

#trial: clinical research in the age of social media

Research programmes, data analysis, and conduct of clinical trials have traditionally been the preserve of clinicians and researchers. Now, however, social media and crowdsourcing are becoming ever present and widely used. For example, *Crowdsourcing Cancer Research: The Role of Quantitative Challenges* was a recent topic at the American Association for Cancer Research annual meeting in San Diego on April 7, 2014. Indeed, social media is empowering patients in ways that are changing how clinical research is done, but are these changes beneficial or do they undermine integrity?

In some cases, crowdsourcing is being used by researchers to actively solicit patients' involvement and input into trials. For example, a phase 2 study of prostate cancer solicited opinions about protocol design from patients online. By contrast with traditional patient representation on ethics boards, this method gathers a greater range of opinions. By engaging patients in the trial design, they will have a better experience, and barriers to trial entry will be reduced, thereby improving recruitment. Social media can also aid trial enrolment via the action of patient support groups—eg, patients of one particular disease-specific support group on a social network site independently contacted researchers asking for more information about their rare disease. The researchers used this direct contact to successfully recruit these patients to a clinical trial. Another way of using social networking to recruit patients into trials is via the US website CureLauncher. This website is a free patient-orientated service that aims to match eligible patients to appropriate trials. Unlike traditional recruitment, the site is not specifically linked to any particular trial; instead, it aims to provide the option of trial enrolment for any patient. Thus, patients themselves are empowered to solicit their own participation into clinical trials, rather than being recruited.

Social networking provides another important function for patients: it gives them with a valuable support network through which they can compare their experiences and ask questions in a safe, accessible, and anonymous environment. However, despite the good intentions of such sites, implicit dangers exist. First, the advice given by one patient to another might be misleading, even if unintentionally. Second, the

anonymity of such fora obscures the source of any proffered medical information and hence, the message could be easily subverted. Third, when patients use the same social media outlets to compare information about their experiences, such fora pose a real danger to the integrity of a clinical trial. The exchange of personal experiences whilst enrolled in clinical trials can lead to patients—or any researchers on the same social network—to inadvertently unblind themselves, leading to knowledge of treatment allocation. Concealment is crucial for unbiased reporting of results, and disclosures by one patient might distort another patient's awareness of their own symptoms, potentially skewing data reporting.

Inappropriate use of social media is not limited to patients. Use of social media by clinicians can disclose patients' private personal information. An analysis of Twitter use by Swedish physicians and medical students showed that roughly 2% of tweets were 'unprofessional', with a small, but important, minority revealing information that could violate patient privacy. Other clinician-led social media ventures—eg, the creation of Facebook pages for clinical trials—raises further questions about the ownership of data and the importance of tightly restricting access to something that is ultimately hosted in a public domain. Furthermore, peer-to-peer conversations on social platforms might be read and misinterpreted by patients and other non-experts.

Enrolment into a clinical trial is the best treatment option for patients with cancer, and if social networking and media can ease this process, its use should be encouraged. However, the dangers should not be ignored. Patients' use of social media should be taken into account when designing trials; patients need education about the use of social media in tandem with protocol-specified restrictions on the risks of sharing certain pieces of information. Clinicians should welcome the benefits that social media can bring in attracting more patients to trials, but should also be aware of their own use of social media. In a world in which excessive sharing of information is becoming increasingly normalised, maintenance of patient privacy has never been more important.

■ *The Lancet Oncology*



For the Swedish Twitter study see *BMJ Open* 2013; 3: e002988
For practical guidance for social media use in oncology see *J Oncol Pract* 2012; 8: e114-24