THE UNIVERSITY of EDINBURGH

SOME ETHICAL CONSIDERATIONS WHEN RETHINKING RESEARCH PROJECTS IN LIGHT OF COVID-19 SITUATION

For College of Arts Humanities and Social Sciences Researchers and PG Students (Version 5)

Rapidly Collated by CAHSS Research Ethics Committee

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Updates to Original Content

17th April: Use of Zoom (no longer applicable – see below)

We have been advised by the University Data Protection Officer that Zoom is not an appropriate system for University use. It is therefore advised that Zoom is not used for research data collection:

> "The University provides and supports a number of collaboration tools to support online/remote meetings (https://www.ed.ac.uk/information-services/computing/desktop-personal/off-site-working/online-meetings for more details)
>
> **Zoom is an unauthorized application and should only be used if an external party such as a research funder insists or a particular research project requires use of Zoom. For specific questions, please contact the DPO and CISO**."

June updates:

Some additions to text throughout.

July Update – Use of Zoom:

The University has now subscribed to Zoom and this has been added to the portfolio of platforms that may used for online meetings and data collection – See - https://www.ed.ac.uk/information-services/computing/comms-and-collab/zoom

October Update

New guidance has been made available regarding potential start/restart of research with human participants both on and off-campus. Please review these for the most up to date guidance

Introduction

The purpose of this document is to provide a resource to support staff in undertaking their own research and supporting students in their ethical decision making, in light of the COVID-19 situation. This document is not intended to be exhaustive, but to provide some guidance and signposting at this time when it is necessary to revise current or planned research projects.

We have created some accompanying slides that available to use to support teaching and supervision of students (particularly PGT).

The information has been rapidly collated by the CAHSS Research Ethics Committee, and intermittently reviewed and edited. We welcome additions from colleagues, and will further update as appropriate.

We are keenly aware of the immense challenges faced by staff, in a context of social distancing/self-isolation, home working, childcare and other caring responsibilities, in addition to the urgent need to develop online teaching. We recognize that research may, rightly, not be possible or limited for some staff at this time due to these challenges and the importance of managing wellbeing.

CAHSS CREC, 30 March 2020;

Updated 12 June/ Updated 2 July/ Updated 23 October

Key Ethical Considerations: Do I need to collect data from human participants?

Update October 2020

The information below was written in March at the height of Lockdown. The situation remains very fluid, but there is now guidance available to support colleagues to navigate decision making regarding the appropriateness and safety of starting or restarting research involving travel and/or human participants. Please see link

Although this is a fluid situation, at the time of writing, face to face data collection is only permitted if there is an exceptional reason, such as clinical need or a significant ethical rationale for non-immediate cessation. Any continuation of face-to-face research will require University approval. For the majority of researchers and postgraduate students, University research projects will need to be paused or revised. Face-to-face research includes interviews, focus groups, observations in public spaces, psychological experiments, and tissue sampling (see FAQs on ERO Sharepoint).

There are alternative non-face to face methods available to collect data from human participants. However, it is **important to consider carefully** as to whether it is appropriate to approach your target sample. Key considerations include:

- If working in the UK or another country on lockdown, are they a key worker whose work is vital to public health and safety during the coronavirus lockdown? (e.g., health and social care, education and childcare, public services, government, etc)

- If so, unless it is essential University research then at this time we propose that it is not appropriate to consider research with this group

- NB At this time, recruitment has been suspended to any new projects that require University sponsorship (typically involving health and social care settings)

If your participant group are not key workers, it is still important to think carefully as to whether it is appropriate to approach your target sample. Some considerations are:

- As with any research, consider the risk of harm to participants by participating in the study

- Previously non-vulnerable participants may have become vulnerable through changes in their personal circumstances.

- At this time, many people are under considerable stress, lowering the threshold for distress, so the assessment of risk of harm requires extra careful consideration

- The usual sources of support (both formal and informal including GPs, support services, families and friends) may be unavailable or disrupted at this time.

- There is a risk that researchers may be seen as 'taking advantage' of the situation as a research opportunity if research is not approached sensitively and with due consideration of the potential issues.

- Be mindful that data collected as part of ordinary research (not coronavirus specific) may not be representative of 'normal' data.

- Alternative desk-based studies may be more appropriate.

In order to inform your decision making, please discuss your project with an appropriate person:

- Students: speak to your supervisor(s) in the first instance to discuss this issue.

- Supervisors: liaise with Subject Area Research Officers, Ethics Officers, or the Research Ethics Committee members as appropriate.

- Staff: liaise with Subject Area Research Officers, Ethics Officers, or the Research Ethics Committee members as appropriate.

Key Ethical Considerations: General Guidance/Signposting

There are a number of methods of data collection that can be undertaken without face to face contact. In this document specific consideration is given to ethical issues related to **online interviews, online questionnaires** and **use of publically available data**, but there will be others**.**

The fundamental ethical principles that apply to all research continue to be applicable using these methods – see College Research Ethics Framework, and discipline specific ethical guidance.

We acknowledge that a pivot to remote digital research is based on an assumption that people have access to digital technology, whereas that may not always be the case. We encourage researchers to consider carefully which voices may be excluded, and how to address these issues.

There are some existing resources that may be helpful to inform decision making including:

- Association of Internet Research (AoIR): http://aoir.org/
- British Psychological Society (2017). Ethics guidelines for internet mediated research. BPS, Leicester. Access via link
- Information on web based studies from PPLS - http://resource.ppls.ed.ac.uk/lelethics/index.php/frequently-asked-questions/web-based-studies/
- Information on social media based studies from PPLS - http://resource.ppls.ed.ac.uk/lelethics/index.php/frequently-asked-questions/research-with-social-media-data/
- National Centre for Research Methods https://www.ncrm.ac.uk/
- Social Media Research: A Guide to Ethics (undated): https://www.gla.ac.uk/media/Media_487729_smxx.pdf
- Useful crowdsourced document on different methods for fieldwork https://docs.google.com/document/d/1clGjGABB2h2qbduTgfqribHmog9B6P0NvMgVuiHZCl8/preview?fbclid=IwAR04YzC83iM1pHL8FKiB4U20tVfVtXw_Nii7h5jeeMutG_vKjrFr2Ug0VRI
- Useful Twitter Thread on different methods of collecting qualitative data remotely - https://twitter.com/DrAdamJowett/status/1240190672960991233
- University of Oxford guidance on internet-based research https://researchsupport.admin.ox.ac.uk/files/bpg06internet-basedresearchpdf

Key Ethical Considerations: Ethical review processes

It is essential that all projects continue to be subject to independent ethical review. At this time, School Research Ethics Committees (RECs) are being asked to prioritise the timely ethical review of any new projects responding to calls relating to COVID 19. Please note that in most cases these new projects will also require University sponsorship, which should be requested via cahss.res.ethics@ed.ac.uk.

We have outlined guidelines and methods of working that are being adopted by RECs in relation to new applications, and applications with amendments:

- There will be a number of existing projects that will require an ethical amendment as the modes of working switch from face-to-face to an alternative approach. Where appropriate and to expedite the process, reviewers will focus on the Participant Information Sheet, consent procedures, and data management.

- Amendments to projects with vulnerable groups, or where the actual method or sample has changed will have greater scrutiny.

- In cases where researchers have already submitted an application that has not yet been reviewed, but will require amendments in light of the current situation, then we advise researchers to please 'recall' this application for revision.

- In cases where researchers have effectively 'paused' their research, we ask them to be considerate about the review timelines as research in progress will be prioritised.

Key Ethical Considerations in undertaking online interviews

'Online' interviews (including focus groups) can be conducted on a wide range of different platforms, and can be a very useful tool for interviewing when face-to-face interviews are not possible (such as when the researcher is unable to travel to where participants are located), or inappropriate (such as when you are in lockdown). Some guidance on key ethical considerations is provided:

Update: The University of Edinburgh recommend that researchers use their Microsoft Teams account, or Skype for Business, which can be accessed using Office 365 credentials, when undertaking online interviews. These are secure platforms that have been assessed for data protection.

IS have provided detailed guidance on using MS Teams

If your interviewee is from outwith the University, then you will need to invite them as a guest (see FAQ)

In Microsoft Teams, it is possible to **record meetings and group calls** (but not one-to-one calls – so researchers will need to set up a Team and invite participants). Participants are required to consent to the recording on Teams in addition to the usual research consent procedures). On completion of the call, the recording is available to all participants for a period of 20 days. This recording can be downloaded to a local drive, and this can then be immediately uploaded to either Onedrive or datastore, and deleted from the local drive. We recommend that you pilot this process.

If participants are unable to use these methods, researchers should use a telephone and an audio-recording device such as a dictaphone which is then connected to the phone.

July Update – the University has now subscribed to Zoom Enterprise, offering an alternative platform for undertaking online interviews

Further guidance on the technology options available for research are available here

Appropriateness/ Potential Risks

- Consider carefully if the topic is appropriate for an online interview, or if it poses potential risks. For example, if the interview is on a sensitive, traumatic or intrusive topic, then researchers need to consider the implications this may have for well-being of the participant during and after the interview.
- Are there accessibility issues that need to be considered?

Consent

- In most scenarios, the participant should receive the Participant Information Sheet in advance of the interview (likely via email), complete an electronic consent form, and email it to the researcher. It is good practice to then verbally re-confirm informed consent for participation at the start of the interview.

- If the interview will be recorded, then the Participant Information Sheet should clearly stipulate this.
- If it isn't culturally appropriate to collect identifiable consent, then consider how typical procedures could be adapted. Perhaps verbal consent at the start of the interview would be appropriate.
- If capacity for consent needs to be determined then it is important to carefully consider if and how this can be achieved
- If consent may fluctuate during the interview, then it is important to carefully consider if and how this can be monitored effectively.
- If parental consent is needed, then it is important to carefully consider if and how this can be achieved.

Confidentiality

- Consider carefully the setting of the interview so that both interviewer and interviewee have privacy on their devices.
- Researchers should take care to ensure they are in a quiet and private location where their screen cannot be seen by others. It can be a good idea to make use of headphones rather than computer speakers to reduce the likelihood of interactions being overheard if the researcher is in a non-private setting.
- The researcher should encourage the participants to also consider the suitability of their location for the data collection to maximise privacy and minimise potential interruptions, where possible.

Data Management

- In addition to usual data management considerations, it is important to also consider carefully where an interview recording will be stored.
- For example, if you record on MS Teams, the recording will be saved in the 'chat' for the meeting for 20 days, and can be downloaded to the local device. This recording should immediately be uploaded to Onedrive or datastore and deleted from the local device.
- Alternatively – record using a secure recording device?
- In this rapidly developing situation, we understand that the Data Protection Office and Information Services are developing guidance on some of these issues, so please look out for that.

Useful references

Archibald, M. M., Ambagtsheer, R.C., Case, M. G., Lawless, M. (2019). Using Zoom videoconferencing for qualitative data collection: Perceptions and experiences of researchers and participants. *International Journal of Qualitative Methods,* 1-8. (NB the University does not support the use of Zoom – but this reference is retained as it includes useful information regarding online video interviews)

Iacono, L. V., Symonds, P., Brown, D. H. K. (2016). Skype as a tool for qualitative research interview. *Sociological Research Online,* 103-117

Sietz, S. (2016). Pixilated partnerships, overcoming obstacles in qualitative interviews via Skype: A research note. *Qualitative Research*, 229-235.

Key ethical considerations in undertaking online surveys

Online surveys offer another mechanism whereby research data can be collected. CAHSS colleagues have access to two platforms that are licensed to the University:

- JISC Online Surveys – access is granted via Information Services (IS.Helpline@ed.ac.uk) and students will need their supervisor to confirm suitability of use https://www.ed.ac.uk/information-services/learning-technology/survey-tools/online-surveys/using

- Qualtrics –offers a higher specification tool than Online Surveys, and CAHSS have a license for this platform. Staff and students can use this via https://edinburgh.eu.qualtrics.com/Q/MyProjectsSection (My Ed login). Guidance available - https://www.ed.ac.uk/information-services/learning-technology/survey-tools/qualtrics-for-cahss-members

- **NB Use of third party online tools (e.g., Survey Monkey) is not recommended because of data security issues**

Both of these platforms offer the facility to create different question types (e.g., closed; Likert scale; open questions). Some guidance on key ethical considerations is provided:

Appropriateness/ Potential Risks

- Consider carefully if the topic is appropriate for an online questionnaire, or if it poses potential risks. For example, if the data collection is on a sensitive, traumatic or intrusive topic, then researchers need to consider the implications this may have for well-being of the participant during and after the questionnaire.
- Are there accessibility issues that need to be considered?

Consent

- Informed consent can be more difficult as researchers may have limited interaction with participants
- As per usual practice, researchers must provide sufficient information so participants can make an informed decision to participate
- Online questionnaires can be set up so that participation is only possible if participants actively consent to taking part by selecting an option to consent/ continue by checking a radio button or check box. This question should require a response.
- Participants should be able to skip questions that they are uncomfortable with, so avoid mandatory settings (except consent). Participants should also be informed how they can withdraw from the research (i.e., include options to exit survey and/or advise to close browser).
- If capacity for consent needs to be determined then it is important to carefully consider if and how this can be achieved

- If parental consent is needed, then it is important to carefully consider if and how this can be achieved.

Data Management

- Data can be saved on JISC or Qualitrics, and can be downloaded directly to SPSS or Excel files, and these should be stored on Onedrive or datastore.
- If personal data are collected in the questionnaire then once it is downloaded it is important to disaggregate this information from the research data (i.e., save in a separate file)
- For data security reasons, **only** use Online Surveys or Qualtrics via Edinburgh University account

Key ethical considerations in using pre-existing publically available data (including social media data)

Pre-existing publically available data offers a data source for research that overcomes many of the challenges of primary data collection. There is increased interest in using new forms of data (including 'big data'), and this is an area of growing specialist expertise (see links below). Pre-existing data come from many sources (see below).

Research projects may involve use of pre-existing publically available data. Some examples include use of:

- Newspapers
- Magazines
- Public health information leaflets
- Websites
- Blogs
- Policy documents
- Parliamentary records
- Social media including twitter, Facebook etc

Guidance on ethical issues relating to use of data from online data are new and emerging. Some points are detailed below and additional useful resources are listed below. Undertaking research using social media data **will require ethical review.**

Consent

- In using these data, there are some ethical issues to consider around the public ('readily accessible by anyone') or private space of data collection for online materials.
- Opinion is mixed on this, with some seeing such material as being 'fair game' and others expressing more concern. (see BPS guidance)
- In many cases, consent would not be possible – but have participants consented to public use of their comments by posting? This requires consideration to ensure participants' rights are being safeguarded.

Risks and confidentiality

- Consider carefully the extent to which use and presentation of such data may be damaging to participants
- Care should be taken to ensure participants are not identifiable or can de-anonymised (e.g., by triangulating data with information on other platforms).
- Data should not be misrepresented
- Care should be taken when presenting the data so that it is not easily findable, and the participant cannot be traced.

Data management:

- Consult the specific Terms and Conditions of the specific platform or data source (regarding retention, re-use, research usage). Will the proposed research and use, management and storage of the data meet with the data sources requirements? Have all the appropriate documents been completed and permissions granted?
- How will the data be managed? If there is identifiable, personal or sensitive data how will confidentiality be maintained and data kept secure?

Useful resources:

- University of Oxford guidance on internet-based research https://researchsupport.admin.ox.ac.uk/files/bpg06internet-basedresearchpdf
- University of Sheffield research ethics policy note: Research Involving Social Media Data - https://www.sheffield.ac.uk/polopoly_fs/1.670954!/file/Research-Ethics-Policy-Note-14.pdf
- British Psychological Society (2017). Ethics guidelines for internet mediated research. BPS, Leicester. Access via link

The ethics of data usage and particularly data science and AI is a growing area of interest, with growing expertise at Edinburgh (more UoE info to follow). See the following for current useful resources:

https://www.turing.ac.uk/research/data-ethics

https://esrc.ukri.org/files/about-us/policies-and-standards/uk-data-forum/research-ethics-and-new-forms-of-data-for-social-and-economic/

Key ethical considerations in using secondary data sets

Secondary data analysis involves use of data that have been collected by researchers for another purpose. In using secondary data sets, researchers construct research questions that may be answered by analysing the data available. Use of secondary data sets is an efficient method of conducting research, and can be highly ethical as it maximises the value of an investment in data collection, and reduces burden on participants. However, it is important to also consider any potential risks, such as determining consent, identification of individuals, and benefits of the research.

Secondary data sets can come from a number of sources, including:

- 'Safe havens' – a secure environment, where data are managed by trained staff and agreed processes. Data are made available to facilitate research (e.g., NHS Scotland; UK Data Service). Typically, researchers will need to register to access these data sets.
- Existing data sets held by researchers
- Publically available resources

Consent

- In using these data, it is important to consider whether participants have consented to use of the data for secondary analysis purposes. Increasingly, the possibility of secondary use of de-identified data are incorporated into the ethical procedures of primary data collection, including Participant Information Sheets. Data from formal safe haven databases will have addressed this issue.
- Where consent has not been provided, or is not clear, then a robust case for use of the data needs to be presented. For further guidance see https://www.ukdataservice.ac.uk/manage-data/legal-ethical/consent-data-sharing/research-without-consent.aspx

Risks and confidentiality

- Consider carefully if there is a risk of identification of participants and/or disclosure of sensitive data (greater risk with micro data and qualitative data, and where data sources are triangulated).
- Unless working within the strict arrangements of safe havens, then data should be disaggregated from personal identifiable data prior to, or on receipt in order to anonymise the data set.

Data management

- In advance of receipt of data, consider carefully how this data will be stored and managed (see link)
- If there is identifiable, personal or sensitive data how will confidentiality be maintained and data kept secure?
- Will the proposed research and use, management and storage of the data meet with the data sources requirements? Have all the appropriate documents been completed and permissions granted?

Useful resources

- NHS Scotland - https://www.nhsresearchscotland.org.uk/research-in-scotland/data/safe-havens
- https://databigandsmall.com/2015/10/18/research-ethics-in-secondary-data-what-issues/
- https://ukdataservice.ac.uk/

Additional ethical consideration relating to research on sensitive subjects

Appropriateness

- As indicated above, researchers should consider carefully if the topic is appropriate for online data collection, or if it poses potential risks. For example, if the data collection is on a sensitive, traumatic or intrusive topic, then researchers need to consider the implications this may have for well-being of the participant during and after the data collection.

- Additionally, in fulfilling researchers' duty of care to their participants, it is common to signpost participants to support services if there is a risk that they may become distressed due to the topic or sensitive nature of the study. However, given the current situation, and considerable pressure that mental health services are already under then we advise researchers to consider carefully the need to undertake research that would require such signposting.