ACR Open Rheumatology
Vol. 4, No. 5, May 2022, pp 410–416
DOI 10.1002/acr2.11360

American College of Rheumatology
Empowering Rheumatology Professionals

BRIEF REPORT

Feasibility and Efficacy of Online Strategies to Recruit Parents of Children With Rheumatic Diseases for Research

Jonathan S. Hausmann,[1,2] Jorge Vizcaino-Riveros,[3,4] Alexandra C. Marin,[4,5] Machiko Minegishi,[4] Rachele Cox,[4] Min-Lee Chang,[6] Laura E. Schanberg,[7] Marc Natter,[6] and Elissa R. Weitzman,[4,5,6]
for the CARRA Legacy Registry Investigators

Objective. We aimed to determine the feasibility and efficacy of online strategies to recruit parents of children with pediatric rheumatic diseases (PRDs) for research and to evaluate the degree to which known features of various rheumatic disease groups were present in the online cohort.

Methods. We studied two cohorts; the first was composed of respondents from a cross-sectional parental survey of children with PRDs contacted through patient support groups and social media platforms, and the second cohort was composed of participants from the Childhood Arthritis and Rheumatology Research Alliance (CARRA) legacy clinical registry.

Results. In the social media cohort, 712 complete surveys were analyzed. Most (65.9%) were referred from Facebook. The most common rheumatic disease was juvenile idiopathic arthritis (JIA) (27.1%), followed by juvenile dermatomyositis (22.1%). In the CARRA registry cohort, 7985 records were included. JIA was the largest disease group (70.3%), followed by systemic lupus erythematosus (12.0%). The age at disease onset for most PRDs was similar between those in the social media and CARRA registry cohorts (mean difference = 1.3 years).

Conclusion. Recruitment through Facebook was the most fruitful. The clinical characteristics of the social media cohort were similar to those of patients recruited through a clinical registry, suggesting the utility of online recruitment for engaging disease-relevant cohorts. Parents of children with rare PRDs were overrepresented in the social media cohort, perhaps reflecting the increased need of those parents to find online information and receive emotional support. Social media recruitment for research studies may help expand the number and diversity of participants in clinical research, especially by including those with rare diseases.

INTRODUCTION

Households raising children with chronic medical conditions experience several challenges, including ones related to the financial, social, and emotional impacts of a chronic illness. It is not surprising, then, that parents of children with chronic illnesses often turn to social media for support and information about their child's health. Through these platforms, parents develop network empowerment by collaborating with other parents, sharing resources, and promoting advocacy for their child's condition

Funded by a Childhood Arthritis and Rheumatology Research Alliance–Arthritis Foundation grant. Dr. Weitzman also receives funding from the following grants: National Institute of Arthritis and Musculoskeletal and Skin Diseases NIH grant R21-U19-AR-06952201 and National Institute of Arthritis and Musculoskeletal and Skin Diseases NIH grant R21-AR-07094401-A1.

[1]Jonathan S. Hausmann, MD: Boston Children's Hospital, Program in Rheumatology, Division of Immunology, Boston, Massachusetts; [2]Jonathan S. Hausmann, MD: Beth Israel Deaconess Medical Center, Division of Rheumatology and Clinical Immunology, Boston, Massachusetts; [3]Jorge Vizcaino-Riveros: Boston University School of Public Health, Boston, Massachusetts; [4]Jorge Vizcaino-Riveros, Alexandra C. Marin, PhD, Machiko Minegishi, MD, MSW, MPH, Rachele Cox, MPH, Elissa R. Weitzman, ScD, MSc: Division of Adolescent/Young Adult Medicine, Boston Children's Hospital, Boston, Massachusetts; [5]Alexandra C. Marin, PhD, Elissa R. Weitzman, ScD, MSc: Department of Pediatrics, Harvard Medical School, Boston, Massachusetts; [6]Min-Lee Chang, MS, MPH, Marc Natter, MD, Elissa R. Weitzman, ScD, MSc: Computational Health Informatics Program, Boston Children's Hospital, Boston, Massachusetts; [7]Laura E. Schanberg, MD: Department of Pediatrics, Duke University School of Medicine, Durham, North Carolina.

Dr. Hausmann has received grants from the Rheumatology Research Foundation and salary support and grants from the Childhood Arthritis and Rheumatology Research Alliance and has served as a consultant for Novartis, Pfizer, and Biogen, all unrelated to this work. Dr. Schanberg has received grants from the Patient-Centered Outcomes Research Institute, Bristol Myers Squibb, and the National Institute of Arthritis and Musculoskeletal and Skin Diseases and salary support from Childhood Arthritis and Rheumatology Research Alliance and has served as a consultant for Sobi, USB, and Sanofi, all unrelated to this work. No other disclosures relevant to this article were reported.

Author disclosures are available at https://onlinelibrary.wiley.com/action/downloadSupplement?doi=10.1002%2Facr211360&file=acr211360-sup-0001-Disclosureform.pdf.

Address correspondence to Jonathan S. Hausmann, MD, Boston Children's Hospital, Division of Immunology, Fegan 6, 300 Longwood Ave, Boston, MA 02115. Email: jonathan.hausmann@childrens.harvard.edu.

Submitted for publication May 2, 2021; accepted in revised form September 20, 2021.

locally and nationally (1). For parents of children with chronic health conditions, the use of social media may decrease feelings of isolation, improve disease-related knowledge, and address non-medical issues not commonly discussed with physicians (1,2). Increased awareness and understanding of their child's condition gained from social media may enhance the parent-physician relationship (3). For many, social media platforms are important sources of knowledge and influence their treatment decisions, thus significantly impacting the clinical care patients receive (4,5).

Parents of children with pediatric rheumatic diseases (PRDs) may be particularly interested in seeking online information about their child's health because of the rarity of these conditions. By definition, rare diseases, which include all PRDs, affect less than 200,000 people in the United States. Within this group, however, some diseases are more common than others. Juvenile idiopathic arthritis (JIA) is the most common PRD worldwide; a recent systematic review calculated incidence and prevalence rates of 7.8 per 100,000 and 32.6 per 100,000, respectively, in White populations (6). In contrast, juvenile dermatomyositis (JDM) has an incidence rate in the United States between 0.25 and 0.41 per 100,000 (7).

When diseases are especially rare, as with some PRDs, clinicians may have little first-hand experience to draw from or accurate medical knowledge to manage affected patients (8) and may have limited time to provide informational and emotional support to families. Families may also have little opportunity to meet and learn from other families with children with similar conditions. As such, families of children with rare conditions may find extraordinary value in engaging with each other online. Similarly, clinicians and scientists may engage with and learn from patients belonging to online communities of rare diseases, who may be difficult to find in large numbers in the clinical setting (9) because it often requires expensive multicenter international involvement that may take several years to recruit adequate numbers of patients (8,9). These online communities may be particularly interested in promoting and participating in research to advance knowledge about their disease (10). However, there is concern about the validity of an online cohort of patients with self-reported diagnoses because the utility of such a cohort depends on a participant's ability to report their medical information accurately (11,12).

In this study, we sought to assess the feasibility of engaging parents of youth with PRDs through online channels and evaluate the quality of these data by comparing clinical characteristics of the online cohort with those from a well-established clinical cohort. We also assessed the relative utility of online platforms to recruit participants for research studies. Our findings highlight the strengths and limitations of recruiting online communities for research, including the recruitment bias associated with an opt-in, self-selecting cohort.

PATIENTS AND METHODS

Study design and cohorts. We studied two cohorts. The first is a social media cohort composed of respondents from a cross-sectional parental survey of children with self-reported PRDs who were contacted through patient support groups and social media platforms. This cohort represented a convenience sample of parents of children with any self-reported PRD who completed an online anonymous survey between January 22 and April 2, 2019. The survey assessed parental social media use relating to their child's health, and consent was implied by survey completion.

The second cohort comprises participants from the Childhood Arthritis and Rheumatology Research Alliance Legacy Registry (CARRA registry), a clinical registry that enrolled approximately 10,000 children with physician-diagnosed PRDs between 2010 and 2014. Children were enrolled from 75 pediatric rheumatology clinics in the United States, Canada, and Israel. Data collected include both physician and child/parent measures of disease activity, demographics, and medications. Inclusion criteria for the CARRA registry were a diagnosis of one of eight categories of defined rheumatic disease, disease onset before the 16th birthday, age 21 years old or younger (13; Appendix A).

Forming partnerships and building the survey instrument. The development and dissemination of the online survey instrument to the social media cohort was accomplished in collaboration with the Patients, Advocates, and Rheumatology Teams Network for Research and Service (PARTNERS), a patient-powered research network funded by the Patient-Centered Outcomes Research Institute. The development of the survey instrument was informed by a prior survey of adolescents with PRDs (14), and the survey was adapted and edited by the authors in collaboration with parents of children with PRDs belonging to the PARTNERS member organizations. The survey was available in English (Supplement 1).

We disseminated the online survey through PARTNERS member organizations, including the Arthritis Foundation, the Lupus Foundation of America, and the Cure Juvenile Myositis (JM) Foundation. Additionally, we collaborated with support groups for families of children with other PRDs to recruit a diverse cohort across the PRD spectrum, including groups not part of PARTNERS: the Autoinflammatory Alliance, the Scleroderma Kids Support Group, the Chronic Recurrent Multifocal Osteomyelitis (CRMO) Foundation, the Autoimmune Encephalitis (AE) Alliance, the Vasculitis Foundation, and the Systemic JIA Foundation. We worked closely with each group to generate comparable recruitment materials and distribute survey links to members.

Survey dissemination. Each patient support organization disseminated survey information and links to members through various online methods, including the organization's website, Facebook and Twitter accounts, direct emails sent to members, or the organization's newsletters (Supplement 2). The recruitment message posted on each platform provided a brief study description and the URL to the anonymous Qualtrics online survey.

Qualtrics recorded the site or platform where the link was clicked, except when the link was directly entered on a browser; no internet protocol address or other identifying personal information was collected. The study was deemed exempt by the Institutional Review Board at Boston Children's Hospital.

Measures. *Clinical characteristics.* For the social media cohort, parents selected from the following diagnoses: JIA, systemic lupus erythematosus (SLE), JDM, scleroderma, vasculitis, autoinflammatory disease, or "other" (with the ability to write in a diagnosis). Additional categories were created after data collection because of the high frequency of write-in answers: CRMO, AE, and Sjögren syndrome. Rheumatic disease diagnoses in the "other" category that had less than five respondents (such as fibromyalgia, mixed connective tissue disease [MCTD], overlap syndrome, relapsing polychondritis, or uveitis) were collapsed into a single grouping. Children with two or more PRDs were also included in the "other" category. The diagnosis of systemic JIA was grouped in with the JIA diagnosis, as per the International League of Associations for Rheumatology classification criteria (15).

Within the CARRA sample, per the original registry criteria (13), data for children with the following PRD groups were reviewed: JDM, JIA, SLE or MCTD, systemic sclerosis, vasculitis, or autoinflammatory disease.

Demographics. Data from the social media cohort and CARRA registry included the child's current age, age at disease diagnosis, and disease duration, all measured in years.

Statistical analyses. We characterized each cohort using descriptive statistics, comparing the two cohorts on group characteristics using *t*-tests ($\alpha < 0.05$). We excluded observations missing the child's age or rheumatic disease diagnosis. SAS Studio 3.5 (SAS Institute, Inc) software was used to conduct these analyses.

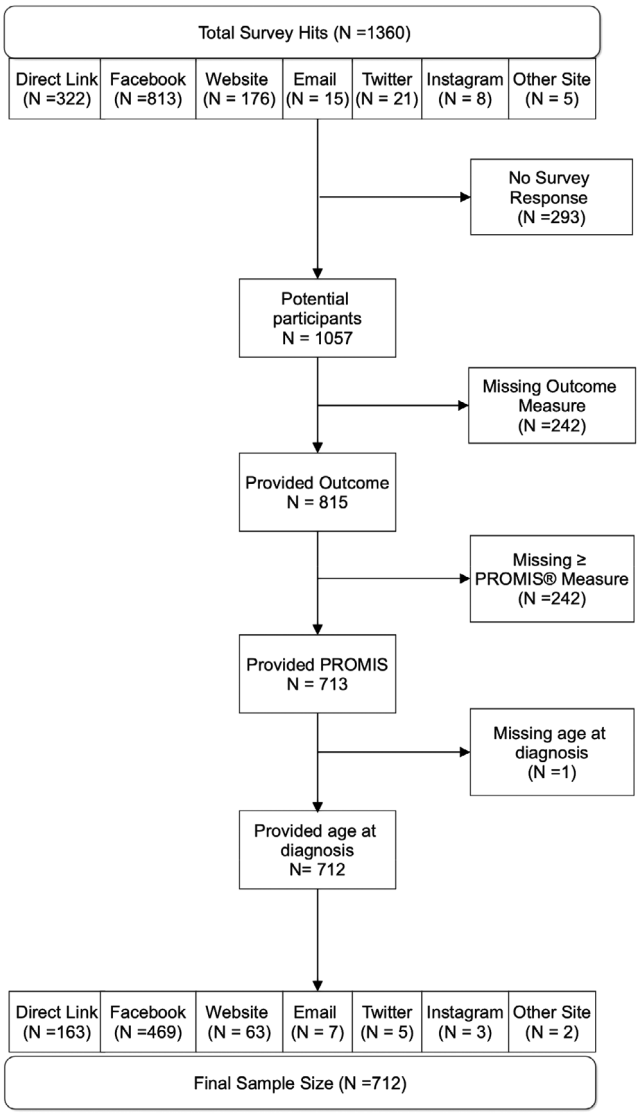

Figure 1. Flow diagram for recruitment, including referrers from various platforms, as well as application of exclusion criteria. PROMIS, Patient-Reported Outcomes Measurement Information System.

RESULTS

The survey was accessed 1360 times. Empty surveys and those with incomplete data on outcomes of interest were removed, resulting in a final analytic sample of N = 712 (Figure 1). Of these, 469 (65.9%) were referred from Facebook, 63 (8.8%) from one of the patient support organizations' websites, 7 (1.0%) from email, 5 (0.7%) from Twitter, 3 (0.4%) from Instagram, and 2 (0.3%) from other sites. For 163 participants (22.9%), reference location was not noted, suggesting they copied the survey link directly into the web browser.

The data of 7985 participants from the CARRA registry that matched our inclusion criteria and were reviewed.

Participants. The demographic characteristics of both cohorts are shown in Table 1. In the social media cohort, the most common rheumatic disease was JIA (27.1%), followed by JDM (22.1%). The mean age at disease diagnosis varied from ages 5.0 and 6.0 for autoinflammatory diseases and JIA to ages 13.0 and 13.5 for SLE and vasculitis, respectively.

In the CARRA registry, JIA was the largest disease group (70.3%), followed by SLE (12.0%). Mean ages at disease diagnosis ranged from 3.0 for autoinflammatory diseases to 11.7 for SLE.

Data comparisons. The age at disease onset for each PRD was similar between the social media and CARRA registry cohorts, with a mean difference in ages across the PRDs of 1.3 years. However, there were statistically significant differences in age at onset for SLE, JDM, autoinflammatory diseases, and vasculitis ($P < 0.05$ for all), with participants from the social media

Table 1. Clinical and demographic characteristics of participants from the social media registry and CARRA Legacy Registry

	Total	Juvenile idiopathic arthritis	p-value	Systemic lupus erythematosus	p-value	Juvenile dermatomyositis	p-value	Systemic sclerosis	p-value	Autoinflammatory diseases	p-value	Chronic recurrent multifocal osteomyelitis	p-value	Sjogren's syndrome	p-value	Vasculitis	p-value	Autoimmune encephalitis	p-value	Other	p-value
Participants n(%)																					
Social media cohort	712 (100)	193 (27.1)		34 (4.8)		157 (22.1)		15 (2.1)		132 (18.5)		14 (2.0)		11 (1.5)		18 (2.5)		62 (8.7)		76 (10.7)	
CARRA clinical registry	7985 (100)	5840 (70.3)		997 (12.0)		563 (6.8)		350 (4.2)		42 (0.5)		27 (0.3)		20 (0.2)		146 (1.8)					
Mean age at diagnosis in years (SD)			0.7609		**0.025**		**0.0194**		0.2772		**0.0062**		0.2125		0.7177		**0.0077**				
Social media cohort	7.0 (4.7)	6.0 (4.2)		13.0 (3.9)		7.0 (4.0)		8.5 (3.5)		5.0 (4.0)		8.1 (2.9)		9.7 (2.3)		13.5 (3.6)		9.1 (5.3)		6.0 (4.3)	
CARRA clinical registry		6.1 (4.5)		11.7 (3.3)		6.2 (3.9)		7.3 (4.1)		3.0 (4.0)		9.3 (2.7)		10.2 (3.9)		10.4 (4.7)					
Current age in years, mean (SD)			0.1631		0.6809		**0.0001**		0.3064		0.7484		**0.0288**		0.6296		**0.0001**				
Social media cohort	11.5 (5.5)	11.4 (4.9)		17.6 (5.6)		11.9 (5.4)		10.8 (3.3)		8.6 (5.0)		10.9 (2.3)		12.4 (2.5)		18.2 (3.8)		12.9 (5.4)		10.3 (5.4)	
CARRA clinical registry		10.9 (4.9)		15.3 (3.2)		10.2 (4.6)		11.9 (4.1)		8.3 (5.3)		12.7 (2.4)		11.6 (4.8)		14.5 (3.7)					
Disease duration, years (SD)*			**0.0168**		**0.0459**		**0.0085**		**0.0175**		**0.0062**		0.522		0.2207		0.4278				
Social media cohort	4.5 (3.9)	5.4 (4.0)		4.6 (4.1)		4.9 (4.5)		2.3 (1.7)		3.6 (3.3)		2.8 (2.6)		2.6 (2.2)		4.7 (2.8)		3.7 (3.6)		4.3 (3.9)	
CARRA clinical registry		4.7 (4.0)		3.5 (3.0)		4.0 (3.5)		4.5 (3.5)		5.4 (4.5)		3.3 (2.3)		4.0 (3.2)		4.0 (3.6)					

* Calculated as current age minus age at disease diagnosis.
Note: Values in bold indicate *p* values < 0.05.

cohort having slightly older ages at disease diagnosis than those from the CARRA registry in all cases.

DISCUSSION

We partnered with communities of patients with rare diseases, including parents and patient support organizations, to design and disseminate an online survey for parents of children with PRDs. We successfully recruited an online cohort of parents reporting a diverse range of child PRD diagnoses and found that the age at disease onset, an important known clinical feature of PRD types, in our online cohort was comparable with that from a clinical registry of pediatric patients. Our findings provide some indication of the validity of the online cohort, suggesting that children in the study have the diseases reported, thus supporting the accuracy of data obtained from online cohort studies. Additionally, we were particularly successful in engaging parents of children with rare PRDs, a community typically challenging to identify and reach in large numbers.

Studies have found that directly recruiting participants online through social media is feasible, efficient, and acceptable to participants (16). Compared with offline recruiting, online methods are more effective, as demonstrated by faster, more cost-effective recruitment (17). Successful approaches to recruiting patients with rare diseases online have included congenital heart disease (18) and hemophilia (19). More recently, social media was used to recruit an international cohort of more than 10,000 adults and parents of children with rheumatic diseases to better understand the COVID-19 pandemic's impact on health, education, and employment (20).

Like other online surveys of patients with rare diseases (18), we found that Facebook was the largest referral source; few participants arrived through an organization's website or email, and even fewer arrived from other social media platforms. A recent systematic review of 110 studies found that Facebook was a highly effective method for research recruitment (21). Our results suggest that families of children with PRDs are especially active on Facebook, as opposed to other social media platforms, and that Facebook is a valuable tool for study recruitment. Through Facebook groups, members can help disseminate the survey link to others who were not part of the formal survey distribution framework, thus creating a snowballing sample leading to greater numbers of participants enrolled through this platform, as opposed to email or web advertisements.

The online recruitment strategy appeared especially useful for engaging parents of children with rare diseases, groups overrepresented in our study relative to the frequency of these diagnoses seen in pediatric rheumatology clinics and cohorts. For instance, although JIA generally makes up 69% to 89% of cases of PRD seen in pediatric rheumatology clinics (22–25), it represents less than one-third of our cohort. At the same time, rare diseases accounted for a greater percentage of our participants than seen in pediatric rheumatology clinics. For instance, although children with JDM account for 2.3% to 5% of PRDs seen in the clinic, they make up more than 20% of our cohort. This discrepancy may reflect a greater need for parents of children with especially rare conditions to find information online. The value of peer-to-peer exchange and the need for emotional and informational support may be greater for families with rare diseases. Parents of children with rare diseases may be especially active in online communities and more likely to participate in PRD research, motivated to fill knowledge gaps.

The age at disease onset was similar across both cohorts, suggesting that online parent-based cohorts are viable sources of reliable information, comparable to clinical reports and registries. Studies recruiting patients from online communities found self-reported diagnoses to be highly accurate compared to participants' medical records (11,12) and produce similar data to those collected under controlled conditions (26). Our findings highlight the validity and benefits of leveraging social media and online communities for study recruitment.

The strengths of our study include the successful recruitment of a relatively large sample of parents of children with a variety of PRDs and the data collected being similar to the characteristics of participants in a clinical registry. However, online surveys of families with children with chronic illnesses are limited by the inability to confirm the diagnosis and other clinical data, as well as the potential for self-report bias. This limitation may be overcome by including questions to ensure disease-related traits (27), as demonstrated here by comparing self-reported age at diagnosis with known disease features. Selection bias is an inherent limitation to our study given that online surveys are only available to persons with Internet access, generally reflecting a population of higher socioeconomic status (21). Recruiting participants through support groups might have helped offset a technology bias and connected us to a more engaged patient population with higher interests in research participation. However, it is important to note that selection bias also affects traditional survey and clinic-based research recruiting. Although online recruitment may not represent an entire population of interest, studies show that participation from online recruitment is similar to that from traditional recruitment methods (21). There were also limitations in the comparisons between the social media cohort and the CARRA registry cohort. The inclusion and exclusion criteria for each disease varied between the social media and clinical registry. For instance, the CARRA registry diagnosis of vasculitis excluded children with Kawasaki disease and immunoglobulin A (IgA) vasculitis, thus excluding conditions with earlier disease onset, which may explain the difference in ages between those in the CARRA registry and those in the social media cohort. Some categories, such as AE, were not included in the clinical registry. Within the social media cohort, we included an "other" disease category composed of patients with multiple diagnoses

and those with other rare illnesses, such as MCTD or relapsing polychondritis. Although this group did not have a direct comparator within the CARRA registry, we included their data to highlight further the ability to recruit patients with rare diseases using online methods. Finally, it should be noted that the data collection for the registry preceded the survey data collection for the social media cohort by several years.

In summary, we demonstrated that partnering with parents and patient support organizations to develop and disseminate an online survey to families of children with PRDs was an effective recruitment method for a survey research study. Recruitment through Facebook provided the largest sample, and the clinical characteristics obtained through this method were similar to those of patients recruited through a clinical registry, suggesting the validity of this approach. Overall, parents of children with the rarer PRDs appeared to be overrepresented, perhaps reflecting the increased need of those parents to find online information and receive emotional support compared with parents with children with more common conditions. Social media recruitment for research studies may help expand the number and diversity of participants in clinical research, especially by including those with rare diseases.

ACKNOWLEDGMENTS

We wish to acknowledge CARRA and the ongoing Arthritis Foundation financial support of CARRA. We would also like to thank PARTNERS and all of our collaborators: Arthritis Foundation (Suzanne Schrandt), Lupus Foundation of America (Karin Tse), Cure JM Foundation (Andrew Heaton, Shannon Malloy), Autoinflammatory Alliance (Karen Durrant, Jennifer Tousseau), Scleroderma Kids Support Group (Christina Loccke), CRMO Foundation (Elizabeth Murray), AE Alliance (Kimberly de Haseth), Vasculitis Foundation (Joyce Kullman, Kalen Young, Peter Merkel), Systemic JIA Foundation (Phil Reardon, Leah Bush, Rashmi Sinha), and Kara Magane for her administrative support. We are also grateful to the hundreds of families who took the time to complete our survey.

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. Hausmann 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. Hausmann, Schanberg, Weitzman.
Acquisition of data. Hausmann, Chang, Schanberg, Natter, Weitzman.
Analysis and interpretation of data. Hausmann, Vizcaino-Riveros, Marin, Minegishi, Cox, Chang, Natter, Weitzman.

REFERENCES

1. Ammari T, Schoenebeck S. Networked empowerment on Facebook groups for parents of children with special needs. Presented at Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems; 2015 April 18-23; Seoul, Republic of Korea. https://doi.org/0.1145/2702123.2702324
2. Akre C, Polvinen J, Ullrich NJ, Rich M. Children's at home: pilot study assessing dedicated social media for parents of adolescents with neurofibromatosis type 1. J Genet Couns 2018;27:505–17.
3. Benetoli A, Chen TF, Aslani P. How patients' use of social media impacts their interactions with healthcare professionals. Patient Educ Couns. 2018;101:439–44. https://doi.org/10.1016/j.pec.2017.08.015
4. Frost J, Massagli M. PatientsLikeMe the case for a data-centered patient community and how ALS patients use the community to inform treatment decisions and manage pulmonary health. Chron Resp Dis 2009;6:225–9.
5. Huber J, Maatz P, Muck T, Keck B, Friederich H-C, Herzog W, et al. The effect of an online support group on patients' treatment decisions for localized prostate cancer: an online survey. Urol Oncol 2017;35:37.e19-37.e28.
6. Thierry S, Fautrel B, Lemelle I, Guillemin F. Prevalence and incidence of juvenile idiopathic arthritis: a systematic review. Joint Bone Spine 2014;81:112–7.
7. Mendez EP, Lipton R, Ramsey-Goldman R, Roettcher P, Bowyer S, Dyer A, et al. US incidence of juvenile dermatomyositis, 1995-1998: results from the National Institute of Arthritis and Musculoskeletal and Skin Diseases Registry. Arthritis Rheum 2003;49:300–5.
8. Stoller JK. The challenge of rare diseases. Chest 2018;153:1309–14.
9. Wicks P, Vaughan T, Heywood J. Subjects no more: what happens when trial participants realize they hold the power?. [CLINICAL TRIALS] BMJ. 2014;348:g368. https://doi.org/10.1136/bmj.g368
10. Black AP, Baker M. The impact of parent advocacy groups, the Internet, and social networking on rare diseases: the IDEA League and IDEA League United Kingdom example. Epilepsia 2011;52 Suppl 2:102–4.
11. Daniels AM, Rosenberg RE, Anderson C, Law JK, Marvin AR, Law PA. Verification of parent-report of child autism spectrum disorder diagnosis to a web-based autism registry. J Autism Dev Disord 2012;42:257–65.
12. Randell RL, Long MD, Cook SF, Wrennall CED, Chen W, Martin CF, et al. Validation of an internet-based cohort of inflammatory bowel disease (CCFA partners). Inflamm Bowel Dis 2014;20:541–4.
13. Beukelman T, Kimura Y, Ilowite NT, Mieszkalski K, Natter MD, Burrell G, et al. The new Childhood Arthritis and Rheumatology Research Alliance (CARRA) registry: design, rationale, and characteristics of patients enrolled in the first 12 months. Pediatr Rheumatol Online J 2017;15:30.
14. Weitzman ER, Marin A, Cox R, Wisk LE. Associations among patient-reported outcomes measures of physical and psychological functioning and willingness to share social media data for research among adolescents with a chronic rheumatic disease. Presented at the 27th Annual Meeting of the International Society for Quality Life Research; 2020 October 23; Virtual.
15. Petty RE, Southwood TR, Manners P, Baum J, Glass DN, Goldenberg J, et al. International League of Associations for Rheumatology classification of juvenile idiopathic arthritis: second revision, Edmonton, 2001. J Rheumatol 2004;31:390–2.
16. Wisk LE, Nelson EB, Magane KM, Weitzman ER. Clinical trial recruitment and retention of college students with type 1 diabetes via social media: an implementation case study. J Diabetes Sci Technol 2019;13:445–56.
17. Brøgger-Mikkelsen M, Ali Z, Zibert JR, Andersen AD, Thomsen SF. Online patient recruitment in clinical trials: systematic review and meta-analysis. J Med Internet Res 2020;22:e22179.
18. Schumacher KR, Stringer KA, Donohue JE, Yu S, Shaver A, Caruthers RL, et al. Social media methods for studying rare diseases. Pediatrics 2014;133:e1345–53.

19. DiBenedetti DB, Coles TM, Sharma T, Pericleous L, Kulkarni R. Assessing patients' and caregivers' perspectives on stability of factor VIII products for haemophilia A: a web-based study in the United States and Canada. Haemophilia 2014;20: e296–303.
20. Hausmann JS, Kennedy K, Simard JF, Liew JW, Sparks JA, Moni TT, et al. Immediate effect of the COVID-19 pandemic on patient health, health-care use, and behaviours: results from an international survey of people with rheumatic diseases. Lancet Rheumatol 2021; 3:e707–14.
21. Thornton L, Batterham PJ, Fassnacht DB, Kay-Lambkin F, Calear AL, Hunt S. Recruiting for health, medical or psychosocial research using Facebook: systematic review. Internet Interv 2016;4:72–81.
22. Bowyer S, Roettcher P, Pediatric Rheumatology Database Research Group. Pediatric rheumatology clinic populations in the United States: results of a 3 year survey. J Rheumatol 1996;23: 1968–74.
23. Huemer C, Huemer M, Dorner T, Falger J, Schacherl H, Bernecker M, et al. Incidence of pediatric rheumatic diseases in a regional population in Austria. J Rheumatol 2001;28:2116–9.
24. Malleson PN, Fung MY, Rosenberg AM. The incidence of pediatric rheumatic diseases: results from the Canadian Pediatric Rheumatology Association Disease Registry. J Rheumatol 1996;23: 1981–7.
25. Symmons DP, Jones M, Osborne J, Sills J, Southwood TR, Woo P. Pediatric rheumatology in the United Kingdom: data from the British Pediatric Rheumatology Group National Diagnostic Register. J Rheumatol 1996;23:1975–80.
26. Hausmann JS, Berna R, Gujral N, Ayubi S, Hawkins J, Brownstein JS, et al. Using smartphone crowdsourcing to redefine normal and febrile temperatures in adults: results from the Feverprints Study. J Gen Intern Med 2018;33:2046–7.
27. Davies W. Insights into rare diseases from social media surveys. Orphanet J Rare Dis 2016;11:151.

APPENDIX A: MEMEBERS OF THE CARRA LEGACY REGISTRY INVESTIGATORS

We thank the following CARRA registry site principal investigators and research coordinators: L. Abramson, E. Anderson, M. Andrew, N. Battle, M. Becker, H. Benham, T. Beukelman, J. Birmingham, P. Blier, A. Brown, H. Brunner, A. Cabrera, D. Canter, D. Carlton, B. Caruso, L. Ceracchio, E. Chalom, J. Chang, P. Charpentier, K. Clark, J. Dean, F. Dedeoglu, B. Feldman, P. Ferguson, M. Fox, K. Francis, M. Gervasini, D. Goldsmith, G. Gorton, B. Gottlieb, T. Graham, T. Griffin, H. Grosbein, S. Guppy, H. Haftel, D. Helfrich, G. Higgins, A. Hillard, J. R. Hollister, J. Hsu, A. Hudgins, C. Hung, A. Huttenlocher, N. Ilowite, A. Imlay, L. Imundo, C. J. Inman, J. Jaquith, R. Jerath, L. Jung, P. Kahn, A. Kapedani, D. Kingsbury, K. Klein, M. Klein-Gitelman, A. Kunkel, S. Lapidus, S. Layburn, T. Lehman, C. Lindsley, M. Macgregor-Hannah, M. Malloy, C. Mawhorter, D. McCurdy, K. Mims, N. Moorthy, D. Morus, E. Muscal, M. Natter, J. Olson, K. O'Neil, K. Onel, M. Orlando, J. Palmquist, M. Phillips, L. Ponder, S. Prahalad, M. Punaro, D. Puplava, S. Quinn, A. Quintero, C. Rabinovich, A. Reed, C. Reed, S. Ringold, M. Riordan, S. Roberson, A. Robinson, J. Rosette, D. Rothman, D. Russo, N. Ruth, K. Schikler, A. Sestak, B. Shaham, Y. Sherman, M. Simmons, N. Singer, S. Spalding, H. Stapp, R. Syed, E. Thomas, K. Torok, D. Trejo, J. Tress, W. Upton, R. Vehe, E. von Scheven, L. Walters, J. Weiss, P. Weiss, N. Welnick, A. White, J. Woo, J. Wootton, A. Yalcindag, C. Zapp, L. Zemel, and A. Zhu. We would also like to thank all participants and hospital sites that recruited patients for the CARRA registry.

The CARRA registry was supported by a grant from the National Institute of Arthritis and Musculoskeletal and Skin Diseases of the National Institute of Health under award RC2-AR-058934. The contents of this article are solely the responsibility of the authors and do not necessarily represent the official views of the National Institutes of Health. The CARRA registry was also supported by CARRA, Friends of CARRA, the Arthritis Foundation, and the Duke Clinical Research Institute.