



Using social media to improve communication with people with cystic fibrosis

To the Editor:

In less than a decade, social media has grown to become firmly established for many people as a major source of communication and information sharing. Concerns over patient confidentiality, medicolegal issues and the perceived time commitment required for a successful social media campaign have contributed to a low adoption rate amongst medical professionals [1]. However, social media is increasingly being recognised as a useful platform for promoting patient engagement, facilitating access to information about health and services, and disseminating and discussing research [2–4]. The demographics of the patient cohort of adult cystic fibrosis (CF) centres mean that a large proportion of patients will have grown up with or be fluent in these technologies (*i.e.* be “digital natives”). Moreover, infection control restrictions in CF mean online communication is particularly well suited to this patient group; indeed, many CF patients already use social media platforms to communicate with others, and as a source of information and support [5].

In view of this, we created a Facebook page (<https://www.facebook.com/macfc.uhsm/>) to aid in communication and promote patient engagement within our large adult CF centre (>430 patients). In order to improve our communications, we were interested in understanding how patients interacted with the site and the impact of the different messages that were posted. Data were generated based on user engagement with items posted on the Manchester Adult Cystic Fibrosis Centre Facebook page between August 1, 2013, and May 31, 2015. “Likes” are the number of unique Facebook users who indicated active approval of a story. “Shares” are the number of unique Facebook users who indicated their approval of the story by actively selecting the “Share” button to pass on the post to their Facebook friends. Likes and shares were combined to represent active engagement with a post, beyond simply reading it. Total “Reach” represents the total number of unique users who were served by the post, either directly or as a result of shares or other links, in the first 28 days. Posts were reviewed and divided by consensus into one of five categories: personal stories (*e.g.* fundraising efforts), health education, unit news, inviting user engagement and associated news (including research updates). Data are presented as median and interquartile range. Differences between groups were analysed by the Kruskal–Wallis test followed by Dunns multiple comparison test to perform pairwise comparisons.

Up to May 31, 2015, the page had received 236 Likes representing 236 unique users who were receiving updates on posts. 67% of these were female users, 57% aged 18–34 years and 92% were users based in the north west of England, the region served by the CF centre. During the analysis period, a total of 180 posts were made on the page. The greatest Reach for an individual post was 2845 users, relating to a story about a fund-raising effort by members of the CF team. Overall, users engaged significantly more with personal stories, in terms of Likes, Shares and overall Reach, than with posts designed to engage them with healthcare (all $p < 0.001$) (table 1).

As clinicians caring for an increasingly technology-aware patient population, it is important that we use all available tools to engage and communicate with patients. As such, social media resources, already firmly embedded in the lives of many patients, are a potentially valuable tool. Used correctly, the interactive features of social media platforms could make these particularly useful vehicles both for informing and for gaining feedback. However, there are challenges to be overcome before they can successfully be used in this way. Some centres have reported negative experiences with social media, with concerns regarding the spreading of inappropriate or misinformation, and inappropriate online conduct including bullying [6]. This has not been our experience with our official Facebook site, where initial concerns that patients might use the site inappropriately have not been realised. In fact, the option for users to post their own comments has been one of the most important features of the page and the one that most differentiates it from a standard website. This outlet also offers an alternative to unregulated patient-organised pages [6].

Our experience of Facebook as a medical communication tool, however, has been mixed. Whilst patients and users clearly engage well with personal stories or news of important research breakthroughs, they are far less likely to respond to (Like or Share) posts focussing predominantly on healthcare. To illustrate this,



TABLE 1 Impact of different categories of posting

Category	Posts n (%)	Likes and Shares per post	Total Reach per post
Personal Stories	40 (22)	16 (5–32)	229 (132–421)
Unit news	66 (37)	9 (3–19)	162 (98–282)
Associated news	13 (7)	8 (3–15)	147 (80–161)
Inviting user engagement	17 (9)	2 (0–8)	88 (67–138)
Health education	44 (24)	1 (0–3)	80 (69–115)
Total	180 (100)	5 (1–15)	137 (84–150)

Data are presented as median [interquartile range] unless otherwise stated. Facebook posts were divided into five categories. The number of “Likes”, “Shares” and total “Reach” have been averaged per post.

the least-successful posts were a series of physiotherapy exercises, which received an average reach of only 68 for all 20 posts, and a combined total of only six Likes and Shares. This presents a challenge to those trying to use social media in this way. While it is important to acknowledge that the tools to gauge reader response are crude and a healthcare posting may still be acted on even though it is not shared with others, we recognise that a Facebook page focussed only on healthcare issues, ignoring the personal stories that seem to be most popular, would be less likely to generate and retain new users. We therefore aim to provide a mix of posts and maintain a steady flow (we aim for at least one post per week) whilst avoiding overwhelming users with excessive updates.

Although social media may be considered particularly relevant in CF (a predominantly young adult population with limited opportunities for contact with the wider patient community), they are also increasingly accessed by many more patient groups [7]. Social media are also increasingly recognised as a platform for the dissemination of research among healthcare professionals [3]. As social media use becomes increasingly widespread, clinicians should consider how they and their patients may benefit from similar approaches.

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Social media has the potential to improve communication with patients with cystic fibrosis

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