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Social media is changing the way health professionals and care organisations engage with patients and the public. Given the increased role of online systems and social media platforms in healthcare delivery, and the vast volume of information generated, it is unsurprising that opportunities to use online data for health surveillance/monitoring and for research are being realised.¹ While these readily available data have obvious attractions for researchers, they also pose challenges to traditional research methods and requires different ethical considerations. This article will briefly outline the key issues when undertaking social media research and the ethical challenges in terms of the risks and benefits to participants and researchers.

Social media in healthcare

In its broadest context, social media refers to the interactions that take place within virtual communities through web-based platforms as a means of sharing information, ideas, personal messages, images and developing networks and collaborations in real time.¹ Although constantly evolving, social media tools and platforms include:

- Social networking (Facebook, MySpace);
- Professional networking (LinkedIn, Researchgate);
- Media sharing (YouTube, Flickr);
- Blogs and microblogs (Tumblr, Blogger, Twitter).

The value and possibilities of these online social media tools and platforms in healthcare include providing health information to global communities and instant messaging between a health professional and individual patient as a means of providing more immediate personalised care. In addition, patient engagement with online support groups, whether peer or professionally led, is a means of gaining additional information and advice to that provided by one-to-one encounters with health professionals and communicating with others with similar experiences.² While there is a range of guidance about using social media with patients, for example, within the UK, the National Institute of Clinical Excellence has produced guidance relating to proving public health information, well-being boards and early childhood services, there is less guidance for researchers entering the social media world. INVOLVE, a UK national advisory group supporting public engagement in health services, has developed guidance for the use of social media to actively involve people in the research process such as the recruitment of participants and/or undertaking data collection.³

Key considerations when undertaking social media research

Online research methodologies such as netnography (or online ethnography) are rapidly emerging and are rooted in ethnographical methods aiming to explore the social interactions of online communities.⁴ However, it is useful

to make a distinction between using social media data to answer a specific health-related question and undertaking research 'on' social media. We will draw on a case example of a study that explored how young people and parents used online support in the context of living with cystic fibrosis.⁵ Exploring how the participants engaged with online support was best met by undertaking virtual observation. Principles underpinning the methods associated with undertaking robust qualitative research were employed but adapted to the study setting. Table 1 outlines the issues that were considered and how they were addressed in order to meet the study aim and objectives.

Social media research: risks and benefits to participants and researchers

The benefits of social media research for researchers include using existing discussions between people/patients who use online support groups that can be analysed and offer insights into real-time experiences. Multiple interactions where concerns are discussed, and decision-making processes can be observed as they occur, are more visible compared to traditional qualitative research methods such as interviewing that might rely on participants' memories of situations.⁶

Risks relating to undertaking research in online settings centre largely around the ethics of using existing data usually intended by participants for purposes other than research.⁶ Strategies for informed consent, privacy and confidentiality can be guided by whether the researcher considers the data to be public or private.⁷ However, the distinction between the two can be unclear due to differences in perceptions of what is intended to be private and publically available data between researchers and those posting information.⁸ Informed consent is only required if the online space is considered to be private; however, confidentiality and privacy should be respected for data that are considered public or private.⁷ Furthermore, researchers need to be aware of the risk of participants being traceable through websites (for example direct extracts can be copied and searched through internet search engines) and ensure strategies are in place for full anonymisation.⁶ These and many more ethical considerations are further complicated when undertaking research on online data posted by children and young people under 16 years of age.

In summary, research using data from social media activities offers a different perspective of people's lives, their concerns and how they manage their health. An ethical framework for undertaking social media research would be welcome by researchers to address informed consent processes and protect participants.⁶ In addition, more specific guidance on using online data generated by children and young people for research is required, where the thorny issues of who should provide consent or assent and how competency to consent is established arise.

Table 1 Research considerations when undertaking virtual observation⁵

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| Background and aim | <p>The internet has a potential role in providing peer support to young people with a long-term condition, an essential element of self-care support. Discussion forums are known to provide emotional and social support, and information. Yet there are concerns about 'inappropriate' self-management and challenges to the health professionals' role as the 'expert'. For young people with cystic fibrosis unable to access face-to-face peer support, the internet offers a safe place for them to share experiences and support each other.</p> <p>Aim: To explore how young people and parents use online support in the context of living with cystic fibrosis.</p> <p>Key message: Ensure the rationale for using social media platforms is clear and congruent with the study aim/s.</p> |
| Research design | <p>Virtual observation or netnography is a design informed by the principles of ethnography to explore online social interactions such as a discussion forum.</p> <p>Key message: Ensure the chosen method will gather the appropriate data to answer the research question.</p> |
| Study setting: participant recruitment | <p>A charity that hosts discussion groups for young people, parents, adults and partners of those with cystic fibrosis was involved from the inception of the study, and facilitated accessing the online groups. The only information about group participants was the name they provide when registering with the group, which could be a pseudonym. Participants were those who posted comments during a 4-month period, chosen at random.</p> <p>Key message: Understand the online organisation/social media network/forum that is being accessed, who are the users and why do they use it, because this will inform the recruitment process and type of data generated.</p> |
| Ethical considerations | <p>The discussion forums were accessible by the public; however, permission to observe the discussion activity was gained from the charity. In addition, discussion forum participants were informed of the research through posting study information on the charity web pages.</p> <p>Key message: Become familiar with ethical principles for 'user-generated' research. Liaise with the host of the site and obtain their permission to use the data. Inform participants of your presence and provide detailed information about the study, maintain anonymity and confidentiality when analysing data and presenting findings.</p> |
| Data collection | <p>103 discussion threads from the parents' group and 48 in the young people's group were collected.</p> <p>Key message: Decide on a timeline for data collection. Observe the data in real time and record field notes in addition to downloading the discussion into a text usable format.</p> |
| Data analysis | <p>An inductive grounded theory approach was used; both researchers analysed all data and agreed on the emergent themes. Descriptive statistics were used to describe the number of discussion threads by topic area.</p> <p>Key message: Data generated are likely to be voluminous, and text based; a qualitative data analysis software package and a structured approach are recommended to help manage the data.</p> |
| Findings | <p>Five themes emerged and were presented using extracts from the discussion threads to add meaning to the themes. There was some cross-posting between the parent and young people groups; for example, parents asked young people about living with the condition. Parents' post mainly focused on treatment options and daily management strategies; in contrast, young people's posts related to how to live a normal life with the condition. The findings demonstrated that online groups provided information and support on managing treatments, emotions, relationships and identity.</p> <p>Key message: Draw on the principles of ensuring rigour in qualitative research, for example, demonstrate trustworthiness by having a clear audit trail and including anonymised extracts from the discussion threads when presenting the findings.</p> |
| Discussion | <p>The advice and support offered by participants enabled parents and young people to share experiences, feelings and strategies to help them live with a long-term condition. There was some evidence of the fostering of empowerment with participants becoming more informed about treatment decisions and their impact, and therefore more able to participate in decisions made with health professionals.</p> <p>Key message: Synthesise the findings, put into context by referring to other research and/or theory and practice.</p> |

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