GUIDANCE NOTES FOR INVESTIGATORS

Online or Social Media Research

The Ethics Review Sub-Committee has approved the following guidance for investigators regarding online research (e.g. Teams, social network sites, Facebook, Twitter, YouTube, Bristol Online Survey (BOS) Tool).

These guidelines are primarily intended to help ensure that online research methods are used correctly and ensure the protection of both the investigators and participants in the research. The current variety and ever increasing development of these types of technologies mean that these guidelines can only be a general guide, but should provide guidance on what is best practice for investigators.

When conducting research online investigators should ensure that they create a separate account that is used only for the study, to prevent their research being linked to their personal accounts on these services.

1. Informed Consent

As in offline research, it is imperative that participants are fully informed of the research they are being asked to participate in, and that they give their consent freely. It is recognised that the standard way of obtaining informed consent (providing participants with an information sheet and then signing a consent form) is not always practical, though it is worth noting that this is still the preferred way of obtaining consent wherever possible. Regardless of the methods used consent should always be obtained and a way to be able to record and verify the consent should be ensured. Parental consent will also be necessary when conducting research involving participants under 18 years old.

The following sections give advice on obtaining consent using different electronic media.

1.1 Telephone or Video Call Research
In the case of telephone or video call research, the participant should be provided with information on the study prior to the call. Consent Forms can be returned as scanned or photographed copies by email or by typing the participants details into the form with the email used to verify completion. The investigator can then confirm that the participant is willing to participate at the start of the call. If the participant does not wish to proceed, they can end their participation by ending the call.

The information sheet should advise participants whether the call will be recorded.

1.2 Online Surveys/Questionnaires
See our Guidance Note on Online Questionnaires.

1.3 Social Network Sites
In the case of social network investigations, there is an emerging consensus regarding informed consent. For private or semi-private sources (mail, closed chat rooms) informed consent is considered essential whereas in observations of open access forum (twitter, newsgroups/bulletin boards), it is suggested that informed consent is not essential if the investigators are merely observing and not interacting with subjects.

Private or semi-private sources

In these cases the investigator should request permission to use the forum from the forum moderators. Once the moderator has consented to this, the participant information sheet should take the form of a forum post, which allows forum users to read and comment on what research will be taking place. The forum post should also inform the users that they may be asked to interact with the investigator, and the means by which they will be contacted. The investigator should then respond to any comments in as an informative way as possible so that as many of the participants concerns are addressed as possible. If a high proportion of the users wish to decline participation in the project, the investigator should withdraw at this stage. If the users wish to participate, the research can then begin.

Open access forum

For observations of open access forum informed consent is not essential as the forum is publically available and open to all to read. The AoIR Ethics Working Committee recommend that the greater the acknowledged publicity of the venue, the less obligation there may be to protect individual privacy, confidentiality and the right to informed consent. If investigators are interacting with subjects on an open forum then consent is required. If an investigator wishes to use disguise or deception in any way during their interaction with participants, the Sub-Committee should be informed. If an investigator has any queries about the 'openness' of the forum they wish to use in their research, they can contact the Sub-Committee for advice and assistance.

1.4 Research involving children

Regardless of the methods used, if you are working with participants aged under 18 years old, parental consent must be obtained in addition to the child's assent to participate. It is good practice to obtain parental consent in written format and this would always be preferred wherever possible. If an investigator wishes to use a different method of obtaining parental consent, this would have to be carefully considered by the Sub-Committee.

2. Anonymity

The anonymity of the participants should be maintained wherever possible. This may be difficult in cases where the study involves a small group of participants, and the investigator wishes to quote the participants. Investigators should always be clear about the level of anonymity they will provide.

3. Covert Research and Deception

An investigator may wish to use covert research methods for their study, e.g. observing interactions on forums without participating, and without stating their intentions to the forum. This form of research would be considered by the Sub-Committee in the same way as any research that involves deception: the level of deception would be considered, as well as factors such as the trust of the participants, consent and how and when the participants would be informed of the deception. Observation of publically available information, which does not require any interaction with subjects, does not require approval.

4. Data Protection and Third Party Privacy Policies

As all studies originate in the UK, the investigators must ensure that the study complies with Data Protection legislation.

In addition, when using a third party program (such as Facebook, Skype etc), investigators should ensure that the participants are aware that they may need to download the program or subscribe to a service. In doing so, the participant will accept the terms and conditions of the program/service, which may include allowing use of any data provided by the program owners. The investigators should make it clear that they will be unable to prevent the program owners from using the data, and that the participants should consider the privacy policy of the program before downloading it and consenting to participate in the research.

5. Conclusion

Most of the issues linked to the use of online research methods are the same offline as they are online but there are some differences. Providing full participant information, obtaining informed consent, the use of deception etc. need to be considered regardless of whether the research is being conducted in the online or offline world. Specifically, however, extra ethical consideration needs to be taken when applying online research methods as they can have their own difficulties. Investigators should note that in order to assist the Sub-Committee in considering these methods, they should provide as much information on their study as possible.

6. Further Information

This is not intended to be an exhaustive list of considerations in relation to the adoption of online research methods. However, it is hoped that these guidelines will encourage researchers to adopt best practice and familiarise themselves with the relevant legislation.

The following website may also be of interest: Association of Internet Researchers

7. References

- AoIR ethics working committee. Ethical decision-making and Internet research 2.0: Recommendations from the AoIR ethics working committee. Approved by AoIR, December 2012.

- Haigh C, Jones N. Techno-research and cyber-ethics: challenges for ethics committees. Research Ethics Review 2007; 3 (3); 80-83

- Ethics of Social Media Research: Common Concerns and Practical Considerations, Megan A. Moreno, MD, MSEd, MPH, 1 Natalie Goniu,1 Peter S. Moreno, MS, JD,2 and Douglas Diekema, MD, MPH3,4, Cyberpsychol Behav Soc Netw. 2013 Sep; 16(9): 708–713

- Eric S. Swirsky, Jinger G. Hoop & Susan Labott, (2014) Using Social Media in Research: New Ethics for a New Meme?. The American Journal of Bioethics 14:10, pages 60-61