The Impact of the COVID-19 Pandemic on People with Rheumatic and Musculoskeletal Diseases: Insights from Patient-Generated Data on Social Media

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The Impact of the COVID-19 Pandemic on People with Rheumatic and Musculoskeletal Diseases: Insights from Patient-Generated Data on Social Media

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Abstract
Objectives
During the COVID-19 pandemic, much communication occurred online, through social media. This study aimed to provide patient perspective data on how the COVID-19 pandemic impacted people with rheumatic and musculoskeletal diseases (RMDs), using Twitter-based patient-generated health data (PGHD).

Methods
A convenience sample of Twitter messages in English posted by people with RMDs was extracted between 1 March and 12 July 2020 and examined using thematic analysis. Included were Twitter messages that mentioned keywords and hashtags related to both COVID-19 (or SARS-CoV-2) and select RMDs. The RMDs monitored included inflammatory-driven (joint) conditions (ankylosing spondylitis, RA, PsA, lupus/SLE and gout).

Results
The analysis included 569 tweets by 375 Twitter users with RMDs across several countries. Eight themes emerged regarding the impact of the COVID-19 pandemic on people with RMDs: (i) lack of understanding of SARS-CoV-2/COVID-19; (ii) critical changes in health behaviour; (iii) challenges in healthcare practice and communication with healthcare professionals; (iv) difficulties with access to medical care; (v) negative impact on physical and mental health, coping strategies; (vi) issues around work participation; (vii) negative effects of the media; and (viii) awareness-raising.

Conclusion
The findings show that Twitter serves as a real-time data source to understand the impact of the COVID-19 pandemic on people with RMDs. The platform provided ‘early signals’ of potentially critical health behaviour changes. Future epidemics might benefit from the real-time use of Twitter-based PGHD to identify emerging health needs, facilitate communication and inform clinical practice decisions.

Keywords
COVID-19, coronavirus, patient-generated health data, rheumatic and musculoskeletal diseases, social media, Twitter

Introduction
The coronavirus disease 2019 (COVID-19) pandemic [1] and resulting safety measures have impacted people’s lives in multiple ways, including their health and medical care access. People had to adjust to social distancing and self-quarantine rules, lockdowns and movement restrictions, wearing masks, and a rapid transition to telework and telehealth approaches. Whether people with rheumatic and musculoskeletal diseases (RMDs) are at an increased risk for poorer health outcomes is currently debated [2].
With the restrictions on public life, much information seeking and conversation about the pandemic occurred online, including social media (SM). Public opinions expressed on SM offer valuable insight to better understand the dynamics and impact of the COVID-19 pandemic on the general and special patient populations. SM provides a new source of analysable data [3] and has led to new research fields, i.e. infodemiology and infoveillance [4, 5]. Self-reported data from patients are referred to as patient-generated health data (PGHD), i.e. ‘health-related data created, gathered, or inferred by or from patients and for which the patient controls data collection and data sharing’ [6]. This type of data is unaffected by “recalling bias” and unprimed by researchers [7]. While traditional survey data can take years to collect, social media data offer insight into health behaviour and public sentiment around health-related topics in a much shorter time frame.

This study provides a thematic analysis of perspectives about the impact of the COVID-19 pandemic on people with RMDs. We used PGHD from the social network Twitter and chose the platform for two reasons. (i) Health surveillance researchers have demonstrated the usefulness of Twitter data to understand public and patient perspectives on various diseases and health topics, such as COVID-19, influenza, schizophrenia, smoking, HIV/AIDS and patient safety [8–15]; in some cases, social media user data also demonstrated a correlation between the disease prevalence and frequency with which Twitter users discussed a disease [16]. (ii) Research has demonstrated the active use of Twitter among patient communities that share their disease experiences, e.g. cancer patients and survivors [17], people with psoriasis [18], patients with diabetes [19] and patients with autism [20].

However, the scientific examination of self-reported patient experiences and health outcomes from social media is under-represented in rheumatology and related fields [21, 22]. The insight gained has the potential to provide new knowledge regarding patient-centric approaches, for example, to pandemic management and the delivery of care.

Methods

Data collection

A thematic analysis was conducted, including public Twitter messages (tweets) in English posted between 1 February 2020 and 14 July 2020 that mentioned keywords and hashtags related to both Covid-19 (or SARS-CoV-2) and RMDs (Table 1). A hashtag is a word or phrase preceded by a hash sign (#) and used to identify Twitter messages on a specific topic (e.g. #arthritis).

<table>
<thead>
<tr>
<th>Topic</th>
<th>Hashtag examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>SARS-CoV-2 infection</td>
<td>#SARS-CoV-2, #SARS_CoV_2, #SARSCoV2</td>
</tr>
<tr>
<td>COVID-19 disease</td>
<td>#COVID-19, #COVID_19, #Covid19, #coronavirus</td>
</tr>
<tr>
<td>General, related to rheumatic diseases</td>
<td>#rheum</td>
</tr>
<tr>
<td>Ankylosing spondylitis</td>
<td>#AnkylosingSpondylitis, #Spondylitis, #spoonie (or #spoonies), #spoonieproblems, #spoonieChat, #spondyloarthritis, #SpA, #ASWarrior, #axialSpA</td>
</tr>
<tr>
<td>RA</td>
<td>#arthritis, #rheumatoidarthritis #rheumatoid</td>
</tr>
<tr>
<td>Lupus (SLE)</td>
<td>#lupus, #lupuswarrior, #SLE, #lupuschat</td>
</tr>
<tr>
<td>PsA</td>
<td>#psoriaticarthritis</td>
</tr>
</tbody>
</table>

A non-probability, convenience sampling method that relied on the manual search of Twitter posts was used. We used Twitter’s public search interface (twitter.com/search) once a week to randomly search for posts using keywords and hashtags (Table 1) relevant to the research question. Tweets were retrieved using a Boolean
keyword search (e.g. ‘#arthritis’ AND ‘#COVID-19’) between 1 March and 12 July 2020. The Twitter search retrieves up to 7 days of historical data or 1500 tweets. Research has shown that a simple random sampling is more efficient than a constructed week sampling in terms of obtaining a more efficient and representative sample of Twitter data [23].

We applied the nomothetic model of generalization [24] by identifying the population to which we wish to generalize the results, i.e. people with RMDs. The population is the totality of people that have common, defined characteristics, and about whom the study results are relevant. However, due to the use of PGHD from the social network Twitter, not every person with an RMD (i.e. those not active on Twitter) had a chance of being included in our sample (non-probability sampling). That said, each person on Twitter that posted content about COVID and RMDs had an equal chance of being included in the sample (probability sampling), thus allowing us to reduce selection bias within the Twitter sample. The data from the Twitter patient population were conveniently available to us. Therefore, we refer to our strategy as non-probability convenience sampling (applying the larger RMD patient community context), which is often used in qualitative research, pilot studies, or exploratory research with time and budget constraints. This sampling approach matched our study goal to conduct in-depth, contextual analysis of perspectives from people with RMDs about the impact of the COVID-19 pandemic where each patient perspective has equal weight. It allowed us to collect data in a timely and cost-effective manner.

The hashtags used in the search were determined using an iterative process based on an established conceptual framework for social data collection and quality assessment [25] and selected based on previous research [21] and the Symplur Signals disease hashtag project [26]. The RMDs monitored focussed on inflammatory-driven (joint) conditions, namely ankylosing spondylitis, RA, PsA, lupus/SLE and gout.

Data processing and cleaning
Included in this study were original messages by people with RMDs (regardless of their location). To confirm the reliability of the data included in the analysis, we used a hybrid approach of machine learning (ML) and qualitative research. First, we verified the Twitter accounts of human users (e.g. @JohnSmith), using the ML program Botometer (formerly BotOrNot) established by Indiana University [27]. The program identifies automated Twitter accounts, so-called bots [28] created by industry and interest groups that influence discussions and promote specific ideas or products [29, 30]. Messages from these accounts pollute social and health research data sets [31]. Botometer analyses multiple variables such as the account’s network (diffusion patterns), user (metadata), friends (account’s contacts), temporal (tweet rate) and sentiment (content of messages), and detects automated accounts with a 95% success rate [27]. Second, we manually reviewed each individual Twitter account (n = 375) to confirm that the account holder was a person living with an RMD. To do so, we reviewed the Twitter profile description (e.g. ‘Writer, mom and living bravely with ankylosing spondylitis’) and the content from the tweets in our dataset. In summary, due to this study’s focus on original perspectives from people with RMDs, we excluded the following types of tweets from the analysis dataset: (i) fake, commercial and bot-like accounts, (ii) retweets, (iii) non-English Twitter posts, and (iv) posts from Twitter users not clearly stating in their Twitter profile description or their tweet(s) that they have an RMD.

Data analysis
Two authors (K.R. and E.N.) independently reviewed the tweets from the confirmed Twitter accounts to classify the content based on a priori and emergent coding categories (Table 2, column 1). Qualitative review of tweet content is important to determine whether search terms identified relevant content. Some terms may generate a high number of false positives, thereby overestimating conversation volume. Taking these steps, we increased the accuracy and reliability of the data. The coding categories were developed, incorporating COVID-related
research [32, 33] and input from rheumatology experts. The authors (K.R. and E.N.) discussed their coding decisions and any discrepancies until they reached consensus.

**Table 2** Primary health themes, thematic analysis of tweets per theme and representative tweets

<table>
<thead>
<tr>
<th>Tweet themes</th>
<th>Thematic analysis</th>
<th>Representative tweets (paraphrased)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding of SARS-CoV-2 and COVID-19 disease</td>
<td>Early on in the pandemic (February and March 2020), RMD patients, including those with comorbidities (e.g. diabetes, asthma) and pregnancy, expressed a lack of clarity regarding the outbreak. Topics included uncertainty regarding finding reliable information, whether to see their physician, the risk in the context of their chronic condition and immunosuppression, their immunity status, differentiating between a SARS-CoV-2 and other infections, preventive measures (e.g. self-isolation, shielding), use of immunosuppression and treatment options.</td>
<td>Anyone on here take an anti-TNF drug? Immune system suppressants? I have ankylosing spondylitis so take a drug called Cimzia for it. Just want to know if it has any affect with Coronavirus. Can I still take my injection?</td>
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<tr>
<td>Health behaviour</td>
<td>Perhaps most importantly, the sampled patient group described changes to their health behaviour in response to the pandemic, e.g. rationing medications, reluctance in attending face-to-face healthcare and lab monitoring appointments.</td>
<td>Today I’ve decided to miss my medication and stay off it for the foreseeable. It’s not a decision I’ve taken lightly—this medication gave me my life back. But ultimately, I lived through 10 years of undiagnosed pain. I'm sure I can deal with a few months more of it to give myself the best possible chance of avoiding and fighting #COVID19.</td>
</tr>
<tr>
<td>Acceptance of public health measures</td>
<td>Patients’ posts implied a high degree of adherence to the safety measures and greater confidence in dealing with the outbreak due to their experience living with a chronic disease. However, they also raised concerns around the stigma associated with wearing a mask before the pandemic, which carried on at the start of the outbreak when mask-wearing was introduced but not yet consistently applied. Simultaneously, this group expressed frustration about those people who did not take safety measures seriously.</td>
<td>I am trying to get enough sleep each night plus drinking tons of water. I am not touching my face or trying to touch as many surfaces as I can. I keep washing my hands plus using my mask and gloves when I leave to go out. Trying to be as diligent as possible.</td>
</tr>
<tr>
<td>Healthcare practice</td>
<td>Regarding medical care, patients commented on healthcare staff’s professional behaviour, expressing confidence in front-line workers, e.g. nurses, ‘as if nothing phased them.’ Still, they also voiced concern about ‘non-staff’ not adhering to safety measures, e.g. wearing masks in the hospital.</td>
<td>My doctor will not let me go to the lab (or anywhere medical if possible). All appointments except for therapy if I’m having unbearable symptoms are cancelled. My home health nurse has been requested to take them and drop them off for me instead.</td>
</tr>
<tr>
<td>Communication with healthcare professionals</td>
<td>In March, as the pandemic began to impact healthcare measures, patients expressed a lack of communication with healthcare professionals, e.g. attending drug infusion appointments and their risk. On the other hand, posts reflected proactive communication where healthcare providers suggested changes to medication intake to comply with the pandemic restrictions, such as shortages of specific medications.</td>
<td>I usually have mine done every 4 weeks. Luckily had them done just before lockdown but have no idea if I’m still supposed to go to the hospital in the next few weeks to have them and my IV infusion. No info yet. Will need to phone the hospital next week.</td>
</tr>
<tr>
<td>Tele- or home-health</td>
<td>Patients acknowledged the healthcare providers' adjustments in support of people with RMDs, e.g. home nurse support, medication home delivery. Patients expressed the benefits of care at home and having the ability to communicate with their healthcare professionals virtually.</td>
<td>Home health care has been very easy. When my nurse was here, he was able to draw blood. I’ve heard from others that home health worked for them as well to get their blood testing done. [paraphrased]</td>
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<tr>
<td>Access to care and medication</td>
<td>It was evident that patients were concerned and frustrated about medication shortages for their underlying conditions, e.g. hydroxychloroquine. An issue for new patients, in particular, was the delay in being seen by a rheumatologist during the pandemic.</td>
<td>I was supposed to go on Plaquenil for arthritis but now I can’t because of the shortages. I have to wait and have only been prescribed anti-inflammatory and pain meds. I am also scared hoping not to need any major medical care.</td>
</tr>
<tr>
<td>Physical health</td>
<td>In April and July, we found patients expressing their COVID-19 infection status. Those who tested positive described both mild symptoms, not necessarily different from a flare related to their underlying rheumatic disease, and more intense symptoms affecting different parts of my body and in unpredictable ways. Between March and June 2020, patients mentioned experiencing symptoms that could reflect a COVID-19 infection and concern about not being able to access testing despite their immunocompromised status.</td>
<td>Will this include people like me who are on immunosuppressants (methotrexate) for chronic conditions? Diabetic as well. How is the list being compiled? Can’t get a grocery delivery so have to go out. #Coronavirus #PsoriaticArthritis #Psoriasis #Fibromyalgia #Diabetes #Osteo</td>
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<td>Mental health</td>
<td>Aside from physical symptoms, patients described the pandemic's psychological impact on their sleep, anxiety levels and depression. They expressed a heightened feeling of isolation but also positive attitudes and hope that ‘that life will return to normal’ and that this ‘crisis has the potential to unite us’.</td>
<td>Oh, bloody hell. Super stressed now. Super tired at 11:30 p.m.; too anxious to sleep.</td>
</tr>
<tr>
<td>Work-related issues</td>
<td>Patients discussed the impact of the pandemic on their work-life. We found a range of issues expressing positive and negative perspectives, including a lack of employer support, pressure to take sick</td>
<td>Place of work isn’t enforcing distancing or masks. As you can see here the barrier was moved up out of the way. I was wrote-up for taking pics. But breaking</td>
</tr>
<tr>
<td><strong>Leave instead of remote work agreements, pressure to either remain or return to work, non-compliance with recommended safety measures, and appreciation for remote work processes.</strong></td>
<td><strong>Policy and putting others at risk goes unchecked.</strong></td>
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<td><strong>Coping strategies</strong></td>
<td>Patients shared coping strategies around leisure activities and expressed the importance of their family and friends, caregivers, and online community during the pandemic, e.g. generosity and support by loved-ones, advice from peers, for example, on securing timely medication refill, overall sense of connectedness and fighting the pandemic together.</td>
<td><strong>Organizing my meds, writing more, playing with my dog, watching too much Law and Order SVU, trying anything not to succumb to anxiety and fear...</strong></td>
</tr>
<tr>
<td><strong>Peer support</strong></td>
<td>Patients posted questions actively seeking input from their peers about the outbreak and the use of specific medications (e.g. non-steroidal anti-inflammatory drugs, biologic immunosuppressives). They also shared opportunities to participate in COVID-related research efforts.</td>
<td><strong>So much support online! I’m checking in regularly with close friends. I’m taking time to be outside every day with my dog. And I’m vacillating between intense anxiety over #COVID19 and what it means to us patients and how I can help and shutting down 4 self-care.</strong></td>
</tr>
<tr>
<td><strong>Advocacy efforts, i.e. raising awareness</strong></td>
<td>Patients attempted to raise awareness of their immunocompromised status and of people downplaying the severity of COVID-19 (e.g. ‘it’s just the flu’). They were appreciative of public health campaigns (e.g. #HighRiskCovid19 on Twitter) that stressed the importance of keeping distance for the most vulnerable. Patients described the campaign’s positive impact in making them feel more informed and ‘less alone’.</td>
<td><strong>Feeling really guilty now for not making more of my immunosuppressed status at other hospital admissions. The alert cards barely get a glance and my problems are treated like hypochondria. Doctors must be taught about biologics, not just rheumatologists.</strong></td>
</tr>
<tr>
<td><strong>Effect of the media and misinformation, response to media content</strong></td>
<td>Despite the need for information, patients commented on the adverse effects of mainstream media during the pandemic, which prompted them to actively limit their exposure. They recognized the importance of being vigilant in checking medical information sources as misinformation is circulated. Patients expressed a general lack of focus in the media on the needs of vulnerable groups.</td>
<td><strong>I am limiting my exposure to the news and other media stories about #Covid_19. I am a news junkie, but the anxiety is more than I can bear.</strong></td>
</tr>
</tbody>
</table>

This study relied on publicly available Twitter data. The authors adhered to Twitter’s terms and conditions, terms of use and privacy policy. The Institutional Review Board at King’s College London confirmed that no additional institutional ethical approval was necessary to analyse public tweets. We received consent via Twitter from the Twitter users whose verbatim tweets are included in this manuscript.
Patient and public involvement
A patient research partner (S.M.) was involved in the study's design and conduct, including the outreach and consent messages and interpretation of the data.

Results
The analysis included 569 tweets published by 375 Twitter users that we identified as people with RMDs in several countries (e.g. UK, Portugal, USA, Taiwan, Australia, Canada). In addition to previously existing hashtags (e.g. #arthritis, #lupuswarrior), the sampled population used newly emerging user-generated hashtags related to COVID-19 in their messages, such as #coronavirusUK, #HighRiskCovid19, #COVIDarthritis, #covidsurvivor, #SocialDistancing, #SelfIsolation, #QuarantineLife, #WithoutMyHCQ, #covidtest, #TreatmentRationing #RationingOfCare, #WearAMask. We did not identify relevant tweets related to gout.

Eight primary themes related to the pandemic emerged in the sampled messages: (i) a lack of understanding of SARS-CoV-2 and the COVID-19 disease; (ii) health behaviour and acceptance of public health measures; (iii) healthcare practice and communication with healthcare professionals; (iv) access to medical care including medication and COVID-19 testing; (v) impact on physical and mental health including coping strategies; (vi) work participation; (vii) effect of the media; and (viii) awareness-raising. Table 2 shows the thematic analysis for each topic and representative tweets. A greater variety of representative tweets and their timing during the pandemic (month posted) are shown in the Supplementary Table S1, available at Rheumatology online.

Discussion
This study demonstrates the value of Twitter as a real-time data source to understand the impact of the COVID-19 pandemic on people with RMDs. Despite the hundreds of scientific manuscripts that have emerged since the onset of the pandemic focusing on quantitative research and specific patient- and disease-related associations with COVID-19 outcomes, studies exploring the direct patient perspective have been scarce.

The COVID-19 outbreak has placed people with RMDs at the centre of this pandemic, due to the multiple uncertainties, including medication shortages [34], their underlying, chronic, autoimmune disease and their treatment needs. Attempts to date to identify how the pandemic affects these individuals have been based primarily on quantitative research but these studies lack the direct patient perspective. We are only aware of one study that identified proxy topics of importance for individuals with arthritis during the COVID-19 pandemic [35]. However, that study included a smaller sample size (n = 149 tweets), only included people with arthritis, and used a shorter search period (20 March to 20 April 2020), compared with the study design presented here.

SM has been proposed as an essential communications tool in global health crises, including the current COVID-19 pandemic [36]. Opinions expressed by RMD patients on SM can provide valuable insights to better understand the COVID-19 pandemic dynamics, for example, gauging attitudes towards safety measures and mapping physical and mental health symptoms.

In our study, the data also provided ‘early signals’ of health behaviour changes that could potentially adversely affect people’s health outcomes (e.g. medication rationing, missing face-to-face lab monitoring appointments). Similar behaviours have been seen in other pandemics such as the 2015 Middle East Respiratory Syndrome (MERS) outbreak in South Korea, where people avoided hospitals even when sick [37]. Additionally, our study detected ‘signs’ of increased anxiety and depression levels among people with RMDs, as reported previously [38]. The presence of patient ‘signals’ provides opportunities for future pandemics. Automated SM surveillance efforts through the rapid analysis of vast amounts of text (i.e. natural language processing) [39] and monitoring for keywords that indicate health-harming health behaviours could help identify individuals for targeted health promotion interventions during a pandemic. Data from a recent survey study suggests that SM has a ‘positive
influence on public health protection’ against the COVID-19 pandemic with public health awareness and public health behavioural changes acting as ‘partial mediators’ [40]. However, the effects of SM interventions on public health protection against a pandemic are still poorly understood.

Our study highlights an unmet need: to provide clear and consistent information and communication between healthcare professionals and RMD patients. Future research could explore to what extent Twitter might serve as a platform to bridge the communication gap with RMD patients through different health promotion interventions. Research has shown that pandemics call for unique health communication and education strategies in which public health agencies need to satisfy the public's information needs about possible risks while preventing risk exaggeration and dramatization [41]. More proactive health promotion activities on SM to inform about the pandemic and safety measures are also highly relevant in light of the COVID-19 ‘infodemic’, i.e. the overabundance of both accurate and inaccurate information that occurs during an epidemic [42]. Platforms such as Twitter are particularly relevant in pandemics since they can provide a dynamic reflection of the impact of a pandemic. The analysis of tweets over the crucial months of the COVID-19 pandemic in our study enabled the exploration of secular trends in health behaviours among vulnerable people with RMDs.

The fact that patients proactively shared research opportunities might indicate a heightened level of research readiness, which could help recruit people with RMDs into research studies during and after a pandemic. Studies reported the successful use of SM for research participant recruitment efforts across different diseases [43], a notion supported by our patient research partner who stated: ‘The importance of this study lies in the fact that it [uses patient-generated] real-time data, [where] patients do not have the stress of answering questions by a researcher, do not worry if they give “the right answer” so their responses are more spontaneous and authentic.’

Study limitations include the lack of representation of perspectives from social networks other than Twitter and hence the wider RMD patient community. The analysis was limited to a convenience sample of tweets in English, by individuals that we could identify as people with a subset of (inflammatory) RMDs based on their profile descriptions and tweet content. Finally, this study was limited to the thematic analysis of emerging themes in tweets from people with RMDs during the COVID-19 pandemic, not including a frequency analysis. The data provided here should be considered a foundation for generating hypotheses for further evaluation within a context of clinical expertise and patient preferences. As noted by Thorne et al., ‘When articulated in a manner that is authentic and credible to the reader, [findings] can reflect valid descriptions of sufficient richness and depth that their products warrant a degree of generalizability in relation to a field of understanding’ [44]. Integrating the patient perspective from social media may offer additional dimensionality to the routine monitoring of health outcomes and drug safety, as well as more broadly capture symptoms or experiences relevant to patients that may otherwise remain under-recorded.

Despite these limitations, our study has several strengths, including its use of direct patient perspective data on a worldwide pandemic, highlighting a range of issues concerning physical and psychological health, access to medication and medical care, work participation, and other stressors. The data provide a better understanding of how safety measures and medical care could be communicated and delivered in the future, e.g. through regular webinars by health professionals that address the emerging questions and concerns of people with RMDs during a pandemic. We advocate using patient-generated health data from the social network Twitter as a knowledge source, similar to focus groups, to help shape the response of health care professionals and government authorities to a pandemic.
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@annakatarinaz; Anna @skeptikosbel; Carmen S. Heath; ChronicallySingle; David Meldrum @vicardave; Debbie Fenelon, Don @drfrasher; Elisa Comer; @Eviljohnna; Fiona Grant; Jackie Dillon, Jennifer @UnxpctdAdvocate; @joelvsarthritis; Judy Nagy; Kate Betteridge; @kimberleyscribe; Marcie Rhysling; Martin Hale; Michael Kuluva @MichaelKuluva; Miss D @Miss_Danielle82; Molly Schreiber; @NessMonet; @Phant0mGam3s; Platypus Custard; @PurpleGimp; Randi Vinton-Stewart @randistewart80; @SpoونieMomBlog; Thérèse @TerezHumphrey; Tinu Abayomi-Paul @Tinu; @twility; and Wendy Hunter. Thank you for supporting this research. K.R. and E.N. conceived the presented research idea, developed the study protocol, coded the data and wrote the first draft of the manuscript. S.M. served as a patient research partner on the project providing input into the study's design and conduct, including the outreach and consent messages and interpretation of the data. M.Z. provided expertise in Internet research ethics. He verified and advised on all aspects of the data use and outreach to Twitter users. A.D. and F.B. verified the approach and coding methods. All authors discussed the results and contributed to the final manuscript.

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Ethics statement: This study relied on publicly available Twitter data. The authors adhered to Twitter’s terms and conditions, terms of use and privacy policy. The Institutional Review Board at King's College London confirmed that no additional institutional ethical approval was necessary to analyse public tweets. The study was registered with the King's Data Protection Register (#DPRF-19/20-15995). Additionally, we received consent via Twitter from the Twitter users whose verbatim tweets are included in this manuscript.

Data availability statement

The study data available upon request due to the fact that it includes original Twitter messages and user accounts that can be identified.

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