Author’s response to reviews

Title: Real-World Data and the Patient Perspective: The PROmise of Social Media?

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Reviewer reports:

Reviewer #1: Samuel Stewart

I don't think the case has been made for incorporating social media data into the EMR. You justify PROs well, and the Sweden example demonstrates well why longitudinal monitoring is of value. My problem is that you use the use of social media analytics in health research to justify using social media data CLINICALLY, which is a different world. Your section on the use of social media for research in health is great, but it has no direct, patient-level clinical examples, so doesn't support your argument for incorporating social-media monitoring into the EMR. You mention the risk of bias (though you fail to use the actual word 'bias''), but only in one section and not related to clinical care. The risk of missed data is problematic in research, but is a much larger peril in clinical care, and needs to be acknowledged. In my opinion that's a fatal flaw, so it needs to be well investigated.

To make an effective case you need to be explain why social media monitoring would be a superior system to purpose-built PRO systems for chronic disease patients. I don't believe that the ease of capture outweighs the biased nature of the data, so if you do then you need to justify
it, or propose some sort of blended model. I think your paper makes a good case for social media monitoring for studying health, but not for incorporation into the EMR.

It is very well written, and I think it can be improved through resubmission, and I encourage the authors to revise and resubmit.

We thank the reviewer for their helpful comments, and for indicating that we had made a strong case for the use of social media data in medical research. In the revised version, we have attempted to focus the argument more acutely on the use of these data for research purposes. We agree with the reviewer’s suggestion that using social media in a clinical setting would require further justification, and have therefore been more tempered in the jump from healthcare data source to a tool with which to improve clinical care. As data in the clinical setting are currently lacking, we have moved commentary of this to the future perspective as we do see potential utility, but acknowledge that more work is needed before this possibility could be realised in real-world clinical practice.

Reviewer #2: Kerstin Denecke

In general, the paper is well-written and the topic is clearly relevant and interesting. However, my main point is that its purpose is not clearly described. What is the aim of this opinion paper? Is it to motivate using social media in clinical practice to include patient reported outcomes into the treatment process? or do you rather think of using social media reported outcomes for clinical research? Adding the purpose would help to understand the main text. Purpose should be also added to the abstract. Afterwards, it should be checked whether the text corresponds to this aim.

In the revised version we have specified that the purpose of this paper is to explore the use of social media data for research purposes. In order to ensure that all following text corresponds to this aim, we have restructured some of the subsequent paragraphs so that points regarding the use of social media data in clinical care are secondary to the overarching aim.

Reviewer #3: Miguel Mayer
In this opinion article the authors reflect on a very important and topical issue related to the use of several sources of health information apart from the EHRs, which are the key source of health information, and in particular the relevance of linking social media to electronic medical records is mentioned.

The authors use the term "Electronic health care records" as the title of the main text section. Electronic Health Records (EHR) and Electronic Medical Records (EMR) are the most common terminology used (EHR is usually used in Europe and EMR in USA) but not EHCR.

Thank you. We have removed this title in the first version, and now refer to electronic medical records (EMR) only, where this is referenced in the paper.

As for the following sentence: "patient-reported data are not regularly collected or recorded as part of routine clinical care", in fact it's more than that, currently it is very odd to collect patient-reported data as part of routine clinical care.

This sentence has been removed in the revised version of the manuscript.

It is mentioned that "...some healthcare systems have begun to allow patients' access to their EMR with the inclusion of functions which facilitate the recording of symptoms and progress in-between clinical visits". Although the authors describe the Swedish rheumatology register, if there are several healthcare systems working on this, it is expected that more examples are mentioned (at least including 3-4 references related to this aspect).

In the revised version, the focus of this discussion is on the use of social media data for research. Although we recognise that this is an interesting area of future application of these data, we acknowledge that at present the evidence is more limited. As such we have tempered our discussion on this topic, and included commentary in the future perspective.

Although this subject is very complex and it requires a lot of research and discussion, some reflections on ethical and legal aspects should be included in this article, this is an important point. In addition, it would have been relevant to comment some technical aspects, for instance, how should we manage the inclusion of social media information in EHRs?
We agree that ethical and governance issues related to the use of publically available social media data are important. We feel that at the centre of this is the assumption that it is correct to presume consent for publically available data, and to use this for purposes other than that which the patient may have intended (or is aware of). We have referenced this point in the challenges and limitations section. While a thorough discussion of the ethically issues involved is out of scope of the current paper, we have included some references to direct the interested reader a more thorough discussion of this important issue.