ATENEO DE MANILA UNIVERSITY
UNIVERSITY RESEARCH ETHICS OFFICE

Research and Data Collection with Human Participants During the COVID-19 Pandemic: ETHICS GUIDELINES & RECOMMENDATIONS for Faculty, Staff, Professionals, and Students

AIMS AND SCOPE OF THE RESEARCH ETHICS GUIDELINES

These guidelines are being disseminated to guide research and data collection with human participants during the COVID-19 pandemic. It presents recommendations for proceeding with research activities in an ethical manner and the essential ethical principles which should be considered by proponents and data collectors.

Abiding by these guidelines does not replace institutional ethics review conducted by the AdMU Research Ethics Committee (AdMUREC) or other designated Department/School RECs. These guidelines are helpful but insufficient for research that is intended for knowledge production and publication in a scientific or academic discipline; such research requires ethics review and clearance.

However, the guidelines may suffice for data collection with human participants in activities not considered as formal research (i.e. administrative surveys, pedagogical exercises, etc.) and that do not require institutional ethics review and approval. If you have questions or concerns, email the University Research Ethics Office at director.ureo@ateneo.edu or univresearchethics@ateneo.edu.

GENERAL CONSIDERATIONS

Those undertaking research and data collection activities should review and comply with the directives issues by the University Research Council (refer to URC memo issued 29 June 2020) and other relevant work- and teaching-related guidelines issued by the University President, the Office of the Vice President for Administration and Human Resources, University Data Privacy Office, and the administrative heads of the different University units (Loyola Schools, Ateneo Professional Schools, and Basic Education).

The following general recommendations are relevant to research with human participants:

1. Research with human participants should abide by policies and procedures of the University Research Ethics Office (UREO).
2. In-person interactions with participants, research staff, and colleagues are strongly discouraged, as well as methods that compromise physical distancing and other safety protocols.
3. Alternative methods and activities that permit remote or online meetings and data collection, or that do not require data from human participants (e.g. systematic review of literature; secondary datasets), should be applied as much as possible. Proponents must possess the requisite training,

competence, and supervision to undertake these alternative methods, such as provided by departments or units that have the expertise in such methods.

4. Undergraduate and graduate students cannot be required to engage in class activities (including data collection for pedagogical exercises) that introduce and/or increase the risks of contracting COVID-19.

ETHICAL CONSIDERATIONS

A. Ensure the welfare and safety of research participants and research staff/data collectors

1. The rights, safety, and well-being of human participants are the most important considerations in a research undertaking. All research activities involve some degree of possible risk to the welfare of the people or communities involved. Living in a time of pandemic has changed and increased these possible risks. Following are examples of different possible harms in the context of COVID-19:

    a) Physical harm: Field work and in-person interactions may increase the risk of infection and spread of COVID-19 for the respondents and the researchers.

    b) Emotional / Psychological harm: Everyone is experiencing various stresses and challenges during the pandemic. Increased stress (or distress) may be prompted by topics concerning employment, finances, mental and physical health; or by activities that are taxing, unimportant, or irrelevant.

    c) Social harm: Information obtained from respondents through online methods may harm their reputation or status (e.g. discrimination, negative evaluation) if privacy safeguards are inadequate and the information is inadvertently disclosed/accessed.

    d) Financial harm: Participation in research may entail time and costs that add to the financial burdens that many are experiencing as a result of the pandemic.

    Research activities that may expose human participants to greater than minimal risk[1] of physical, social, psychological, or financial harm are strongly discouraged at this time unless they have the potential to directly mitigate the negative effects of the current crisis.

2. The aforementioned harms cannot be completely eliminated, but must be minimized and reasonable vis-à-vis the potential benefits of the study. Following are key considerations that should shape research objectives, design, and procedures:

    a) Justification for the study: What are the potential direct and indirect benefits for the participants/community/society? Do the potential benefits of the study outweigh the potential risks?

[1] Minimal risk research = probability and magnitude of harm or discomfort anticipated in the study are not greater than those ordinarily encountered in daily life or during performance of routine physical or psychological examinations

Can the study be feasibly and safely done at this time and context? Can the research aims be achieved via methods involving the lowest possible risk of harm?

If in-person or field methods are necessary, can the research be postponed?

b) Scientific soundness and researcher competence: Considering that "bad" science is inherently unethical and can place participants at greater risk, are the objectives and methods sufficiently sound?

Do all the researchers have sufficient competence to undertake (or supervise) the study as designed? Are the researchers trained in the alternate or web-based methods?

c) Mitigation of harm/s: Do the researchers recognize the various possible harms their participants may be exposed to? Are there sufficient safeguards in the procedures to reduce the likelihood and severity of possible harms? Have the researchers identified realistic and reliable steps they would take to adequately repair possible harms should they occur?

d) Data Privacy: Will the research obtain personal information,[2] sensitive personal information[3] and/or privileged information[4] (collectively, personal data) from the respondents? If so, will the collected data be processed in accordance with the Data Privacy Principles? Will there be appropriate safeguards in place to protect the collected data?

Will the respondents be properly informed of the scope and nature of the research, including the extent of data processing that will be involved? Will their consent be secured prior to the data collection? Will they be informed of their rights as data subjects?

3. The potential harms and mitigating considerations also apply to online or web-based data collection.

Online data collection is a relatively safer recourse than in-person interactions but may still involve risks to respondents. It may eliminate physical harm, but still entail psychological, social, and/or

[2] Personal information refers to any information whether recorded in a material form or not, from which the identity of an individual is apparent or can be reasonably and directly ascertained by the entity holding the information, or when put together with other information would directly and certainly identify an individual.

[3] Sensitive personal information refers to personal information:

(1) About an individual's race, ethnic origin, marital status, age, color, and religious, philosophical or political affiliations;
(2) About an individual's health, education, genetic or sexual life of a person, or to any proceeding for any offense committed or alleged to have been committed by such person, the disposal of such proceedings, or the sentence of any court in such proceedings;
(3) Issued by government agencies peculiar to an individual which includes, but not limited to, social security numbers, previous or cm-rent health records, licenses or its denials, suspension or revocation, and tax returns; and
(4) Specifically established by an executive order or an act of Congress to be kept classified.

[4] Privileged information refers to any and all forms of data which under the Rules of Court and other pertinent laws constitute privileged communication.

financial harms (sec A.1). Questions or tasks may be intrusive or provoke distress, and the accessibility of intervention by a qualified professional is difficult at this time. Data collectors do not obtain immediate or reliable feedback on whether their respondents are undergoing distress. The use of web-based applications also increase privacy risks. The aforementioned considerations to mitigate risk should also be applied to online methods.

B. To uphold respect for persons, research or data collection activity must undergo a full informed consent process

1. A fundamental human right and ethical principle is for persons to be able to decide what is in their best interest (assuming they are competent to do so). They can choose freely, without undue influence or coercion, whether or not they will participate in a study and provide the data being requested. Consent can also be withdrawn easily and at any time.

2. To prevent undue influence to participate, offer compensation that is just and commensurate to the effort and time involved in the study, rather than benefits that respondents cannot refuse especially during the pandemic (e.g., offering substantial money or food).

3. Consent must be clear, specific and separate from other terms and conditions whenever possible. To ensure it is informed consent, potential participants must be provided with complete information on:

    a) The purpose of the activity

    b) The risks and benefits of the activity, both direct (affects them personally) and indirect (affects general public), and including physical, social, psychological, and financial risks and benefits

    c) A description of the task/s that respondents will do and/or the questions they will answer, and how much time it will take

    d) The personal data that you will obtain from them, the purpose of obtaining it, how you will secure/keep it confidential, who will have access, with whom it will be shared, when and how you will dispose of it. If the data collection is anonymous, inform the respondent

    e) The complete name and contact information of research proponent (and faculty supervisor, if student) should they wish to withdraw their consent; correct, update or delete any personal data submitted; or if they have questions about or problems with the activity

4. The informed consent must be written or otherwise recorded and given before the respondent provides any personal data. Following are examples of the consent process:

    a) The first page of an online survey contains the purpose of the activity or research and the basis for the consent. The participant must indicate via a tick box that 'YES', they are agreeing to participate. This would prompt the survey to go to the next page. If the

respondent does not give consent and ticks 'NO', then this would prompt a message to close the window or the browser.

b) If data collection is via phone or web-based application (e.g. Zoom, Google Meet, etc) then recorded verbal consent must be solicited after reading a standardized script of the study information (i.e. all info under sec C.2). If the respondent does not agree to give information, then the data collector must accept this and end the call immediately. Alternatively, a written informed consent process may proceed via email correspondence prior to the phone or web call/interview.

c) The strong recommendation (consistent with the Data Protection Act) is to retain a record or evidence that consent was provided, at least for the duration of the study. This can be in the form of online consent that is captured by the web application, or the email correspondence, or an audio/video recording of the respondent giving consent. It is also to the benefit and protection of the respondents if they retain a record of their consent and the information about the study.

d) There may be instances when the informed consent information/process (sec B.3) can be altered or simplified, such as for very minimal risk studies wherein data is collected anonymously. In such cases the alteration of the consent process should not adversely affect the rights and welfare of participants. Research that entails withholding of full information or "deception" in the consent process (e.g. to obtain valid unbiased behaviors) must undergo ethics review by AdMUREC.

5. Involving minors (children below age 18) or persons incapable of giving consent entails more risks and would require consent from parent/s or legal guardians. We do not recommend data collection involving these individuals at this time unless it will directly mitigate the negative effects of the crisis for them. In online research, researchers must take extra care to determine the actual age and judicial capacity of their respondents.

6. For additional guidance on obtaining proper consent, you may also consult the University Data Protection Office's Advisory No. 18-05.

C. Ensure privacy and confidentiality of personal data (see also section A.2.d)

1. As a general rule, the recommendation is to only collect anonymous data (i.e. no means to identify the source) or to pseudo-anonymize data as soon as possible (i.e. identify via codes), if the objective of the research can be achieved using these methods.

   Note that individual email addresses and social media accounts (e.g., Facebook, Instagram, Twitter), often used to solicit research participation especially in this pandemic period, are already considered personal information and must therefore be used judiciously and in accord with the

individuals' privacy rights. Do not provide or forward this information to other parties or use it for purposes other than the research without the explicit consent of the individuals.

2. Ensure that the application used to collect data (e.g. Zoom, Google Meet, Google Forms, etc.) is technically and sufficiently protected from privacy or security threats (e.g., access by third parties who may use the personal data of the respondents for malicious purposes). Be mindful that there are privacy issues in these apps that researchers may not be able to fully control, but they should practice due diligence and take all reasonable measures to mitigate the risks.

   The researchers are responsible for reviewing the privacy policies and terms and conditions of these applications and for communicating possible risks to the respondents. For example, the researcher can include the statement "Google privacy policies apply" with the appropriate link to such policies when a participant is being asked to respond to a Google Form.

3. See to it that there are sufficient safeguards and procedures to ensure the collected data are: (i) stored in a confidential and secure way, (ii) accessible only to a limited number of persons, (iii) processed fairly and lawfully, (iv) used only for the specific purpose, (v) accurate, relevant and kept up to date, and (vi) disposed completely in a secure manner after the specified purpose has been achieved. If the collected data will be retained by the researcher beyond the duration of the study and used for other research projects, this must be reviewed and approved by the AdMUREC.

Contact the UREO for Advice and Assistance

For ethics-related questions and concerns, kindly send an email to: director.ureo@ateneo.edu or univresearchethics@ateneo.edu.