

This is a repository copy of Social Media Use for Health-Related Purposes By People with Rheumatic and Musculoskeletal Diseases - Results of a Global Survey.

White Rose Research Online URL for this paper: http://eprints.whiterose.ac.uk/139216/

Version: Accepted Version

Proceedings Paper:

Studenic, P, Alunno, A, Stones, SR orcid.org/0000-0002-5943-1310 et al. (2 more authors) (2018) Social Media Use for Health-Related Purposes By People with Rheumatic and Musculoskeletal Diseases - Results of a Global Survey. In: Arthritis & Rheumatology. 2018 ACR/ARHP Annual Meeting, 19-24 Oct 2018, Chicago, IL, USA. Wiley .

https://doi.org/10.1002/art.40700

© 2018, American College of Rheumatology. This is the peer reviewed version of the following article: Studenic, P, Alunno, A, Stones, SR et al. (2 more authors) (2018) Social Media Use for Health-Related Purposes By People with Rheumatic and Musculoskeletal Diseases - Results of a Global Survey. In: Arthritis & Rheumatology. 2018 ACR/ARHP Annual Meeting, 19-24 Oct 2018, Chicago, IL, USA. Wiley, which has been published in final form at https://doi.org/10.1002/art.40700. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving. Uploaded in accordance with the publisher's self-archiving policy.

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk https://eprints.whiterose.ac.uk/

Social Media Use for Health-Related Purposes by People with Rheumatic and Musculoskeletal Diseases – Results of a Global Survey

Paul Studenic¹, Alessia Alunno², Simon R. Stones³, Valentin Ritschl⁴, Elena Nikiphorou⁵

¹Division of Rheumatology, Department of Internal Medicine III, Division of Rheumatology, Medical University of Vienna, Vienna, Austria

²Department of Medicine, Rheumatology Unit, University of Perugia, Perugia, Italy

³School of Healthcare, University of Leeds, Leeds, United Kingdom

⁴Center for Medical Statistics, Informatics, and Intelligent Systems, Section for Outcomes Research, Medical University of Vienna, Vienna, Austria, Vienna, Austria

⁵Academic Rheumatology, Department of In1ammation Biology, King's College London, London, Great Britain

Background/ Purpose: Smartphone applications and social media (SM) are increasingly used, transforming the way in which people communicate. Peer interaction, remote information access and community building are just some of the uses of SM, presenting novel opportunities and challenges, especially for people with chronic conditions such as rheumatic and musculoskeletal diseases (RMDs). This study aimed to explore the perspectives of people with RMDs on using social media for health-related purposes.

Methods: A questionnaire-based survey, co-designed in English by rheumatologists and patient research partners and translated into German, Italian, Spanish, Russian and French, was launched at the beginning of May 2018, distributed via patient organizations and SM platforms. We report on interims data analyzes after 4 weeks of data collection.

Results:

A total of 417 complete responses were received across 44 countries (50% of the UK, Russia, Spain and Italy). 13% of respondents were from non-European countries, with USA and New Zealand being the largest contributors. More than half of respondents were between 35 and 54 years, 87% were female, two thirds had >1 RMD, with infl1ammatory arthritis and connective tissue diseases being most prevalent. Sixty percent of participants had multimorbidity, with gastrointestinal, thyroid disease and hypertension leading. 38% were involved in patient organizations or as research partners and 65% had a higher education diploma. Practically all (96%) were using SM, half of them more than 6 hours per week. Three quarters reported using SM for health-related purposes, in particular to connect with other people living with the same condition (63%), with Facebook, YouTube and Twitter being the top 3 commonly used platforms (Figure 1A). There was an overall positive perspective for SM, as an easy means to acquire different experiences and exchange knowledge with peers. However, more than half voiced concerns regarding con1fidentiality (Figure 1B + C). Only 6% had experiences with virtual medical appointments, in most cases for follow-up, with 28% indicating to have more than one RMD. SM use was comparable between groups with di1fferent levels of multimorbidity, although general health rating was poorer than those with ≤ 1 comorbidity (p=0.002), they were older and more frequently considered that information provided by primary care physicians was inadequate (p=0.005).

Figure:

A Why did you start using social media for health-related reasons?

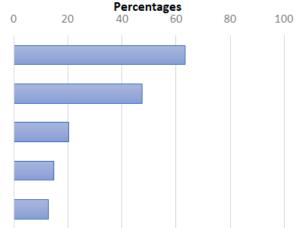
I wanted to connect with other people who had experience of living with my condition(s)

To gain additional independent information

Information and/or advice from my primary care physician / general practitioner was inadequate

It is difficult to see my rheumatologist or other healthcare professional on a regular basis

Information and/or advice from my rheumatologist or other healthcare professional was inadequate Information and/or advice from my rheumatologist or other



B In your opinion, what are the advantages of using social media for health-related reasons? Percentages

0

20

40

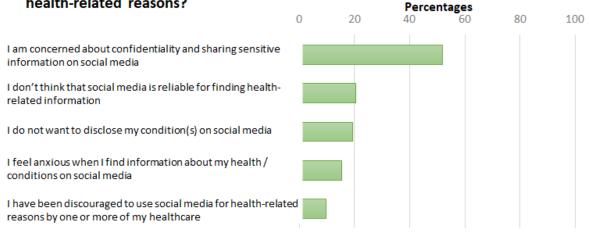
80

60

100

To hear the experience of other people with the same or similar conditions
To gain knowledge about my condition(s)
To learn about treatment of my condition(s) and the options available
To develop friendships and support networks with those who understand my condition(s) and health needs
To become more involved in self-managing my health and wellbeing

C In your opinion, what are the disadvantages or barriers of using social media for health-related reasons?



Conclusion: This study demonstrates that use of SM for health-related purposes is widespread among people with RMDs and is mainly used as a means to connect with peers and exchange knowledge and experience, supporting empowering patients in managing their disease. Despite concerns about con