

Ethical Considerations for Doing Research Remotely: Interviews and Focus Groups

Research done by virtual methods carries risks, including a possible increase in data privacy risk. It is possible that information could be intercepted by unauthorized people (hacked) or otherwise shared deliberately or by accident. These risks can't be eliminated completely, so it is incumbent upon researchers to ensure participants should be made aware of this and steps are taken to minimize this risk.

Researchers may need to prepare flexible informed consent processes for remote methods. And, while logistics might be challenging for obtaining informed consent in person, the ethical principles for obtaining and documenting informed consent have not changed.

Researchers should be aware of the challenges posed by COVID-19 and, in their REB applications, describe the steps clearly that will be taken to ensure informed consent is obtained from participants. As always, the intended informed consent process must be reviewed and approved by the REB prior to implementation.

Researchers should consult <u>Chapter 5</u> of the Tri-council Policy Statement, particularly section <u>C. Safeguarding Information</u>, when in-person activities are replaced by virtual ones.

Considerations

- Is the research sensitive?
- Are any modifications to approved study procedures needed to responsibly carry out these activities?
- Would modifications increase any risk to participants, researchers, the community at large or the institution?
- Are there potential risks to participants, particularly if there is a breach of confidentiality?
- Is it possible to obtain consent in ways other than a signed consent form? Options may include:
 - oral consent via telephone (required: oral script and evidence of documented consent such as via audio-recording);
 - written consent received via email attachment;
 - online consent via Survey Monkey or equivalent.

A 'yes' to any of the above will require the ethics review application to show what steps will be implemented to minimize risk to all involved.



Technologies

Yukon University has technologies to support remote research and allow research teams to communicate with each other and with participants that include:

- Videoconferencing options: Microsoft Teams and Zoom
- Office 365 Suite: deemed secure for collection, transfer, storage of some sensitive information (e.g., de-identified research data)

Recruitment

Researchers should plan to use distance-friendly approaches and formats for recruitment, such as digital or online posters, social media, email, text and telephone calls. An ethics application should describe how the researcher will gain access to email addresses and phone numbers.

Obtaining Consent

Research participants must be provided a full disclosure of all the information necessary for making an informed decision to participate. As noted above, written consent may not be the best method when conducting research remotely. Even with digital forms, it may not be possible for some participants to print, sign, scan and email back signed consent documents. You may need to consider alternatives such as using mail, e-signatures, or having the participant use a mobile scanning app such as Adobe Scan or Microsoft Office Lens, or taking a photo of the signed consent form (if printer but no scanner).

However, an alternative is an **oral consent process**, which is easier for both participants and the researcher during the COVID-19 pandemic.

For **oral consent**, it is best to send a Letter of Information (signature lines removed) ahead of the interview or focus group and follow up to obtain consent using an Oral Consent Script and document consent (see the companion Yukon University oral consent template).

Researchers will need to confirm that the participant has had an opportunity to read through the Letter of Information. An oral consent script will allow the researcher to cover the key ethics information at the time of oral consent without having to read the full Letter of Information as part of the oral consent process. You can also read through the full Letter of Information and confirm that the participant(s) understands and determine if they have any questions before they agree and confirm their participation.

Clear and open communication is vital to ensure that prospective participants understand that different options are available and the researcher will work with them to resolve any challenges or concerns.

Researchers should consider incorporating the following into the consent discussion:



- Confirming at the beginning of the discussion that the individual has the letter of
 information/consent with them and can follow along with the document during the
 discussion. If the consent discussion is conducted using videoconferencing software,
 consider sharing these materials on the screen;
- Pausing during the consent discussion to ask for questions or ask if the prospective participant wants clarification of any information;
- Asking questions throughout the consent discussion to gauge understanding;
- Supporting participants in their use of any technological platforms. Explain in plain language how participants can complete the documentation process.

Online surveys, where the participant is provided a link to the Letter of Information/Consent Preamble and the survey, should continue to obtain consent as before, with participants selecting a "yes" consent button to continue to the data collection or "no" button to leave the study.

The REB application must contain a clear discussion of all aspects of how informed consent will be obtained and documented for the research project. Specifically, the REB will be looking for information on the following:

- Context or location of consent-giving process;
- Timeline between a participant receiving the information letter/consent and being asked to document consent;
- How a participant will receive a fully executed copy of the information letter/consent;
- How subsequent assent will be obtained, if necessary;
- How the informed consent discussion and/or identity verification will occur.

Where applicable or possible, more than one process may be used. The consent process (and any changes) must be approved by the REB prior to implementation.

Following Securing Informed Consent

The participant should receive a fully signed, complete copy of the Letter of Information/Consent in a timely manner. The entire informed consent process, including the details of the informed consent discussions, should be documented for each participant.

Consent is an ongoing process. It may be necessary to provide updated information to participants and obtain their ongoing informed consent. Researchers must remain responsive to participant questions and concerns and ensure they remain informed throughout the course of the research project.



Remote Data Collection: Recommended Practices for Recording Online Interviews and Focus Groups

Recording

The most secure way to audio record interviews/focus groups is to record audio data directly to your computer or device using a recording application. Another option is to record audio through the online meeting platform (Zoom) directly to your computer (i.e., NOT to a remote server or a cloud service). For the latter option, you need to confirm that the platform you are using can record directly to your computer. As soon as the interview/focus group is finished, the audio file should be encrypted and saved to a password protected storage device (computer, external drive). This data security process information must be included in the participant letter of information/consent form. A clear consent statement needs to be included in the Oral Consent Script if audio recording.

Attendance

- Consider the location of the participant(s) and confirm their ability to participate while being in a private location.
- In a focus group setting, audio only increases the confidentiality of participation.
- Consider whether participants can join the interview/focus group by audio only, given not all
 participants may have access to video and there may be bandwidth or other technical
 limitations to the location from which a participant can join.
- If audio only is not an option, this must be made clear in the recruitment and consent materials.

Video Recording

- Online platforms make it easy to video record a meeting.
- Video recording should not be used unless it is essential to your research methodology and is justified.
- If video recording is needed, then this must be stated in the participant information letter and a clear consent statement needs to be included in the Oral Consent Script. Most interviews will not need video recording and in those cases both the participant information letter and consent form (script) should inform participants that the interview/focus group will be audio recorded only and not video recorded.
- If videoconferencing platforms will be used, researchers should be either at the institutional site or log in through a secure remote system (i.e., see Zoom guidance document for information).

Steps to protect participant confidentiality and data when conducting phone and online interviews/focus groups

The following should be considered and addressed in ethics applications if applicable.



- <u>High-Risk Studies</u>: If a researcher will be collecting highly sensitive data and/or there is a
 significant social risk for participants if their data were to be disclosed or it was known they
 participated in the study, researchers should contact the Research Ethics Coordinator for
 advice on how to proceed. Most of the available online services or a standard phone
 connection are appropriate for low- to moderate-risk studies, but higher risk studies may
 need a more secure option.
- Participant Recording of Focus Groups: Any participant could covertly record an in-person focus group if they were so inclined. However, it is even easier to make a good recording of an online focus group without other participants or the researcher knowing, and it could include video. In the section of the Focus Group Guide where confidentiality is discussed with participants, include a statement requesting participants not record the session. Additionally, this risk to participant privacy should be clearly stated in the Letter of Information along with a reminder that researchers cannot guarantee that all participants will refrain from recording the session. For more sensitive data, one-on-one interviews may be preferable to a focus group.
- Recording and Storing Interviews: See the "Recording" section (above).
- Privacy Risks from Using Online Meeting/Voice Calling Platforms:
 - No online platform is 100% secure, so participants should be given enough information to make their own decisions about participating on the selected platform.
 - The Letter of Information should include language that makes it clear what platform(s) is being used, and that no guarantee of privacy of data can be made, so the risks of participation are clear. Here is some sample wording:

This study will use the X platform to collect data, which is an externally hosted cloud-based service. A link to their privacy policy is available here (LINK). Please note that whilst this service is approved for collecting data in this study by the Yukon University Research Ethics Board, there is a small risk with any platform such as this of data that is collected on external servers falling outside the control of the research team. If you are concerned about this, we would be happy to make alternative arrangements for you to participate, perhaps via telephone. Please talk to the researcher if you have any concerns.

Researchers should understand that for data stored outside of Canada there is less control over data protection. For example, data stored on servers based in the USA are subject to the United States Patriot Act that permits US law-enforcement officials to seek a court order that allows access to the personal records of any person without that person's knowledge. Participants should be informed of this. Including the link to the privacy policy is not necessary when using one of the Yukon University licensed videoconferencing platforms (MS Teams or Zoom) for low risk research.



• Keeping Focus Group and Interview Sessions Private: Before using online platforms for interviews or focus groups, <u>researchers</u> should become familiar with the settings and invitation options and take steps to prevent unauthorized persons from accessing the session (e.g., "Zoom bombing"). Most of the time, unauthorized access occurs because the meeting link becomes public. This should be less of a threat for research as the link is likely only to be shared privately with participants. Nevertheless, participants could accidentally disclose the link, and therefore researchers should be aware of options to prevent unwanted access (e.g., two-factor authentication and passcodes) and to address the situation if someone gains access to a focus group (e.g., have screen sharing turned off, know how to remove someone, etc.). For those using Zoom, there is a <u>guide to preventing unauthorized access</u> posted by the company.

Additional guidance available for video conferencing

- REB Guide: Using Video-Conferencing platforms for data collection from human participants
- Using Zoom for research involving human participants
- REB Guidelines for Interviews on Zoom (draft)
- Using Microsoft Teams for research involving human participants

Researchers must maintain appropriate document security and practice good data management practices by ensuring secure storage and eventual destruction of identifiable data. Such considerations are even more important with electronic data retention and third-party platforms and with study staff potentially working remotely.

This information has been adapted from online sources of McMaster University, Western University and the University of Ottawa.