

Digital crowdsourcing: unleashing its power in rheumatology

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ABSTRACT

The COVID-19 pandemic forces the whole rheumatic and musculoskeletal diseases community to reassemble established treatment and research standards. Digital crowdsourcing is a key tool in this pandemic to create and distil desperately needed clinical evidence and exchange of knowledge for patients and physicians alike. This viewpoint explains the concept of digital crowdsourcing and discusses examples and opportunities in rheumatology. First experiences of digital crowdsourcing in rheumatology show transparent, accessible, accelerated research results empowering patients and rheumatologists.

‘Scientia potestas est—Knowledge is power’—This quote, which is linked to Sir Francis Bacon (1561–1626), is particularly true in medicine. It is the knowledge about the patient and his disease that empowers the physician to provide the best possible care.

An economic perspective refers to the information superiority of the physician in relation to the patient as the theory of ‘asymmetric information’, leading to a competitive advantage.

Modern medicine naturally leads to a higher level of specialisation and, thus, an increase in asymmetric information. The global COVID-19 pandemic reduced information asymmetry to almost zero and this scenario was entirely new for patients and physicians alike. There are a lack of data concerning COVID-19 in general, the influence of immunosuppression on its course, the interaction with rheumatic diseases and therapeutic use of immunosuppressive drugs (eg, hydroxychloroquine, anti-interleukin (IL)-1 or anti-IL-6 medication).

Digital crowdsourcing promises to clear the mist of current nescience. Crowdsourcing uses the power of many, using the collective wisdom and resources of the crowd, to complete human intelligence tasks.¹ It is not a new concept. Historically, crowdsourcing has often been used in competitions for problem solving. It originated in England in 1714, where the British government proposed £20 000 to anyone who could find a solution for calculating the longitudinal position of a ship.² Digitisation, the internet, global networks and simple and instant data transfer have amplified the idea into a game-changing concept in many scientific fields.

COVID-19 GLOBAL RHEUMATOLOGY ALLIANCE

A significant example of successful digital crowdsourcing in rheumatology is the ‘COVID-19 Global Rheumatology Alliance’ (<https://rheum-covid.org>). The international registry collects information pertinent to COVID-19 infection in patients with rheumatic and musculoskeletal diseases (RMD). The

registry was set up in record time and is supported by virtually all international professional and patient organisations in the field of rheumatology. Rheumatologists and patients from around the globe are working together to collect data to improve the treatment of patients with RMD with COVID-19. So far, 526 patients have already been enrolled (status: 16 April 2020), and the first important results have been published.^{3–6}

However, even more remarkable is that the initiative and results are not limited to medical professionals. Crowdsourcing directly involved patients with RMD and results are published constantly, accessible to everyone at any time via the homepage and Twitter feeds. So far, the response from patients was overwhelming. To date, over 9894 patients (status: 18 April 2020) have participated in the survey, actively joining the effort to create and distil clinical knowledge.

OPEN-ACCESS PREPRINT PLATFORMS

Even before the COVID-19 pandemic spread around the globe, open-access digital platforms such as medRxiv and bioRxiv have gained increasing popularity in the scientific community.⁷ These platforms enable researchers to share preprinted data and manuscripts with the scientific community to discuss their research prior to journal publication. Via crowdsourcing, open-peer review can be carried out, allowing for collaboration among researchers and the acceleration of scientific progress. Therefore, these digital platforms improve the openness, accessibility and most of all quality of scientific research.

SOCIAL MEDIA

Social media in particular significantly facilitate crowdsourcing.^{8,9} Using platforms, like Twitter, Instagram or Facebook, it is easy and instantly possible to get in touch with people from all over the world and different disciplines, to network, discuss topics and issues or to initiate collaborative projects.¹⁰ Twitter journal clubs (ie, @RheumJC¹¹ and @EULAR_JC¹²) are examples of educational digital crowdsourcing that allow the rheumatology community to discuss new scientific work location and time independent.

DATA DONATION AND ARTIFICIAL INTELLIGENCE

Various studies have already shown the great willingness of patients to donate medical data for research purposes to advance scientific progress and thus potentially influence the disease positively for themselves and others.^{13,14}

Especially for rare diseases, digital crowdsourcing has led to significant patient empowerment and



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clinical outcome improvements via registries¹⁵ and digital information exchange platforms.¹⁶ Robust datasets can be rapidly crowd-funded to answer complex and frequently asked questions.^{17 18} These datasets can be used as a basis for artificial intelligence (AI) and machine learning. Moreover, these methods are able to identify new disease subtypes^{19 20} and to predict therapy response²¹ or individual disease progression.²² AI also has the potential to empower the autonomy of patients, for example, by providing individual treatment propositions.²³ New telemedicine approaches such as passive gait analysis²⁴ and remote patient self-monitoring with teleguidance²⁵ and AI-based real-time feedback²⁶ will further encourage the patient empowerment and decrease current information loss in follow-up appointments.

OPPORTUNITIES FOR DIGITAL CROWDSOURCING IN RHEUMATOLOGY

'Knowledge isn't power until it is applied.' Dale Carnegie (1888–1955, American writer and lecturer)

The COVID-19 pandemic marks a significant turning point in modern medicine. The global healthcare community is confronted with an infection for which almost no prior knowledge or guidelines pre-exist. Frequently, comparisons are made to the Spanish influenza. However, a fundamental difference to the past is the possibility to exchange data and experiences electronically in real time. Via crowdsourcing, the medical community creates a bowl of knowledge that can then be distilled and translated into practical and desperately needed clinical knowledge.

In the long term, COVID pandemic improvisations born from despair could lead to a lasting paradigm shift and information asymmetry cutback also in rheumatology. Digital crowdsourcing and AI should be used to advance global medical collaborations, facilitate patient empowerment and decrease medical barriers. As a rheumatology community, we should embrace the principle of 'connect and engage to target'.

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