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### Recommended Citation

Coler-Reilly, Ariella; Graef, Elizabeth R.; Kim, Alfred H J; Liew, Jean W.; Putman, Michael S.; Sattui, Sebastian E.; Young, Kristen J.; and Sparks, Jeffrey A., "Social media for research discourse, dissemination, and collaboration in rheumatology." *Rheumatology and Immunology Research*. 3, 4. 169 - 179. (2022).

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# Social media for research discourse, dissemination, and collaboration in rheumatology

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Received October 24, 2022 accepted November 24, 2022

## Abstract

Social media has become an important venue for rheumatologists, patients, organizations, and other stakeholders to discuss recent research advances in diagnosis and management of rheumatic disorders. In this article, we describe the current state of how social media may enhance dissemination, discourse, and collaboration in rheumatology research. Social media may refer to social platforms like Twitter and Instagram or digital media like podcasts and other websites that are operated for providing as free, open-access medical education (FOAM). Twitter has been one of the most active social media venues and continues to host a vibrant rheumatology community. Examples of research discussions on Twitter include organic user tweets, educational threads (“tweetorials”), live-tweeting academic conferences, and journals posting recently-accepted articles. Some research collaborations have been initiated through social media interactions. Social media may also directly contribute to research by facilitating the recruitment of study participants and the collection of survey-based data. Thus, social media is an evolving and important tool to enhance research discourse, dissemination, and collaboration in rheumatology.

## Keywords

free open-access medical education • research • rheumatology • social media • Twitter

## Introduction

Social media has become integrated in all parts of life related to family, friends, work, school, news, and leisure. Like other medical specialties,<sup>[1,2]</sup> rheumatology has also found a place as a subject for discussion and knowledge-sharing on social media, and is used to connect people sharing rheumatology as a common sphere of interest, for disseminating or exchanging information about this topic.<sup>[3]</sup> Users may include people with rheumatic diseases, rheumatology providers, rheumatology clinical practices, academic journals, and rheumatology organizations. In this article, we will focus on the current landscape related to social media and rheumatology research. Social media can enhance the entire life cycle of research, including forming collaborations, collecting data, disseminating findings, and discussing impact and rigor. Twitter is currently the most active social media outlet for rheumatology.

However, we will also describe other social media platforms, including podcasts, blogs, Facebook, Instagram, TikTok, and other contributions to free, open-access, medical education (FOAM) related to rheumatology research.

## Organic Tweets about Rheumatology Research

Organic tweets about rheumatology can lead to wide-reaching user engagement and provide an informal metric on enthusiasm for research findings or even identify urgent research needs. For example, a user may tweet about a recent article they found interesting or relevant to their practice. This tweet ends up on others' feeds, particularly as others interact with and comment on it. This interaction can also be rooted in clinical scenarios. One should be very mindful that tweets live in the public domain, and so no identifying patient information, including dates or laboratory values, should be posted. Rheumatologists may also post about topics they are interested in, such as social determinants of health in rheumatic diseases or the importance of vaccination. Thus, organic tweets provide an ever-changing landscape of interest and discourse that helps to promote and disseminate research in

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rheumatology and identify research gaps in diagnosis, management, and treatment.

## Tweetorials about Rheumatology Publications

While individual tweets are, by definition,  $\leq 280$  characters long (perhaps with images/videos), a user can post a string of individual tweets, referred to as a thread. Alternatively, some refer to this as a “tweetorial” when the content is educational, as used before in medical education.<sup>[4,5]</sup> Tweetorials are now a common way to disseminate findings about research papers, typically from authors of papers.

While each user has their own style for tweetorials, the series of tweets often mirrors the structure of a research paper (Figure 1). Some tweetorials may be relatively brief (even as short as 2 tweets) or relatively lengthy. The first tweet often announces the paper’s recent acceptance into a journal with a link to the abstract or full paper at the journal’s website. Linking to the paper’s page on the journal website may enhance the Altmetrics for the publications, since most journals now track tweets as well as traffic to the abstract and full text on the website. Thus, tweets and tweetorials provide an important and timely method for journals to direct users directly to their website. The next series of tweets may be related to the background and research gap that the paper is attempting to fill. Some tweetorials may briefly summarize the methods used, particularly to highlight timely or novel strengths of the paper related to sample size, measurement, or statistical analysis. The next section of the tweetorial summarizes research findings. Finally, clinical implications, limitations, and future directions may be included in the tweetorial. Co-authors, institutions, and other researchers involved in or interested in the topic may be tagged in the tweetorial to alert them and garner more interest. User engagement is often enhanced by including the key figures from the paper and tagging other users interested in the research topic. An example of a tweetorial summarizing a recent research publication in rheumatology is mentioned in Figure 1 (or at [https://twitter.com/zach\\_wallace\\_md/status/1569832766535073793](https://twitter.com/zach_wallace_md/status/1569832766535073793)). An example of a longer tweetorial is available here: <https://twitter.com/jeffsparks/status/1570175303200411651>

## Live-Tweeting Rheumatology Conferences

Live-tweeting is roughly defined as tweeting about presentations in real time, occurring in-person or virtually. Live-tweeting has occurred sporadically for some time. However, the pandemic enhanced the number and reach of live-tweets. Prior to the pandemic, taking pictures of abstracts was generally discouraged, much less tweeting them to a wide audience. This sentiment has undergone a dramatic turn as conference organizers and researchers realized the benefits of research dissemination over social media. The risks of disseminating research findings prior to peer review have also

**Zach Wallace** @zach\_wallace\_md · Sep 13

Thrilled to share our latest @MGHrheumatology / @BrighamWomens collaboration examining the association of #RA phenotypes with #COVID19 outcomes in collaboration with @MayoClinic rheumatology. @TheLancetRheum

sciencedirect.com  
Risk of severe COVID-19 outcomes associated with rheuma...  
Rheumatoid arthritis has been associated with severe COVID-19, but few studies have investigated how ...

**Zach Wallace** @zach\_wallace\_md · Sep 13  
Replying to @zach\_wallace\_md

We found that #RA patients vs comparators have a higher risk of severe #COVID19 outcomes. In particular, those with RA-ILD had poor outcomes, likely mediated by lung dz and frequent treatment with B cell depletion. But seropositive & those w/ erosions also had high risk.

Group	Hazard ratio (95% CI)
Comparator group	1.75 (1.45-2.10)
All patients with rheumatoid arthritis	1.97 (1.58-2.46)
Comparator group	1.46 (1.02-2.09)
Patients with seropositive rheumatoid arthritis	1.93 (1.41-2.63)
Patients with seronegative rheumatoid arthritis	1.63 (1.30-2.06)
Comparator group	2.5 (1.66-3.77)
Patients with erosive rheumatoid arthritis	1.61 (1.31-1.99)
Patients with non-erosive rheumatoid arthritis	
Patients with rheumatoid arthritis and interstitial lung disease	
tients with rheumatoid arthritis without interstitial lung disease	

**Zach Wallace** @zach\_wallace\_md · Sep 13

Our RA-ILD patients need particular attention during the ongoing #COVID19 pandemic, especially for pre-exposure prophylaxis, early treatment, and appropriately timed vaccination.

**Zach Wallace** @zach\_wallace\_md · Sep 13

A few caveats. Our study was done largely before vaccination and before Omicron surge during which we have seen some improvements in outcomes.

**Diseases**  
The EULAR Journal

ard.bmj.com  
Temporal trends in COVID-19 outcomes among patients with systemic...  
Objectives To investigate temporal trends in incidence and severity of COVID-19 among patients with systemic autoimmune rheumatic ...

**Zach Wallace** @zach\_wallace\_md · Sep 13

This would not have been possible without amazing collaborations among @jeffsparks @BrighamWomens @AilDuarteMD @MayoClinic and our team at @MGH\_ClinEpi @NaomiRheumMD @MassGeneralNews.

Figure 1: Example of tweetorial to disseminate research findings of a recently-published rheumatology paper. COVID-19/COVID19, coronavirus disease 2019; RA, rheumatoid arthritis; ILD, interstitial lung disease.

been tempered with the wide acceptance of preprint journals as well as conference abstracts that are routinely published online. Similarly, images of posters at conferences are routinely tweeted and available for screenshotting on virtual platforms. However, many conferences do provide presenters the option to state publicly whether screenshots of images

are allowed. With annual conferences going completely virtual in 2020, the American College of Rheumatology (ACR) introduced a volunteer Twitter Ambassador program that further encouraged live-tweeting.

The promotion of conference hashtags and live-tweeting is not new within rheumatology<sup>[6]</sup> or in medical and scientific conferences as a whole.<sup>[7]</sup> Even prior to the pandemic, the Twitter engagement increased each year and multiple fields in medicine have analyzed these data.<sup>[7]</sup> With more people introduced to the concept of live-tweeting rheumatology conferences each year, benefits and best practices should be considered (Figure 2).

### Benefits of Live-Tweeting Rheumatology Conferences

- Active engagement. In trying to distill down information to fit in a post, you are actively engaging with and digesting the content, while encouraging discussion.
- Promoting your own work and that of colleagues. Through social media, you may reach a wider audience than if you were presenting a poster at the in-person meeting.
- Extending the conversation outside of the in-person conference.<sup>[8,9]</sup> Allowing people who are not able to attend the conference in-person to join in scientific discussions extends the meeting's accessibility.

### Best Practices for Live-Tweeting Rheumatology Conferences

- Use the official conference hashtag.
- Confirm permission to post photos. There are concerns that preliminary and unpublished data should not be widely shared online. When taking photos of speakers at their posters, it is preferred to ask the presenter if online posting is allowed.

- Give proper attribution. Ensure there is a clear way to give attribution, at least by name, to the person who originally presented the work. Similar to other written work, avoid plagiarizing others' tweets that may have been particularly impactful.
- Keep threads short and intersperse the text with images.
- Differentiate your content, opinions, and interpretations from those of the speakers.<sup>[8]</sup>
- Tweeting in real time may lead to miscommunication.<sup>[7]</sup> It can be difficult to synthesize and distill down a talk in real time and write posts about it simultaneously – so consider limiting the number of posts or composing them later.

### Social Media and Rheumatology Journals

Since the implementation and increasing availability of electronic journals, reading and uptake of the scientific literature have changed. The use of social media platforms, especially Twitter, has become an important tool both for medical learning and information dissemination, and rheumatology is no exception.<sup>[10]</sup>

Citation indices have been historically used to assess the impact of both scientific articles as well as academic journals. However, these metrics have been often criticized, and with the advent of social media, new alternative metrics (e.g., Altmetric score) that capture web-driven scholarly interactions have emerged.<sup>[11]</sup> These interactions include a variety of sources such as policy documents, news, blogs, and social media activity on platforms like Twitter, Facebook, and YouTube. Although there has been some debate about the discrepancy between social media presence and academic significance, recent studies have shown that Twitter promotion of manuscripts can have a positive impact on dissemination.<sup>[12]</sup> In a recent randomized study of cardiovascular articles, Twitter promotion was associated with both an increased Altmetric score as well as an increased number of citations.<sup>[13]</sup>



Figure 2: Anatomy of a medical conference tweet.

Use of social media for the identification of new literature is also appealing to readers. A survey highlighted the frequent use of social media platforms to follow journals as well as the high acceptance of article promotion through visual abstracts.<sup>[14]</sup> Given the opportunities provided by social media, rheumatology journals have increased their social media presence through the creation of Twitter accounts (Table 1).<sup>[15]</sup> However, the use of Twitter for the promotion of recently-accepted and published articles still seems to be very variable, even if a Twitter account is active. Journals that actively promote articles through tweets may collect Twitter handle information at the time of acceptance to tag authors and institutions, and some even ask for a “tweet draft” to be associated with the publication link. Many rheumatology journals will tweet about articles soon after their acceptance. For researchers interested in the latest rheumatology findings, following journals on Twitter can be an optimal strategy to remain apprised of the most current literature.

Finally, journals have also incorporated the position of social media editors (also called digital editors or social media advisors) within their editorial boards (Table 1). The role of social media editors is focused on the creation and dissemination of content in various forms compatible with effective online sharing, including graphical/visual abstracts, video interviews, and podcasts, to help build the journal’s brand.<sup>[16]</sup> The incorporation of social media editors/boards in rheumatology journals seems to have increased in the past few years, demonstrating the recognition of social media as an important tool in academic publishing.<sup>[17]</sup> Among 26 rheumatology journal families, 21 (81%) have active Twitter accounts. Nearly all high-impact rheumatology journals regularly tweet about recently accepted or published articles. Many also tweet tables of contents for issues. However, only 5 (19%) have a designated social media editor. Some journals also post about articles on other social media platforms such as Facebook and Instagram. Many journals and other rheumatology organizations now

Table 1: Rheumatology journals and their Twitter activity as of November 2022

Journal	Twitter account	Use of Twitter for promotion of new publications	SoMe position in editorial board
<i>The Lancet Rheumatology</i>	@TheLancetRheum	Yes	No
<i>Nature Reviews in Rheumatology</i>	@NatRevRheumatol	No	No
<i>Annals of the Rheumatic Disease/RMD Open**</i>	@ARD_BMJ	Yes	Yes (advisory board)*
<i>Arthritis &amp; Rheumatology/Arthritis Care &amp; Research/ACR Open Rheumatology**</i>	@ACR_Journals	Yes	Yes
<i>Arthritis Research &amp; Therapy</i>	@ArthritisRes	No	No
<i>Rheumatology/Rheumatology Advances in Practice**</i>	@RheumJnl	Yes	Yes (advisory board)*
<i>The Journal of Rheumatology</i>	@jrheum	Yes	No
<i>Current Opinion in Rheumatology</i>	@CO_Rheumatology	No	No
<i>Clinical and Experimental Rheumatology</i>	@Clinexprheum	No	No
<i>Clinical Rheumatology</i>	@ClinRheumatol	Yes	Yes
<i>Journal of Clinical Rheumatology</i>	@JRheumatology	Yes	No
<i>European Journal of Rheumatology</i>	@EurJRheumatol	No	No
<i>Indian Journal of Rheumatology</i>	@IJRheum	No	No
<i>Reumatismo</i>	@reumatismoJnl	No	No
<i>Reumatologia (Rheumatology)</i>	@ReumatologiaW		
<i>Global Rheumatology</i>	@GlobalRheum	No	No
<i>Rheumatology and Therapy</i>	@RheumatolTher	Yes	No
<i>Advances in Rheumatology</i>	No	NA	NA
<i>Best Practice &amp; Research in Clinical Rheumatology</i>	No	NA	Yes
<i>BMC Musculoskeletal disorders</i>	@BMCSeries	No	No
<i>Joint Bone Spine</i>	No	NA	NA
<i>Lupus</i>	@SAGEHealthInfo	Yes	No
<i>Lupus Science and Medicine</i>	@Lupus_SM	Yes	Yes
<i>Osteoarthritis and Cartilage</i>	@OACJournal	Yes	No
<i>Rheumatic Disease Clinical of North America</i>	No	NA	NA
<i>Rheumatology and Immunology Research</i>	No	NA	NA

\*Advisory boards composed by multiple individuals.

\*\*Affiliated journals.

SoMe, social media; NA, not applicable.

embed direct links to their respective social media accounts on the organization's website. Frequently used platforms across a range of rheumatology organizations, journals, and patient groups include Facebook, Twitter, YouTube, Instagram, and YouTube (Table 2). These trends show that rheumatology journals have embraced social media as an important outlet to disseminate research findings and broaden the scope of their reach.

### Graphical and Visual Abstracts in Rheumatology Research and Care

A graphical or visual abstract is descriptive figure representing the key point(s) of a research article in an accessible style. Similar to the ubiquitous text-based abstract, these figures provide a means of summarizing long articles at a glance. In contrast with the text-based abstracts, these images are well suited for visual learners and for social media propagation. Imagery such as distinct shapes and colors may also serve as a visual cue to quickly distinguish between the many scientific papers with similar wording in the titles, rendering the article more memorable and recognizable.

While often used interchangeably, the terms “graphical abstract” and “visual abstract” represent distinct formats (Figure 3). The term “graphical abstract” signifies a figure with a single panel depicting the core take-home message of an article, such as the mechanism of a novel drug or pathogen, a newly proposed molecular or physiological pathway, or the key result of a new intervention. Research methods and limitations are generally not described. It is steadily becoming more common for journal editors to solicit graphical abstracts as part of the submission process and to publish these figures in the journal alongside the article, juxtaposing

the traditional, text-based abstract.

The term “visual abstract,” on the other hand, signifies the translation of the traditional text-based abstract into a visual format by arranging its components into a multi-panel figure or chart. Just as a traditional abstract may sometimes be broken down into sub-headings for background, methods, results, and conclusions, a visual abstract is sometimes comprised of panels with similar sub-headings. Some high-profile journals, such as those in the *JAMA* network, have an editorial graphics team that now creates professional visual abstracts in a strictly uniform, branded format for press releases and social media.

Graphical and visual abstracts are widely acknowledged to widen the reach and increase the impact of journal articles. For example, when we compare the results of tweeting a link to the article with versus without a visual abstract, larger numbers of impressions, retweets, and article visits are demonstrated in the case of the former.<sup>[18]</sup> While it is common knowledge that tweets with images receive more engagement in general, another study showed that simply including any relevant image such as a key figure from the article was inferior to tweeting a visual abstract.<sup>[19]</sup> Rheumatologists indicate support for social media promotion in general as well as visual abstracts in particular.<sup>[20]</sup> However, visual and graphical abstracts are currently uncommonly used in rheumatology. *Seminars in Arthritis and Rheumatism* is one of the few rheumatology journals that regularly encourages authors to make graphical abstracts, though most accepted articles do not construct them. Some Twitter users create their own graphical or visual abstracts exclusively for social media to amplify their article's reach, particularly among lay audiences.

Table 2: Use of embedded social media links on rheumatology organizations' homepages

Organization name	Facebook	Twitter	YouTube	Instagram	LinkedIn
ACR	x	x	x	x	x
EULAR	x	x	x	x	
PANLAR	x	x	x	x	x
APLAR	x	x			
AFLAR	x	x		x	
CreakyJoints.org	x	x	x	x	
National Psoriasis Foundation	x	x		x	x
Lupus Foundation of America	x	x	x	x	
Scleroderma Foundation	x	x			
Arthritis Foundation	x	x			x
<i>Annals of the Rheumatic Diseases</i>	x	x	x		
<i>Arthritis &amp; Rheumatology</i>	x	x			x

Access date: November 11, 2022. ACR, American College of Rheumatology; EULAR, European Alliance of Associations for Rheumatology; PANLAR, Pan American League of Associations of Rheumatology; APLAR, Asia Pacific League of Associations for Rheumatology; AFLAR, African League Against Rheumatism.

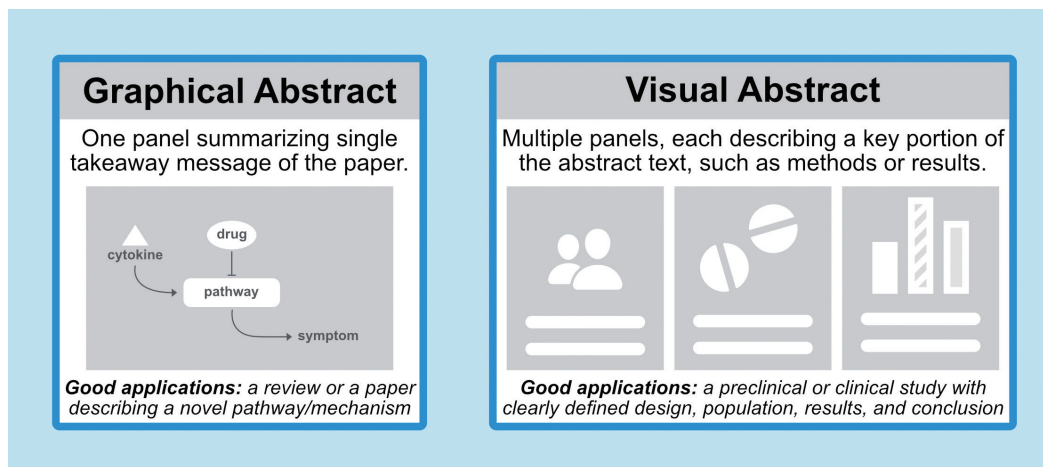


Figure 3: Graphical and visual abstracts for biomedical and clinical publications.

Rheum OnePagers (created by Dr. Mithu Maheswaranathan) is on Twitter and is an independent site that employs visual abstracts to effectively summarize research studies, guidelines, clinical content, and classification criteria. The site also tweets about differential diagnoses, interpretation of laboratory results, and management considerations for rheumatic diseases.

Whether a formal program or an informal post, those creating these graphics should balance the desire for consumer-friendly simplicity and impact with the risk of generating misinformation due to lack of nuance.<sup>[18]</sup> It is important to avoid biased oversimplifications that might arise from the perceived need for making the content accessible to a wider, non-medical audience, and endeavor to make it enticing for readers to read the full article, so that readers do not form a strong conclusion or judgment merely based on the pictorial information presented.

### Twitter Journal Clubs in Rheumatology

Social media merged with the long-held medical tradition of journal club with the advent of Twitter-based journal clubs. Twitter-based journal clubs allow broad dissemination and discussion of scientific literature while including authors, collaborators, trainees, and patients.<sup>[21]</sup> Many medical specialties now have active Twitter journal clubs.<sup>[22–26]</sup> Although most Twitter journal clubs are synchronous in real time, there are some that are asynchronous and occur over hours or days or have several sessions to accommodate different time zones. Twitter journal clubs are common among many specialties, and having an article discussed in a twitter journal club can boost Altmetrics and amplify research to a broad audience with post-publication peer review.

Rheumatology Twitter journal club (#RheumJC) was founded in 2015.<sup>[27]</sup> Other periodic rheumatology Journal

Clubs on Twitter have included EMEUNET ([https://emeunet.eular.org/emeunet\\_journal\\_club.cfm](https://emeunet.eular.org/emeunet_journal_club.cfm)) as well as one dedicated to polymyalgia rheumatica and giant cell arteritis (#PMRGCAJC). Authors of papers are often invited to discuss the paper with other users. Some challenges for Twitter journal club include: choosing an impactful article worthy of lengthy discussion, amassing a sizable and engaged audience, broaching criticism and limitations while the author is present, and variable sophistication of the audience to research methods expertise.

### FOAM in Rheumatology

Trainees across medicine have become increasingly reliant on FOAM resources.<sup>[28]</sup> In contrast with textbooks or academic publications, which have both financial and logistical barriers to access, FOAM resources are widely and immediately available for access through the internet. They may include print resources such as newsletters or blogs, audio resources such as podcasts, or visual media such as videos or infographics.

The FOAM movement has matured in various phases, which may be aptly illustrated by the evolution of such resources in rheumatology. In the early 2010s, a “Founders Wave” occurred in fields outside of rheumatology, including emergency medicine and critical care. These early adopters saw the potential of social media platforms and novel delivery mechanisms, such as blogs or podcasts, for disseminating information. Rheumatologists joined the movement in the Second Wave, “Adoption by Enthusiasts.” The first notable example was *The Rheumatology Podcast*, which is no longer published but inspired<sup>[29]</sup> many subsequent projects. This period also saw the creation of *RheumNow*, *Healio Rheuminations*, and *The Evidence Based Rheumatology Podcast*. These projects generally maintained the ethos and formats of the Second Wave. The past few years have



seen a rapid transition into the Third Wave, or “Structure and Formalization”. Within a short time period, professional societies and academic publishing journals launched branded podcasts within their sphere, which aimed to disseminate their content. These podcast projects lent further legitimacy to the podcasting ecosystem and often, though not always, maintained the original freewheeling and conversational styles.

More recently, the movement has spilled over and democratized into what has been dubbed the Fourth Wave, or “Engagement and Activity by End Users.” This period has been characterized by omnidirectional engagement, whereby content creators publish podcasts and blogs that receive immediate feedback on social media platforms, such as Twitter. By engaging directly with their end users, content creators can both receive and respond directly to feedback. This feedback may not always be thoughtful or kind, which may discourage ongoing content creation. It also has many positive aspects, which include: (1) opportunities to clarify information when needed, (2) greater engagement from users who feel more connected to the media they consume, and (3) the formation of a broader social media community within rheumatology.

RheumMadness is another example of FOAM that was widely disseminated on Twitter and other venues, starting in 2020, and founded by Dr. David Leverenz. RheumMadness is modeled after NephMadness, a popular annual nephrology FOAM event.<sup>[30,31]</sup> Both RheumMadness and NephMadness follow the structure of the annual US college basketball national tournament called March Madness. Instead of competing basketball teams, RheumMadness matches high-impact research studies/topics against each other to determine the most impactful research study/topic of that year. Each match-up has a “scouting report” that summarizes the major findings and research methods. A “blue ribbon panel” of experts picks between each pair, in succession until the winner is chosen. There are multiple rounds, each lasting a few days, during which users on Twitter and other venues discuss each match-up. Prior to the blue ribbon panel picks, users can submit their picks (or “brackets”) to win a prize.

While not entirely focused on FOAM, rheumatology researchers and clinicians also interact regularly at some websites. These include ResearchGate (<https://www.researchgate.net/>), which catalogs and provides metrics on research publications; MedNet (<https://www.themednet.org/>), a crowdsourced question-and-answer platform of clinical scenarios; Web of Science (<https://access.clarivate.com/login?app=wos>), which provides wide-ranging data on publication and peer review metrics; Figure 1 (<https://www.figure1.com/>), which provides medical education from images of cases; and Doximity (<https://www.doximity.com/>), a social network that is aimed at all physicians and also provides secure audio/video and fax services for clinical care.

## Social Media and Patient Education in Rheumatology

Patients are active participants in social media and access various social media platforms to learn more about their disease, find physicians to care for them, and connect with people with similar diseases. The global reach of social media brought rheumatology patients together and made access to information about their disease (often rare in their immediate social community) easier and more convenient. For example, Cheryl Crow (@realcc) is an occupational therapist with rheumatoid arthritis who shares content about her experience with this disease, along with other educational content related to rheumatology, on Twitter and TikTok. Another example is #LupusChat (@Lupus\_Chat), a regular Twitter event where people living with systemic lupus erythematosus discuss current issues related to that disease. Facebook has been a particularly popular platform among patient groups to host similar online communities. Clinicians can harness the power of social media to create platforms for patient education and connecting with patient groups. Organizations can also provide educational videos covering clinical and/or research topics on YouTube for independent patient use. On the Johns Hopkins Rheumatology channel, content ranges from disease overviews, research updates, and medication injection demonstrations.

Plain language summaries (PLS) are another way for researchers to connect with patients. The *Annals of the Rheumatic Diseases* selects particularly impactful publications to generate PLS, and other organizations collaborate to create PLS independently of the journals, most notably the coronavirus disease 2019 (COVID-19) Global Rheumatology Alliance (GRA). PLS serve the purpose of educating patients, but also are an important avenue to communicate research to other stakeholders.

## Social Media as the Catalyst for Collaborative Research in Rheumatology

While social media has been a vehicle for the spread of both information and misinformation (e.g., hydroxychloroquine<sup>[32,33]</sup>), researchers have leveraged the simplicity and accessibility of it to rapidly create impactful infrastructures and studies during an especially challenging time. Perhaps the most impactful way social media has positively influenced the rheumatology community during the pandemic was the initial organization of the COVID-19 GRA.<sup>[34]</sup>

The GRA is an international organization that runs a global registry collecting, analyzing, and disseminating data regarding the impact of COVID-19 on patients with rheumatic diseases. The genesis of the GRA came from a tweet by Dr. Leonard Calabrese, who quoted a tweet on March 11, 2020 from Dr. David Rubin (@IBDMD) that described the

initiation of the Surveillance Epidemiology of Coronavirus Under Research Exclusion-Inflammatory Bowel Disease (SECURE-IBD; <https://covidibd.org/>) registry to collect COVID-19 outcomes data in those with IBD: “Totally smart thing to do – Are we doing this in RHEUM? I am unaware” – @LCalabreseDO, March 11, 2020 (<https://twitter.com/lcalabresedo/status/1237888297398972416>).

Within hours, dozens of rheumatologists and epidemiologists on Twitter digitally crowdsourced real-time solutions addressing the feasibility, required infrastructure, and the necessary variables needed to rigorously collect and report these data. Remarkably, within 24 hours, the GRA became active with support from the ACR<sup>[35]</sup> and a workspace on Slack for internal discussions (Figure 4). Over 250 members joined within the first week, and within 2 weeks, the registry went live (March 24, 2020 at [www.rheum-covid.org](http://www.rheum-covid.org)). Furthermore, the final survey of the GRA registry was shared

with the European Alliance of Associations for Rheumatology (EULAR), and this became active on March 27, 2020. Over 30,500 cases have been submitted to the GRA registry, resulting in over 30 original research publications, most of which have PLS for patients.

Social media has also served to disseminate surveys from dozens of studies, most of which have led to important observations. For example, the GRA heavily utilized social media to increase awareness of the GRA COVID-19 Patient Experience and Vaccine Surveys. The first patient-facing GRA survey investigated patient behavior early in the pandemic.<sup>[36]</sup> The second patient-facing GRA survey investigated clinical experience and uptake/attitudes related to the novel COVID-19 vaccines. These data identified that patients with rheumatic diseases had prolonged COVID-19 symptom duration<sup>[37]</sup> and low rate of disease flare post-vaccination,<sup>[38]</sup> and identified the need to reassure patients about vaccine efficacy and safety as critical variables in vaccine uptake.<sup>[39]</sup> The Vaccination Against COVID in Systemic Lupus (VACOLUP) exclusively used social media for participant recruitment.<sup>[40]</sup> The COVAD study is another survey related to vaccine experience for people with rheumatic diseases that successfully recruited over social media.<sup>[41]</sup> The ability of obtaining informed consent electronically without direct participant–investigator interactions was critical for the success of these studies during a period where those on immunosuppression may increase the risk of severe COVID-19 if person-to-person interactions were required. While there are some challenges related to sampling bias and unclear denominators, leveraging online platforms will likely reach a larger participant population than traditional paper/in-office surveys. It is inevitable that this will become the new norm as best practices are developed to rigorously execute primary research online. Finally, the COVID-19 Vaccine Responses in Patients with Autoimmune Disease (COVaRiPAD) is a multi-center prospective patient-oriented study that was partially forged through GRA collaborations. This study of people with immune-mediated inflammatory diseases before and after vaccine doses has investigated the impact of specific immunosuppressants on vaccine immunogenicity,<sup>[42]</sup> reactogenicity,<sup>[43]</sup> and booster effects.<sup>[44]</sup> Thus, social media can be the catalyst for research studies that lead to impactful findings and research funding.

### Other Social Media Venues And Rheumatology

Other social media platforms rely more on photos or videos to disseminate content. TikTok, which launched in 2017, consists of an algorithm-based feed of short videos often including music and colorful graphics. Videos can have searchable hashtags and be reposted by other users often with corresponding commentary. Currently, only a few rheumatologists and rheumatology organizations have a presence on TikTok.



Figure 4: Achievements of the COVID-19 GRA organized via Slack workspace. COVID-19, coronavirus disease 2019; GRA, Global Rheumatology Alliance.

This is likely due to lack of familiarity with the platform as well as the additional effort required for content generation on a video-based platform compared to text/image platforms such as Twitter. TikTok represents an opportunity for research dissemination, particularly as younger demographics continue to embrace the site. LinkedIn is another social media site where many rheumatology researchers have profiles and post career-related updates including publications. However, substantive discourse about research findings is relatively uncommon. Instagram is another popular social media site in which many rheumatology researchers and journals post images and content. However, discourse is again relatively uncommon and most rheumatology journals do not post content regularly. Mastodon has recently emerged as another social media site similar in structure and concept to Twitter. Mastodon is composed of many decentralized servers with more rigorous moderation than Twitter, but also allows cross-posting content to Twitter. However, uptake for Mastodon is currently small and users on different servers may experience difficulty in accessing content.

## Conclusion

Social media has become an active venue to discuss, disseminate, form collaborations, and even collect data for

research studies in rheumatology. Twitter is currently one of the most active venues for social media in rheumatology research, but others include podcasts, blogs, Facebook, and TikTok. While not everyone will embrace social media, researchers, patients, organizations, and stakeholders need to be aware of the wide landscape and opportunities that social media may offer. For example, social media is an excellent resource which enables the participation of not only rheumatologists and those casually seeking health care suggestions concerning this topic but also the interested segment of the wider general public (such as those interested in participating in surveys); participation may assume the form of, e.g., staying updated on the latest research findings in rheumatology by following rheumatology journals and digital opinion leaders. This can supplement traditional methods that rely on print journals, periodic visits to journal websites, research conferences, or tables of contents by email. Beyond staying on top of current research findings and research gaps, social media is also relevant for finding collaborators interested in similar research topics. Finally, research studies may actually recruit patients and collect data through electronic surveys via social media. Thus, social media is a powerful tool for innovation in rheumatology research that will likely continue to grow and evolve in its sophistication.

## Acknowledgements

*The authors wish to thank the rheumatology social media community, in particular the COVID-19 Global Rheumatology Alliance and the #HCQbrigade.*

## Funding

*None declared.*

## Author Contributions

*Conceptualization: JAS; Original draft: AC-R, ERG, AHJK, JWL, MSP, SES, KJY, JAS; Reviewing and editing: AC-R, ERG, JAS; Figures: AC-R and JAS; Final approval: AC-R, ERG, AHJK, JWL, MSP, SES, KJY, JAS.*

## Informed Consent

*None declared.*

## Ethical Statement

*None declared.*

## Conflict of Interest

*Dr. Kim is supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (grant No. P30 AR073752), National Center for Advancing Translational Sciences (grant No. UL1 TR002345), Leona M. and Harry B. Helmsley Charitable Trust, Rheumatology Research Foundation, and National Multiple Sclerosis Society. Dr. Kim has received research support to Washington University from GlaxoSmithKline*

and Foghorn Therapeutics, and performed consultancy for Alexion Pharmaceuticals, ANI Pharmaceuticals, AstraZeneca, Aurinia Pharmaceuticals, Exagen Diagnostics, GlaxoSmithKline, Kypha, and Pfizer unrelated to this work. Dr. Kim is the inventor of patent No. 11029318 unrelated to this work. Michael Putman participates in clinical trials funded by Abbvie (SELECT-GCA) and AstraZeneca (MANDARA) and has received consulting payments from Novartis. Dr. Sattui is supported by the Rheumatology Research Foundation RISE Pilot Award and by the Bristol Myers Squibb Foundation Winn Career Development Award, outside of the submitted work. Dr. Sattui reports research support from AstraZeneca and consulting for Sanofi (not paid). Dr. Sparks is supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (grant Nos R01 AR077607, P30 AR070253, and P30 AR072577), the R. Bruce and Joan M. Mickey Research Scholar Fund, and the Llura Gund Award for Rheumatoid Arthritis Research and Care. Dr. Sparks has received research support from Bristol Myers Squibb and performed consultancy for AbbVie, Amgen, Boehringer Ingelheim, Bristol Myers Squibb, Gilead, Inova Diagnostics, Janssen, Optum, and Pfizer unrelated to this work. The funders had no role in the decision to publish or preparation of this manuscript. The content is solely the responsibility of the authors and does not necessarily represent the official views of Harvard University, its affiliated academic health care centers, or the National Institutes of Health.

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