

## Project summary:

Understanding how people with rheumatic and musculoskeletal diseases (RMDs) use social media for health-related purposes

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## Background

With the continued popularity of smartphones in recent years, both smartphone applications (apps) and social media are increasingly used and have transformed the way in which people communicate.[1] In 2017, worldwide users of social media were estimated at 2.789 billion, accounting for 37% of the global population.[2] Social media use has grown enormously in the last decade, with a plus of 20% in 2016 alone, particularly among those below the age of 40 years. Nearly 2.8 billion people around the world use social media at least once a month, with over 91% of those doing so via smartphones.[3] Facebook remains the world's most popular social platform, with more than one billion every day users. Other platforms, like Instagram and Twitter, could register additional growth of use in 2016.[2] These platforms enable people to conveniently interact and access knowledge, regardless of geographical location and professional background.[4]

Therefore, social media also provides people with health conditions, particularly chronic conditions such as rheumatic and musculoskeletal diseases (RMDs), with new opportunities to identify information about their disease and treatment, as well as the ability to connect with other patients, carers, patient organisations and healthcare professionals.[5-7] However, despite the premise of social media for people with RMDs, it is less clear how and why people with RMDs use social media in relation to their healthcare.

## Aims

We aim to explore how and why people with RMDs use social media and mobile technology for health-related purposes. Specifically, we aim to:

- Assess the prevalence of social media use by people with RMDs and their parents/carers, evaluating the user behaviour of different platforms and/or apps
- Explore how and when people with RMDs and their parents/carers decide to search for health-related information or support; connecting with the respective app or SM channel
- Explore perceptions and beliefs about the use of mobile technologies, related to trust, reliability of information and practicality;
- Explore the potential of social media and mobile technology as a communication tool between patients and healthcare professionals;

## Methods / Patient recruitment

An online survey was designed by Simon Stones (University of Leeds, UK), Paul Studenic (Medical University Vienna, Austria), Alessia Alunno (University of Perugia, Italy) and Elena Nikiphorou (Kings College London, UK) and hosted on Sosci Survey.[8] A decision on the final survey questions will be made by a Delphi like process by the members of this project. The hyperlink to the online survey will be disseminated through a variety of channels (Table 1). The survey landing page will detail a short description of the study, including information about anonymity and the adherence to good clinical practice guidelines, for providing the basis for an informed consent. By proceeding to the survey the participant consents to the information provided. Basic demographic information will be collected (age, ethnicity, country of residence, highest degree of education, diagnosis, disease duration), in order to identify associations between respondents' SM use and their demography.

Table 1. Survey Dissemination routes.

EULAR Young PARE mailing list
EULAR PARE mailing list
Facebook, Twitter, Instagram, and LinkedIn
EULAR Young PARE and EMEUNET websites
Website of country specific patient organisations

### Anticipated outcomes

- This study aims to map the extent of social media and mobile technology use by people with RMDs and their parents/carers, with a particular focus on health-related issues. Do people with RMDs feel confident with the information they retrieve via social media sources?
- Do people with RMDs feel confident to distinguish between evidence-based and anecdotal health evidence?
- Are people with RMDs overwhelmed by information or can they handle it?
- Do people with RMDs see the benefit of social media as an option of improved communication with healthcare professionals?
- What is the current use of SM as toll to communicate with health care professionals

### Perceived benefit

By mapping the current use of social media among the community of people with RMDs, possibilities and a future outlook for people with RMDs, parents/carers and healthcare professionals can be explored. Discrepancies between envisaged use and current practice can be compared and highlighted. This will enable people with RMDs and those involved in their care to target a patient oriented integration of social media into healthcare management.

### Project team

**Senior investigator:** Dr Elena Nikiphorou (Kings College London, UK)

**Project leads:** Mr Simon Stones (University of Leeds, UK) and Dr Paul Studenic (Medical University Vienna, Austria)

**Project team:** Dr Alessia Alunno (University of Perugia, Italy), Ms Sara Badreh (Lupus Europe, Sweden), Dr Heidi Lempp (Kings College London, UK), and Ms Nina Unesi (Reumatikerförbundet, Sweden), Valentin Ritschl Msc. (Medical University Vienna, Vienna, Austria)

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