake requires examining both individual-level apprehensions and group-specific characteristics that include 1) the person or group being vaccinated and their knowledge of vaccines and trust in the provider or health care system; 2) the socio-cultural and institutional determinants in supporting individual decision-making, including the role of communication and messaging, politics, and perceptions related to the pharmaceutical industry; and 3) vaccine-specific concerns, including delivery mechanisms, risk-benefit analysis, and scheduling of vaccines, as well as ease of access and equitable distribution of vaccines.

METHODS

Steering committee. The Autoimmune Research Collaborative (ARC) convened a comprehensive multistakeholder steering committee (SC) representing four autoimmune conditions, including rheumatic and musculoskeletal diseases, inflammatory bowel disease, multiple sclerosis (MS), and vasculitis (13). The ARC is an alliance of patient-powered research networks (PPRNs), including the Inflammatory Bowel Disease Partners, iConquerMS, ArthritisPower, and the Vasculitis PPRN, aimed at advancing PCOR and CER for autoimmune and systemic inflammatory diseases (13). PPRNs are co-led by researchers, clinicians, and people living with specific disease conditions and are closely associated with patient advocacy, education, and support organizations that conduct patient-centered research. The investigators of each PPRN invited two individuals to serve on the SC: one provider or researcher with expertise in vaccines and one patient living with an autoimmune disease deciding whether to get one of the vaccines of interest. Selection of patient partners was based on including representation of disease from specific

patient advocacy and PPRNs and organizations. Patient stakeholders were selected primarily based on their affiliation with patient advocacy organizations for the autoimmune conditions of interest. As representatives of organizations that have a diversity of patients as part of their constituency, the patient stakeholders' role was to help represent and identify the key concerns related to relevant vaccines that their patient communities have expressed or would be likely to express. By representing the patient perspective, patient partners remained key to ensuring that research is aligned with patient-identified priorities.

SC identification of topics for research prioritization. Through regular monthly meetings and discussions informed by a literature review, the 10-member SC developed patient-centric research topics affecting vaccine uptake among adults living with autoimmune conditions, which were then prioritized through a modified Delphi exercise with a larger multistakeholder alliance.

A background literature review using the PubMed database was conducted to evaluate the existing evidence base in people with autoimmune diseases for the five vaccines evaluated. Search terms used were autoimmune and vaccination OR vaccine uptake AND autoimmune disease OR shingles, human papillomavirus (HPV), pneumococcal, covid, influenza vaccine AND autoimmune disease. The search was limited to English-language studies published between 2003 and 2021, which was chosen as a point in time when the use of immunomodulating drugs for rheumatic disease became more frequent and several of the vaccines evaluated in this study became available for clinical use. Studies addressing the use of and barriers and facilitators to vaccination for the five vaccines of interest in cohorts that included people with rheumatic and inflammatory diseases or systemic autoimmune diseases were included. Studies conducted outside the US or with pediatric participants were excluded. An overview of this literature review was then presented to the SC during the second monthly meeting. Through iterative discussions conducted online and via teleconference following SC members generated research topics based on their areas of expertise to be rated and ranked through the planned prioritization exercise by a larger multistakeholder alliance in a Delphi process. In addition, SC members also discussed the methods for developing Delphi consensus in advance and agreed to conduct three Delphi survey rounds and inclusion of stakeholders representing clinicians, patients or patient advocates, vaccine manufacturers, pharmacists, and individuals working with underrepresented and marginalized groups in all survey rounds. Statements developed for inclusion in the survey were distributed to SC members, and comments and responses on content and format were invited and discussed at SC meetings conducted online. All items were presented during SC meetings and, with an attempt to be as comprehensive as possible while removing or combining redundant items, project leads edited suggested items for inclusion on the final list for the Delphi prioritization exercise. The aim of the discussions was to arrive at consensus

on content, format, and framing of the statements to be included in the Delphi rounds. Any new items suggested by the broader alliance were addressed in future rounds of the Delphi for this project. The list of agreed upon items were then programmed into the Delphi survey program. SC members reviewed the list of items to address any repetitions, confusion, or questions related to individual items.

Multistakeholder alliance. The SC convened a broader multistakeholder alliance to rate and rank identified topics and develop a research agenda of prioritized topics for PCOR or CER on vaccine uptake among adults with autoimmune conditions. Alliance members were collaboratively identified by SC members, and the selection of alliance members was guided by the stakeholder groups specified in "A New Taxonomy for Stakeholder Engagement in Patient-Centered Outcomes Research," which outlines the seven types of stakeholders necessary to successfully design and conduct PCOR (14). Alliance members received an orientation to the project that included an overview of project aims and methods. Stakeholders in the alliance were organized into three groups and included patient advocates (Patients/Advocates); clinicians and researchers (Clinicians/ Researchers); and policy makers, regulators, and vaccine manufacturers (Other Stakeholders), all with substantial expertise on the topic of vaccine uptake either through lived experience as a patient, their research or practice, or implementation in policy and regulatory affairs.

Table 1. Stakeholder demographic characteristics (N = 36)

Characteristics	N (%) or mean ± SD
Age (y)	45.3 ± 17.5
Female	26 (72.2)
Race	
White (origins in European countries)	26 (72.2)
Black/African American	5 (13.9)
South Asian (such as origins in Afghanistan, Pakistan, India, Nepal)	4 (11.1)
East Asian (such as origins in China, Japan, South Korea, North Korea)	2 (5.6)
Hispanic, Latino, Latina, LatinX, or Spanish origin	1 (2.8)
Middle Eastern or North African (such as origins in Egypt, Turkey, Sudan, Iraq, Iran)	1 (2.8)
Multiracial	1 (2.8)
Education	
Postgraduate degree (Master's, Doctoral)	31 (86.1)
Undergraduate degree (Bachelor's)	3 (8.3)
Some college (no degree)	1 (2.8)
Associate degree	1 (2.8)
Region	
Northeast	18 (50.0)
South	12 (33.3)
West	4 (11.1)
Midwest	2 (5.6)
Population density	
Urban	35 (97.2)
Rural	1 (2.8)

Note: Some values for race are not mutually exclusive.

Table 2. Topics prioritized as critical by more than 70% of stakeholders (n = 31) during Delphi survey round 3

	Not important (rated 1-3) N (%)	Important, but not critical (rated 4-6) N (%)	Critically important (rated 7-9) N (%)
How vaccine safety profile affects vaccine uptake	0 (0)	1 (3.2)	30 (96.8)
How severity of vaccine side effects has an impact on vaccine uptake	0 (0)	7 (22.6)	24 (77.4)
How well a vaccine works for adults with autoimmune conditions	0 (0)	2 (6.5)	29 (93.6)
How vaccine efficacy for adults with an autoimmune condition is affected by the underlying disease	0 (0)	6 (19.4)	25 (80.7)
How medications should be adjusted around time of vaccination to improve vaccine efficacy	0 (0)	7 (22.6)	24 (77.4)
How the exclusion of adults with autoimmune conditions from vaccine trials affects vaccine uptake	0 (0)	9 (29.0)	22 (71.0)
How source of information about vaccines affects vaccine uptake	1 (3.2)	4 (12.9)	26 (83.9)
How myths or misinformation about vaccines affect vaccine uptake	1 (3.2)	5 (16.1)	25 (80.7)
How trust in health care system/provider affects uptake of vaccines	1 (3.2)	2 (6.5)	28 (90.3)
How treatment regimen affects vaccine uptake	0 (0)	8 (25.8)	23 (74.2)
How beliefs about vaccine safety affect vaccine uptake	1 (3.2)	2 (6.5)	28 (90.3)
How barriers to health care access affects vaccine uptake	1 (3.2)	4 (12.9)	26 (83.9)
How health care provider behavior affects vaccine uptake	1 (3.2)	7 (22.6)	23 (74.2)

Alliance prioritization of topics with modified Delphi exercise. To gain insight into stakeholders' topic prioritization, a modified Delphi exercise was conducted with all members of the multistakeholder alliance, including SC members. In the Delphi process, items were rated and ranked by the alliance to decide on the relative importance of topics to prioritize for future research.

We licensed and used DelphiManager software to program and deploy at least two rounds of rating surveys and a final ranking round. Each member of the alliance was sent an email with a message outlining the purpose of the Delphi process, the number of planned rounds, and a hyperlink to complete the survey in DelphiManager. For the rating rounds, participants were asked to rate the importance of each potential research topic keeping in mind the stakeholder group they represented. All responses were collected on a 9-point Likert scale where a rating of 1-3 was considered "Not important," 4-6 "Important but not critical," and 7-9 "Critically important." Each item had an option to select "Unable to score." In the rating rounds, participants were also given the option to provide feedback on any items listed and to suggest additional items, which were then reviewed and approved by project leads and included for rating in the subsequent round(s). During Rounds 2 and 3, each participant was able to review each of their item ratings from the previous round. During Round 2, participants could see the aggregate Round 1 ratings from participants in their stakeholder group, and during Round 3 participants could see the aggregate Round 2 ratings from all stakeholder groups. Participants could retain the ratings they made in the previous round or revise their ratings for each item after consideration of information presented from other participants. Only respondents from the preceding round were contacted for the subsequent rounds.

In the final ranking round, participants ranked topics in descending order from most to least important; each of the topics were rated as "Critically important" by more than 70% of participants in the third rating round.

Analysis. An analysis was conducted to identify consensus on research topics that were considered most important to alliance members for future PCOR or CER on vaccine uptake in adults with autoimmune conditions. Descriptive statistics and frequency distributions were used to assess the data from each of the three Delphi rounds. After the ranking round, a weighted summary score was calculated for each critical topic. Items were ranked based on the number of participants ranking it as their first, second, third, etc, choice and weighted by multiplying the rank number by its inverse to achieve a single weighted score for each measure. For instance, a measure scored 1 of 1 if ranked as most important, 1 of 2 if second most important, and so on. Values were then summed across all participants to produce a weighted summary score for each topic. The weighted summary scores were also stratified by the three stakeholder groups. The weighted summary scores from each stakeholder group were standardized to account for differences in sample size among the three groups by multiplying the stakeholder group score by the total sample size divided by the stakeholder group sample size.

RESULTS

A total of 36 stakeholders with a mean age of 45 years (standard deviation [SD]: 17.5) who were primarily female (72.2%), white (72.2%), and highly educated (86.1% postgraduate degree) were invited to participate in the modified Delphi exercise

Table 3. Percentage of 30 stakeholders ranking topics considered critically important by 70% or more at each rank, and final weighted summary scores per topic

	1	2	3	4	5	6	7	8	9	10	11	12	13	Weighted summary score
How well a vaccine works for adults with autoimmune conditions	8 (26.7)	5 (16.7)	2 (6.7)	1 (3.3)	1 (3.3)	3 (10.0)	1 (3.3)	4 (13.3)	0	2 (6.7)	1 (3.3)	1 (3.3)	1 (3.3)	13.2
How beliefs about vaccine safety affect vaccine uptake	6 (20.0)	4 (13.3)	0	6 (20.0)	3 (10.0)	1 (3.3)	1 (3.3)	0	1 (3.3)	0	3 (10.0)	3 (10.0)	2 (6.7)	11.2
How barriers to health care access affects vaccine uptake	2 (6.7)	4 (13.3)	4 (13.3)	3 (10.0)	1 (3.3)	2 (6.7)	2 (6.7)	4 (13.3)	3 (10.0)	2 (6.7)	0	3 (10.0)	0	8.2
How myths or misinformation about vaccines affect vaccine uptake	3 (10.0)	3 (10.0)	1 (3.3)	0	3 (10.0)	3 (10.0)	1 (3.3)	4 (13.3)	2 (6.7)	0	6 (20.0)	3 (10.0)	1 (3.3)	7.7
How treatment regimen affects vaccine uptake	3 (10.0)	0	1 (3.3)	3 (10.0)	4 (13.3)	2 (6.7)	2 (6.7)	3 (10.0)	4 (13.3)	1 (3.3)	2 (6.7)	4 (13.3)	1 (3.3)	7.0
How vaccine efficacy for adults with an autoimmune condition is affected by the underlying disease	0	5 (16.7)	5 (16.7)	3 (10.0)	0	3 (10.0)	4 (13.3)	2 (6.7)	0	1 (3.3)	2 (6.7)	2 (6.7)	3 (10.0)	6.9
How trust in health care system/provider affects uptake of vaccines	3 (10.0)	1 (3.3)	0	1 (3.3)	4 (13.3)	3 (10.0)	2 (6.7)	4 (13.3)	1 (3.3)	3 (10.0)	3 (10.0)	3 (10.0)	2 (6.7)	6.9
How vaccine safety profile affects vaccine uptake	1 (3.3)	2 (6.7)	6 (20.0)	1 (3.3)	3 (10.0)	1 (3.3)	2 (6.7)	3 (10.0)	2 (6.7)	3 (10.0)	3 (10.0)	3 (10.0)	0	6.7
How medications should be adjusted around time of vaccination to improve vaccine efficacy	1 (3.3)	3 (10.0)	1 (3.3)	4 (13.3)	5 (16.7)	2 (6.7)	2 (6.7)	0	3 (10.0)	3 (10.0)	1 (3.3)	2 (6.7)	3 (10.0)	6.6
How the exclusion of adults with autoimmune conditions from vaccine trials affects vaccine uptake	1 (3.3)	2 (6.7)	3 (10.0)	2 (6.7)	0	2 (6.7)	4 (13.3)	2 (6.7)	2 (6.7)	3 (10.0)	3 (10.0)	1 (3.3)	5 (16.7)	5.9
How source of information about vaccines affects vaccine uptake	1 (3.3)	1 (3.3)	2 (6.7)	2 (6.7)	3 (10.0)	4 (13.3)	1 (3.3)	4 (13.3)	5 (16.7)	6 (20.0)	0	1 (3.3)	0	5.8
How severity of vaccine side effects has an impact on vaccine uptake	1 (3.3)	0	3 (10.0)	1 (3.3)	2 (6.7)	2 (6.7)	6 (20.0)	0	5 (16.7)	3 (10.0)	1 (3.3)	3 (10.0)	3 (10.0)	5.3
How health care provider behavior affects vaccine uptake	0	0	2 (6.7)	3 (10.0)	1 (3.3)	2 (6.7)	2 (6.7)	0	2 (6.7)	3 (10.0)	5 (16.7)	1 (3.3)	9 (30.0)	4.0

Note: Topics rated as critical by >70% of respondents in the Round 3 rating; table displays percentage of respondents assigning a particular rank order to each topic; items were ranked based on the number of participants ranking it as their first, second, third, fourth, etc, choice and weighted by multiplying the rank number by its inverse to achieve a single weighted score for each measure. For instance, a measure was scored 1/1 if ranked as most important, 1/2 if second most important, and so on. Values were then summed across all participants to produce a weighted summary score for each topic.

(Table 1). In Round 1, 35 stakeholders participated in rating 33 topics. One new topic was proposed by a Round 1 rater. In Round 2, 34 stakeholders participated in rating 34 topics, and in Round 3, 31 stakeholders participated in rating the same 34 topics. Although two rating rounds were initially planned, an additional rating round was added to our Delphi process in order to determine whether any items could be removed from voting and reduce the number of items deemed "Critically important" for the final ranking step. Participants confirmed or changed their previous ratings after seeing the aggregated ratings from all three stakeholder groups. This reduced the number of items that more than 70% of participants rated as "Critically important" from 20 topics in Round 2 to 13 topics in Round 3 (Table 2). When these 13 topics advanced to the ranking round, 30 participants ranked the 13 topics from most to least important (Table 3).

The two highest-scoring "Critically important" topics from the ranking round among all stakeholder groups were "How well a vaccine works for adults with autoimmune conditions" and "How beliefs about vaccine safety affect vaccine uptake," with a weighted summary score of 13.2 and 11.2, respectively (N = 30; Table 4). Both the Patient and Patient Advocate group (n = 14) and the Researchers and Clinician group (n = 14) assigned top priority to the same two topics in the ranking round: "How well a vaccine works for adults with autoimmune conditions" (12.4 and 13.5, respectively) and "How beliefs about vaccine safety affect vaccine uptake" (9.9 and 13.3, respectively). The Patient and Patient Advocate group, however, also prioritized "How myths or misinformation about vaccines affect vaccine uptake" (9.2) and "How trust in health care system/provider affects uptake of vaccine" (9.0), whereas the Researchers and Clinician group prioritized "How barriers to health care access affect vaccine uptake" (9.2) and "How vaccine safety profile affects vaccine uptake" (8.4) (Table 4).

DISCUSSION

This study produced a comprehensive, data-driven list of topics considered by the multistakeholder panel as top priority for research on vaccine uptake for adults living with autoimmune conditions. Few studies have brought together a multistakeholder panel to vote on topics related to vaccine uptake for this population. Most interventions have focused only on provider behavior to improve vaccination rates; however, getting vaccinated is a behavior resulting from an interdependent complex set of systems that include people, funding, policies, and permissions (7,12).

Topics pertaining to vaccine efficacy for adults with autoimmune conditions and how beliefs about safety affect vaccine uptake were top priorities, with the Patient/Patient Advocate stakeholder group also prioritizing how myths or misinformation and trust in health care system or provider affect vaccine uptake. This emphasizes the need for increased patient education about vaccines from trusted sources. Myths about vaccines hinder uptake (15) and are related to worsening of symptoms, disease flares, fear of side effects, and deeming vaccines as unnecessary.

Table 4. Weighted ranking score of critical topics by stakeholder group, standardized by sample size of group

	Overall (N = 30)	Clinicians and Researchers (n = 14)	Patients and Patient Advocate (n = 14)	Others (n = 2)
How well a vaccine works for adults with autoimmune conditions	13.2	13.5	12.4	16.5
How beliefs about vaccine safety affect vaccine uptake	11.2	13.3	9.9	4.5
How barriers to health care access affects vaccine uptake	8.2	9.2	7.1	9.0
How myths or misinformation about vaccines affect vaccine uptake	7.7	7.1	9.2	3.0
How treatment regimen affects vaccine uptake	7.0	6.4	7.9	4.5
How vaccine efficacy for adults with an autoimmune condition is affected by the underlying disease	6.9	6.0	7.3	10.5
How trust in health care system/provider affects uptake of vaccines	6.9	3.6	9.0	16.5
How vaccine safety profile affects vaccine uptake	6.7	8.4	4.9	7.5
How medications should be adjusted around time of vaccination to improve vaccine efficacy	6.6	6.9	6.4	4.5
How the exclusion of adults with autoimmune conditions from vaccine trials affects vaccine uptake	5.9	7.1	4.7	7.5
How source of information about vaccines affects vaccine uptake	5.8	5.1	6.9	3.0
How severity of vaccine side effects has an impact on vaccine uptake	5.3	4.7	5.8	6.0
How health care provider behavior affects vaccine uptake	4.0	3.9	4.1	3.0

Note: "Clinicians": clinical expert/physician/researcher/pharmacist. "Others": payer, vaccine manufacturer, policy maker, regulatory representative, Community/retail pharmacy.
Topics rated as critical by more than 70% of respondents in the Round 3 rating; items were ranked based on the number of participants ranking it as their first, second, third, fourth, etc, choice and weighted by multiplying the rank number by its inverse to achieve a single weighted score for each measure. For instance, a measure scored 1/1 if ranked as most important, 1/2 if second most important, and so on. Values were then summed across all participants to produce a weighted summary score for each topic. The weighted summary scores from each stakeholder group were standardized to account for differences in sample size among the three groups by multiplying the stakeholder group score by the total sample size divided by the stakeholder group sample size.

Source of information, disseminating reliable information, and tailoring messaging about the importance and safety of specific vaccines are imperative.

Adults with autoimmune conditions have concerns ranging from how vaccines interfere with their underlying disease, to blunted vaccine response due to their underlying condition or use of immunomodulatory therapies. Other concerns relate to a lack of guidance around timing and scheduling of vaccination and consequent adjustment of immunomodulatory therapy and overall trust in the health care system.

This study provides data to support several recommended next steps for PCOR or CER to improve vaccine uptake. First, ensure that all stakeholders from the autoimmune disease research arena are familiar with the topics prioritized by this project. Second, ensure adequate support for PCOR or CER studies to better understand efficacy, immunogenicity, and safety of applicable vaccines for adults with autoimmune disease. This should necessarily expand to including predefined subgroups of populations of patients with auto-immune conditions in clinical trials for vaccines. Patient advocacy organizations are uniquely situated to conduct PCOR in this area and disseminate evidence to relevant patient communities and raise awareness around the need for vaccines. Third, vaccine advisory committees and agencies dealing with vaccine-related communication should be encouraged to include representatives from patient advocacy organizations to better understand the concerns of those living with immune system disorders as guidelines are developed and to shape and distribute tailored messaging to increase confidence in vaccines. Finally, studies that encourage patient-generated information to track and document the experience of adverse events related to vaccines per underlying disease can help to address patient concerns around side effects and help informed decision-making as patients are constantly faced with trade-offs that require assessing benefits versus risks while making medical decisions including what vaccines to take and when to receive them.

In conclusion, a multistakeholder panel identified key priorities for research aimed at improving vaccine uptake among adults living with autoimmune conditions, especially a need for greater evidence regarding vaccine efficacy and safety in the autoimmune population. This project provided a structured framework for patients to communicate directly with health care providers, policy makers, regulatory representatives, and vaccine manufacturers, and it revealed topics such as trust in the health care system that were especially prioritized by patients; it can serve as a model for future projects that seek to develop a consensus-driven research agenda through multistakeholder input. The process of co-identifying priority topics through expert input and end user (patient) input can enhance the validity and credibility of results, help to establish trust across disparate stakeholders, and motivate studies to fill research gaps. The results of this study can serve as a research agenda, and continued engagement with stakeholders who participated in this project will serve a critical role in developing research studies that will lead to improved vaccine uptake.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Dr. Venkatachalam had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Venkatachalam, Gavigan, Stradford, Dronadula, Degrassi, Nowell, Banerjee, Merkel, George, Gordon, Shaw, Larsen, Emrich, McBurney, Sullivan, Blazer, Banbury, Weaver, Kappelman, Curtis.

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