



ELEPHANT

IN THE LAB

SHORT ANALYSIS

Social media use in research

Short title	Social media use in research
Long title	Is it appropriate for researchers to use social media posts in their research?
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Date published	25 June 2018
DOI	10.5281/zenodo.1292828
Cite as (APA)	Golder, S., Norman, G. (2018). Is it appropriate for researchers to use social media posts in their research? <i>Elephant in the Lab</i> . DOI: https://doi.org/10.5281/zenodo.1292828

Social media is increasingly seen as a valuable source of data for research – one which is highly current and immediately accessible. However recent news has focused on the ethics of using information posted for one reason for another purpose entirely.

If you were to ask ten researchers if it is ok for them to use social media posts in their research you might well receive ten different answers. Whilst at one extreme there will be the ‘never’ camp – that is it is never ok for researchers to use social media posts; at the other extreme are those who regard it as unethical not to use potentially valuable data from social media posts to inform research. In the middle, however, are the ‘well, it depends’ camp who may stipulate caveats or conditions on use: “Are the data public?” “Are the data sensitive?” “Can people be identified?”

Academic journals have published many discussion papers on this topic by individual researchers or small research groups on this topic. However, we were interested in not just the overall views of researchers but, even more importantly, the views of the people who post on social media themselves. What does the public think?

To answer these questions we conducted a systematic review of the literature to look for surveys or questionnaires that ask researchers or the public exactly that.

After extensive searching we found 17 studies – 12 studies which asked the public what they thought and five which asked researchers. These studies included a total of well over 5000 participants and an international representation, with participants from around the globe contributing. They also included sources which ranged from forums dedicated to specific health conditions to Facebook and twitter.

So what did people think? Well that depends. For most respondents it is not black and white and there are many factors that need to be taken into consideration. These factors could be categorised as falling under the following headings: researchers, social media users, consent and, lastly, social media site.

1) Researchers

A big question was related to the perceived benefit of the research. Essentially if the research was seen to be for a ‘good cause’ or of benefit to society than people were more accepting.

I have no reservations about your mining information from forums...it will provide much information about the human side of illness and how individuals singly and collectively approach and cope through sharing. Dare I say its importance cannot be understated.

Diabetic forum user (Bond et al., 2013)

On the flip side if the research was for a ‘bad intention’ – such as commercial gain or to drive an agenda – then people were less accepting.

Linked to the question of ‘beneficial’ research was the question of who was undertaking the research. University researchers or third sector ‘not for profit’ researchers were preferred over commercial analysts, governmental organisations or journalists.

Another link was to the quality of the research and the potential bias from using social media posts; there were concerns that social media posts were not fully representative.

I've never once posted anything negative. So if you took that data, it would not be accurate, because of course I've had bad days or sad days.

Twitter user (Mikal et al., 2016)

2) Social media users

The starting point for all research should be 'do no harm' and this was reiterated by the respondents. Identified risks varied from worry about abuse and ridicule to being used or exploited. Issues surrounding the original purpose of the posts and privacy were seen as important. This was a particularly important issue where social media users were members of a vulnerable group; the definition of such a group may vary between countries; an example would be gay people in countries where homosexuality is illegal or taboo. More generally children, adolescents and people living with mental health conditions were considered especially vulnerable. The nature of specific posts was also a consideration in determining whether special care was needed. It seems possible that awareness of social media research could actually prevent people from using sites and forums as fully as they otherwise would in situations where it may be most important that they are able to do so.

With the some of the stuff I write, I am uncomfortable thinking it is going to be accessible for a long time but this is after all the internet and it's hardly private..... The alternative (that is) total privacy is to sit here in my house alone and not communicate. I'd give it about three weeks before total insanity set in.

Discussion list member (Bakardjieva & Feenberg 2001)

3) Consent

Consent was a tricky issue. Social media posters obviously have no intention of contributing to research when they post and may have no expectation that anyone outside of a small forum or group will read their posts. This means they may post things which they would not knowingly volunteer to researchers. Informed consent is a particularly tricky issue in this type of research. Whilst the practicalities of gaining informed consent were well recognised it was still felt important to some, although others acknowledged that privacy should not be expected on social media. This links to the question of whether there is an obligation for researchers to disclose their presence and intent on the sites they are using.

Any researcher that joins a mailing list should identify themselves as such as they have joined or better yet before they have joined and ask permission of the list owner. As a person I have the right to know I am being experimented on or studied.

List owner (Chen et al., 2004)

4) Social media site

The type of site from which the posts are extracted played an important part in the acceptance of research using social media and this was wrapped up in the expected level of privacy from the site. Terms of service and site administrators were not seen as enough to overcome the need for ethical approval. The question was seen as being not so much whether researchers' activities were legal but whether they were ethical and moral. Another issue which arose was intellectual property – users views about who owned the material posted.

If someone decided to republish my post in another forum or document I would expect my comments to be kept in context and credited to me.

Diabetic forum user (Bond et al 2013)

This review highlights the multiplicity of complex ethical considerations that face researchers using social media data. Whilst these require careful advance thought and planning the evidence from users suggest that researchers should not be deterred: most social media respondents are supportive of well-planned research conducted for public benefit.

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