WITS HREC (Non-Medical) Distress Protocols

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A distress protocol should be submitted to the HREC (Non-Medical) with the ethics application if the risk includes psychological/emotional harm or distress to participants and/or the researcher. A distress protocol is a step-by-step document which details how the researcher will deal with any distress to participants and/or the researcher during and/or after the data collection process. Research studies categorised as **Low, Medium** or **High Risk** may require a distress protocol that should be submitted along with the ethics application to the HREC (Non-Medical). **Please carefully consider the specific counselling/ support/ informational needs of the community and/or participant groups involved in your research project, in relation to the risk level, topic and research process of your study.**

Information about applicable counselling/support/informational services should be given in full on the participant information sheet. These services must be free and accessible to participants. For **Medium/High Risk studies**, the name and contact details of a particular person (at an organisation) who has agreed to provide support/counselling services to participants should be given on the Information Sheet. The researcher must supply a letter from this counsellor in which they agree to counsel participants in this study, including whether this a free service or who is going to pay for it if not. (NB: participants should not have to pay – if payment is involved, the researcher should be responsible.) Ensure that the nominated counsellor is located in close proximity and/or accessible to the participants. Where possible, avoid making referrals to a generic support hotline like Lifeline or SADAG. For **Low Risk studies**, it may be appropriate to refer participants to more general community-based or NGO support structures.

When negative emotions are expressed during data collection, verbally and/or non-verbally, the researcher will need to consider carefully whether these emotions constitute distress and may cause harm or not. When data collection is taking place remotely (e.g. online or telephonically), the researcher will need to be much more sensitive and attentive to participant responses indicating psychological/emotional distress, because body language may not be easily observable. In addition the researcher cannot immediately intervene physically should distress arise. Therefore, some remote data collection activities may need to be considered very carefully in this regard and in-person data collection may be preferable for some studies - e.g. interviews with persons who may be suicidal, or with persons who have just lost a family member to COVID-19.

The sequential steps to designing a distress protocol (Adapted from guidelines available at https://i.unisa.edu.au/staff/research/research-ethics/human-research-ethics/distress-protocol-guidance2/):

1. Consider and identify the likelihood that risks or distress of different types (physical, psychological / emotional distress) will arise during the data collection process;
2. Identify any key stages during the project when participants could be more likely to experience distress (e.g., during recruitment, during data collection, following data collection);
3. Identify what occurrences/signs will trigger action, including what the researcher will actively monitor / look for during data collection (e.g., the participant breathing abnormally, their facial expressions changing, starting to cry, turning pale or feeling faint);
4. Specify what initial actions will be taken at this point by the researcher;
5. Specify what follow-up actions, if any, can be done by the researcher should a participant suffer adverse events;
6. Identify any support resources that might be referred to / made available by the researcher to the participant, and at what points during the project this information will be provided / reiterated. Contact details for sources of support should ideally be tailored to participant groups – e.g., migrant services for migrant participants, child resources for children, etc. Consider if there are any local services that might be suitable / accessible for the relevant participant group, rather than using a national helpline;
7. Identify how participants may be able to disclose reportable events to the researcher or the Ethics Committee during or after the study, or any mandatory reporting requirements for the researcher and, if applicable, clarify how this will be managed and whether (and under what circumstances) information may be reported to relevant authorities. Please familiarise yourself with relevant Acts that mandate reporting of certain illegal activities and/or abuse. Participants may need to be alerted to the researcher's obligation to report these to relevant authorities.
8. The final distress protocol should be a written document or guide that the researcher should follow if or when an adverse event takes place. This needs to be submitted with your application where applicable.

LOW RISK

Where the only **foreseeable risk is that of discomfort**, e.g., uneasiness, disturbance, mild pain, or where there may be some sensitivity involved in terms of the questions asked.

A distress protocol might be necessary depending on the level of potential discomfort and sensitivity of the questions. Information about free, accessible and appropriate support/ counselling services must be provided for participants on the information sheet if required. ***Include a statement on the risk of mild discomfort due to certain questions in your information sheet.***

MEDIUM RISK

Where there is **a likely risk of some harm** that refers to damage incurred (which may include physical, psychological/emotional, social, economic or legal harm as an outcome of an action, or through emotional distress) for participants and/or the researcher, **but where appropriate steps can be taken to mitigate or reduce risk.**

A distress protocol and/or researcher debriefing strategy should be submitted to the HREC (Non-Medical) if the risk includes psychological/ emotional harm or distress. Information about free, accessible and appropriate support/ counselling services must be provided for participants on the information sheet. ***Include a statement on the risk of likely emotional distress due to certain questions in your information sheet.***

HIGH RISK

Where there is **a real and foreseeable risk of harm** that refers to damage incurred (which may include physical, psychological/emotional, social, economic or legal harm) as an outcome of an action, or through emotional distress, which may lead to **serious adverse consequences if not managed in a responsible manner**.

A distress protocol and/or researcher debriefing strategy should be submitted to the HREC (Non-Medical) if the risk includes psychological/ emotional harm or distress. Information about free, accessible and appropriate support/ counselling services must be provided for participants and/or the researcher on the information sheet and in the application form. ***Include a statement of the risk of real and foreseeable emotional distress in your information sheet.***

DISTRESS PROTOCOL IN THE CONTEXT OF AN INTERVIEW

When a participant indicates during an interview that she/he is experiencing a high level of stress or emotional distress, OR exhibits behaviour such as a trembling voice, crying or shaking, do the following:

- Stop the interview.
- Assess the psychological/emotional status of the participant by probing what her/his thoughts and feelings are.
- If the participant indicates that they feel able to continue, resume the interview.
- If not, arrange to reschedule an appointment to continue with the interview and encourage the participant to contact the counselling service provider indicated on the information sheet if they experience increased distress in hours/days following the interview.
- Follow up with a courtesy call to the participant (if the participant consents).

DISTRESS PROTOCOL IN THE CONTEXT OF A FOCUS GROUP

Ideally, there should be two people, a researcher and an observer, when facilitating a focus group, especially when sensitive topics are involved. When a participant indicates during a focus group that they are experiencing a high level of stress or emotional distress, OR exhibits behaviour such as a trembling voice, crying or shaking, do the following:

- Pause the focus group and offer the participant immediate support, or the observer could remove the distressed participant from the focus group and render the necessary support.
- Assess the psychological/emotional status of the participant by probing what their thoughts and feelings are.
- If the participant indicates that they feel able to continue with the focus group, resume with the focus group.
- If not, excuse the participant from participating and encourage the participant to contact the counselling service provider indicated on the information sheet if they experience increased distress in hours/days following the focus group.
- Follow the participant up with a courtesy call (if the participant consents).
- One distressed participant in the focus group might also cause other focus group participants to become distressed. The researcher should not just focus on the one person but the group as a whole.
- Ask the rest of the focus group members whether they would like to continue with or reschedule the focus group session.
- If the other participants indicate that they would like to continue with the focus group, resume the focus group.
- **Debriefing:** After the focus group has ended and the content summarised to participants, key issues around confidentiality and anonymity should be reiterated. Potential sensitive and problematic issues that were raised during the focus group discussion should be clarified and contextualised where it was not appropriate to so at the time. Participants can then be invited to share their reactions to such matters. The researcher can stay in the room at the end of the focus group and make her or himself available to give individual participants an opportunity to share their reactions.
- If not, reschedule the focus group and encourage the participants to contact the counselling service provider indicated on the information sheet if anyone of them experience increased distress in hours/days following the focus group.

Further reading:

Draucker, C.B., Martsolf, D.S. & Poole, C. (2009) Developing Distress Protocols for research on sensitive topics. *Archives of Psychiatric Nursing*, 23(5), 343-350.

Labott, S., Fendrich, M., Feeny, N.C. & Johnson, T.P. (2016) Evaluating and addressing emotional risks in survey research. *Survey Practice*, 9 (1), doi:10.29115/SP-2016-0006.

Haigh, C. & Witham, G. (2015) *Distress protocol for Qualitative Data Collection*. Manchester Metropolitan University.

Sims, J. & Waterfield, J. 2019. Focus group methodology: some ethical challenges. *Quality & Quantity*, 53, 3003–3022