

Social media and clinical research

“...social media analysis ... adds a potentially valuable source of insight to our work in developing new medicines.”

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Social media such as Twitter, Facebook, discussion boards and blogs created specifically for patients and healthcare professionals, generate a vast number of conversations on diseases, drugs and treatments.

The output of social media analysis can be used to supplement our understanding of patient experience, disease burden, unmet medical need, perceptions of participation in clinical studies, research news, and thus adds a potentially valuable source of insight to our work in developing new medicines.

There are many ways that the analysis of social media can benefit decision making in the drug development pipeline. Not least, providing a connection to patients, their journeys and what their healthcare providers and caregivers say.

There is substantial work that uses social media to understand brand sentiment and in the support of commercial purposes, for example, brand perception, sponsored communities, brand awareness, and brand and topic education. What does not yet seem common is the use of social media in support of clinical research.

Listening, sharing & engaging

Social media can provide a valuable insight into matters of importance to patients. It represents an increasingly important medium for sharing and discovering research. And social media is becoming accepted as a useful medium for engagement with patients and colleagues.

With its origins in the 1970s, social media is not new. However, it is only with the ubiquity of smartphones and the emergence of

easily accessible platforms like Twitter and Facebook that social media has moved from being the preserve of an elite group of technology wizards [1]. Social media now seems a common medium [2–4] for many of us to share our thoughts and experiences with a number of family, friends, acquaintances, connections and others.

My interest in the potential for social media as a source of information to support drug development started around 2004. In some of our patient insight efforts we followed a number of blogs [5] written by patients. One example of blogs of the period is Jerry Mayfield's CML blog [6]. To pick a few exemplary blogs, read posts and comments and reflect on them seemed rational and reasonable. We would use the information gained as we considered the scope of a study or program design. The blogs added a dynamic and vivid reminder of the various statements we had gathered from formal insight work with patients, advocacy groups and others. What could we do today, now that many more people can easily share their experiences publicly?

In considering that question, I was reminded of my clinical work. Patients would share their study and treatment experiences while waiting for investigations. Perhaps some of those conversations were now shared online?

A fortunate conversation with a colleague in late 2013 led to our use of a commercial aggregation and analytics platform to quickly test these two questions. Our work indicated that people did share relevant and insightful material online. Moreover, modern social media analytics (SMA) offered a means to create overall themes of interest, expression



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of sentiment and specific examples of interest. ‘Listening’ work of this nature was subsequently described in Brian Mondry’s Kantar Health blog [7].

As a source of news about medical research, social media has some credibility. My own work revealed large flurries of relevant content following announcements at ASCO 2013 and ASCO 2014. Canvasser *et al.* [8] showed use of social media sharing of announcements and research from the 2013 World Congress of Endourology.

As a medium for engagement, there is more caution. This was recognized in the June 2014 report from the Tufts Center for the Study of Drug Development [9]. This report provides a clear summary of the current state of social media use in the pharmaceutical industry. We can find examples of cautionary statements [10] and of how we are learning to engage in this setting [11]. Considering research outside the industry, three speakers at ASCO 2014 addressed social media specifically. Oliver Bogler presented his view as a research professional and as a patient. Mike Thompson provided an education session. And Robert Miller offered a bioinformatician’s view of the use of social media in clinical studies. Robert Miller’s presentation included information on the potential for functional unblinding, which the Tufts’s report shows concern about and which Craig Lipset referenced specifically in his Nature article in March 2014 [12].

“...analysis of social media can benefit decision making in the drug development pipeline [by] providing a connection to patients...”

Even in this cautious environment, there are examples of some bold attempts to engage with patients including Eli Lilly’s pilot for their LVJJ Muscular Dystrophy study [13] and Janssen’s schizophrenia 24x7 [14] developed by Havas Lynx [15].

Listening to thousands of voices can be easier than picking one or two

Ten years on from my first ‘professional’ use of blogs, easy access has made it possible for anyone with access to a smartphone to share their thoughts and experiences through multiple platforms simultaneously. This volume of shared material represents both a challenge and an opportunity to anyone seeking insight from social media.

We now have a greater variety of people posting and potential for more concise and immediate posts.

To maintain a blog in the way Jerry Mayfield and others did is tough. Especially when you are dealing with the added burden of participation in treatment regimens or even in clinical studies. However, the ease of sharing experiences occasionally in a modern blog, or in other social media offers a much lower

entry barrier and a lower maintenance effort. Blogs themselves have moved on from being handcrafted, personal websites to easy and sophisticated content management systems. One of the most popular is WordPress [16,17]. A recent example on this platform is ‘a red-blooded male: me and severe aplastic anemia’ [18].

We now have far more choice in whose thoughts we choose to read regularly if we wish to pick some exemplary writers. We also have the opportunity to use the output of other online contributors through SMA. SMA offers a means to analyze social media content in the search for specific interests, for example, discussion or mention of a particular study or treatment. The existing application of SMA to marketing insights offers some tools of relevance to drug developers including sentiment analysis [19]. However, several authors including Donecke and Soltani [20] identify a problem with the kind of language that we are interested in analyzing in SMA. There is a lot of work to be done for us to be able to consistently listen clearly and effectively to what people say about subjects relevant to our research.

Listening & participating carry risks

Some ask whether it is right to ‘listen’ to social media chatter without explicit consent. If you suggest the alternative is ignoring what people say this may seem an odd question. However, Michael Zimmer [21] poses the question: ‘(is it) ethical for researchers to follow and systematically capture public Twitter streams without first obtaining specific, informed consent by the subjects?’ The risks he describes may be reasons that social media use is not already as common in clinical research as it is in some other fields.

In reviewing the potential effects of social media on study conduct, Seth Glickman *et al.* [22] called for ‘... a broader evaluation of both the benefits and potential risks of social networking among research participants during the course of a clinical trial...’ That evaluation is ongoing.

Social media participation continues to increase as the platforms continue to emerge and develop. It seems reasonable to expect that participation to encompass a number of elements of clinical research. And it seems reasonable to expect the unexpected even if we plan ahead. Thankfully, no one can predict the future. The best we can hope for is to be part of it. And we can only do that by being part of things today.

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