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A Proposed Protocol on the Disclosure of Sensitive Issues in Research Data Gathering: Inputs to Research Ethics Review

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EXECUTIVE SUMMARY

In 2015, the Philippine Normal University (PNU) Research Ethics Committee (REC) was established to ensure that the conduct of research meets the highest ethical standards of justice, respect, beneficence and non-maleficence. Since then, the committee reviewed more than 500 proposals and endorsed approximately 300 completed research reports. Over the years, the committee has been led by esteemed faculty members in the field of research. Likewise the REC passed a number of guidelines including those concerning external and commissioned research projects. In the time of the pandemic, the REC has advocated for online processing of research ethics review with an efficient turn-around time. The whole process is regarded as one of the best practices of the university. In the effort to refine the current implementation of the committee, further guidelines are necessary to ensure research participants' safety and protection. This policy brief covers explorations on how research participants' disclosure of sensitive information be handled in the process of data gathering. The protocol is relevant especially in unexpected disclosures and display of distress. The developed protocol is intended to be part of the current University guidelines to be observed especially when the researchers had explicitly reported that their research projects do not cover sensitive issues. Other higher education institutions (HEIs) are encouraged to develop their own protocol for the same purpose.



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The PNU Research Ethics Committee (REC) currently handles the evaluation of graduate students' proposals, faculty research projects, and commissioned and internally-funded research projects. The research projects are evaluated prior to its actual conduct and after its implementation to ensure that the ethical guidelines were observed and followed. The guidelines serve as bases for approval and certification, with each research project evaluated by content and method experts. Currently, the REC is managed by a chair and co-chair and assisted by the secretariat in ensuring that all research studies are distributed, evaluated, and issued their respective compliance certifications. To date, the REC has issued 58 certifications in the first quarter of 2021, and has released 712 clearances in the past 6 years of implementation.

Applicants for the research ethics review go through a clear screening process in collaboration with various university units, i.e. the Graduate Research Office (GRESO). The bulk of research papers being evaluated is handled by GRESO as students submit their papers for their theses or dissertations. These studies commonly discuss educational constructs which may not need a high level clearance procedure like what is done in medical institutions. However, there are disciplines where the need for a full review is compulsory. As documented, these studies were concerned with counseling and studies involving a special population. The full reviews conducted among these studies required the graduate students to produce clear and unambiguous protocols in handling research participants. Nonetheless, there are research projects where the constructs under study may not be explicitly sensitive in nature but the participants' background may be indicative of information described to be distressing. These information may be outcomes of the selection process or the community that the researcher has chosen. It is also imperative that the types of disclosure be addressed to serve as a buffer for the researchers who in return may experience emotional distress as well (Orr et al., 2021).

This policy brief addresses the needs of the research participant and the researcher. Whether the research discusses a sensitive topic (e.g., abuse, death and dying, depression), or may be potentially sensitive such as parental involvement, the emotional demands may be difficult to handle (Decker et al., 2011). In these cases, an appropriate and reasonable safeguarding measure must be considered to reduce the risks associated with confidentiality breach and data privacy. In studies done where distress is anticipated due to the nature of the topic, recruitment protocols are clear in identifying experiences of high level of stress or emotional distress (Dickson-Swift et al., 2008). Questions pertaining to explorations of thoughts, current emotions, functionality, and safety are outright asked prior to the data gathering proper and information on who to call in case of distress display is asked. Risk assessments are a two-pronged approach with one end highlighting the protection of the participant and the other end the protection of the researcher. There are research ethics committees requiring researchers to report specific information on how researchers will cope with psychological distress from the conduct of interviews or focus-group discussions, however, this practice is not explicitly discussed in the University's REC.

To provide a safety net for both the research participant and the researcher, a set of guidelines is presented to inform, capacitate and provide means for the students and faculty of the University in observing the ethical principles in the conduct of research. The protocol is designed to address disclosures made in the process of research data gathering that are sensitive in content. In a way, the guidelines encourage collaboration when it comes to people who should be involved when dealing with minors, the special population, and other individuals who may be at-risk of experiencing distress during data collection in research. The protocol provides processes that the researchers may use in addressing distress, including referral to professionals (mental health professionals or medical personnel).

In the interest of this policy brief, the following terms are operationally defined:

- a. *Sensitive topic*: is an area which may pose a potentially substantial threat to the research participant. The emergence of topics or concerns in a data gathering session may cause problems for the researcher and/or the data collection, as well as in data holding and dissemination.
- b. *Screening/recruitment guide*: is a guide which includes a script advising non-participation to a research participant who may be displaying or reporting "significant stress or severe emotional distress" because of the research content. The guide acts as a filter which may give information to the researcher to discontinue data gathering and refer the research participant to professionals who may better address the distress.
- c. *Certificate of confidentiality/Non-disclosure agreement*: This is a legal document issued by the researchers to the data gatherers (if applicable and in the case of commissioned or group research). The document



explicitly informs the data gatherers and other research participants not to release identifiable and sensitive information about the research and the other research participants.

The protocol should adhere to the research ethics principles of respect, justice and beneficence. The guiding posts are developed to ensure that the respondents are safe and protected within the confines of the research data gathering. Draucker, Martsof, and Poole (2009) presented assumptions of disclosure among research participants:

1. Participants may want to share their experiences on potentially sensitive topics
2. Participants may be able to endure discussions on sensitive topics;
3. There may be potential benefits in sharing experiences about these topics;
4. Their responses may not necessarily lead to distress or harm; and
5. In rare occasions, there would be participants who would be distressed prior to sharing their experiences and may report negative effects from participating.

A screening protocol for recruitment was earlier mentioned to approximate the mental health of the research participants. This protocol is recommended to be used prior to the actual interview. The suggested questions in the screening may be:

1. Tell me what you are experiencing at this time (*Maaari mo bang ibahagi sa akin ang iyong nararamdaman ngayon?*)
2. Given the types of questions that will be asked, would you like to proceed with the data gathering? (*Gusto mo bang magpatuloy sa panayam na ito, sa kabila ng maaari naming itanong sa iyo?*)

However, researchers may refer to these interventions during recruitment:

- a. If the respondents expressed willingness to be included in the research, they may not be considered to be in imminent danger or acute emotional distress. The researcher may proceed to discussing consent, non-disclosure, and scheduling of the interview with the participant.
- b. If the respondents expressed willingness to be part of the research, but answers to follow-up questions and consent considerations indicate distress or concerns about safety, the researcher should:
 1. Postpone/cancel the interview.
 2. Ask if the respondent needs help and refer him/her to a mental health practitioner.
- c. In rare occasions where the respondents expressed willingness to participate and reported that he or she is imminent danger, or suggested that he or she is, the researcher is advised to:
 1. Report to the authorities (e.g., Violence Against Women and Children Desk (VAWC) desk, local police)
 2. Ask if there are people whom the respondent trusts (e.g. immediate family) to call and make the call.

When it comes to the actual data gathering process, the following guidelines are suggested in handling distress. The researchers should be aware of the following indicators of emotional distress (Draucker, et.al. 2009):

1. When the participants communicate or behaviorally displays that that the interview is too stressful
2. When the participants communicate intentions of self-harm
3. When the participants communicate that he or she may harm others
4. When the participants communicate that he or she might be in danger if another person finds out that he or she is being interviewed



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Table 1 shows instances of distress during interview and the course of action researchers may take.

Table 1

Course of action in case of distress (adapted from Draucker et.al. 2009, Figure 2, p. 348)

Indications of distress during interview	Course of action
When research participants communicate that they are experiencing emotional distress and a high emotional stress OR were observed to display behaviors suggestive that the data gathering e.g. incessant crying, incoherent speech, palpitations, etc.	<ol style="list-style-type: none"> 1. Stop interviewing the participant. 2. Try to provide support. 3. Check his or her well-being by asking: <ol style="list-style-type: none"> a. What are you thinking? b. How are you feeling? c. Do you need help? d. Do you see yourself to be safe here? 5. Identify behavior symptoms and check whether the person can continue in another time. 6. Inform the REC through EPRDC for referral assistance.
When research participants report that they would self-harm	<ol style="list-style-type: none"> 1. Stop interviewing the participant. 2. Try to provide support. 3. Check his or her well-being by asking: <ol style="list-style-type: none"> a. What are you thinking? b. Are you thinking of hurting yourself? c. How do you think would you hurt yourself? d. When do you intend to harm yourself? 4. Check whether the person is an actual threat to himself/herself. 5. Inform the REC through EPRDC for referral assistance.
When the participants express that they are thinking of harming others	<ol style="list-style-type: none"> 1. Stop interviewing the participant. 2. Try to provide support. 3. Check his or her well-being by asking: <ol style="list-style-type: none"> a. What are you thinking? b. Are you thinking of hurting someone else? Who? c. How would you hurt him/her/them? d. Do you have access to them? When are you thinking of hurting them? 4. Check whether the person is an actual threat to others. 5. Inform the REC through EPRDC for referral assistance.
When the participants communicate that they are in danger because of their study participation	<ol style="list-style-type: none"> 1. Stop interviewing the participant. 2. Try to provide support. 3. Determine his or her safety by asking: <ol style="list-style-type: none"> a. What are the reasons why you might be in danger? b. How would the person know that you are part of this study? c. How would the person harm you if they knew of your participation? 4. Check for safety concerns and actual safety measures to be provided. 5. Inform the REC through EPRDC for referral assistance.

In cases where REC is sought for help, the committee through EPRDC will assist the researcher by providing agencies that may address the distress. In particular, referrals may directly be made to the PNU Office of Student Affairs and Student Services (OSASS) for counseling if the research participants are connected with PNU. Likewise, the OSASS counselors are expected to be competent in handling psychological distress felt by the researcher/s. When the researchers are confronted with psychological distress, mitigation strategies are recommended. Protocols for this may include subjecting the researcher for counseling and a debriefing will be held between the REC and the researcher/s (with the adviser if a graduate student).

The protocols presented can add to the good research practices of the University. This practice highlights the synergy between the different units of the University and the researchers, making research everyone's business. More importantly, the use of the proposed protocol promotes better ethical treatment of research participants. Other higher education institutions (HEIs) are encouraged to develop their own protocol for disclosure of sensitive issues during research data gathering. The proposed protocol discussed in this brief can be adopted or serve as a model for the development of their own protocols.

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