

Policy in relation to dealing with distress in research

When undertaking research on potentially sensitive subjects, it is important to take account of a participant's wellbeing as well as that of the researcher and anyone else who might be exposed to potentially distressing conversations or material. Even if the research is about a seemingly non contentious topic, it is also worth remembering that events in the participant's life might influence how they feel.

Preparation

Before the focus group or interview, ensure that participants are made fully aware that they may find some of the topics and questions distressing. This needs to be made clear in information sheets and other documentation, and in discussions with potential participants. However, it is important to make the purpose and potential benefit of the research clear to help participants decide on the balance of benefits and risks. These documents also need to stress the voluntary nature of the research and that participants do not need to answer all the questions. In addition, researchers should prepare a list of relevant local and national support or counselling organisations and include this with the information documents given to participants. Potential participants need to have sufficient time (at least 48 hours) after receiving information about the study to decide whether they want to take part.

Researchers should consider offering participants a copy of the questions or discussion areas in advance to help them decide whether to participate, and if they do decide to participate, whether there are some areas they do not wish to talk about.

For interviews and focus groups, researchers should consider whether the venue offers a private and comfortable space. Wherever possible consider the venue or the environment in which the data collection is taking place and consider its impact on privacy and confidentiality. If the environment is a very public setting, advise the participant about your concerns for their privacy and suggest an alternative venue, or time (some venues can be quieter at certain times of the day).

Whatever the setting, researchers should check whether people are contactable if help is needed. This includes interviews and other contacts by telephone or video conferencing platforms.

While the consent process is taking place, remind research participants that they can stop at any time without it being a problem and remind them that they do not need to answer any question if they do not wish to do so.

Participant distress during an interview / focus group

For interviews and focus groups where sensitive topics are being discussed face to face or remotely, researchers could consider asking participants whether they would like a family member or friend to sit in with them or have someone they can talk to afterwards if needed. Bear in mind this would need mentioning in the ethics application. Under most circumstances it would not be appropriate for this accompanying person to join a group discussion in order to retain confidentiality of the contributions unless they were an advocate or communication supporter and so on, but they could be accommodated nearby, so that they might be available to support the participant, if needed. In staffed settings, researchers should check with participants whether it is acceptable for the researcher to let staff know that participants may need some support after taking part. This will also need considering in terms of ethics and information sharing.

It is not always obvious what a sensitive topic is, and an innocent question may trigger a memory of a distressing event. It is worth remembering that studies of people's attitudes have suggested that there may be a willingness to accept that questions may cause upset providing they can see how the findings of the study might benefit others in future.

If a participant expresses distress or appears to be distressed during an interview or focus group, the researcher should suggest a break and offer support. It is good practice for two researchers to facilitate a focus group or group discussion. This enables one of the facilitators to offer to have a private conversation with a distressed participant outside the main room and involve any supporter if one is present. The other researcher can continue the group discussion, if appropriate. In both focus groups and interviews, the researcher should listen and empathise, ask whether the participant wants to continue taking part and see whether they are able to do this.

If the research participant does not wish or is not able to resume the interview or discussion, they should continue to be offered support and advised to contact a family member, staff member or friend as appropriate,

as well as any agency that may be providing them support. The researcher should be understanding, and researcher should refer the participant to any list of other sources of support given to participants.

If the interview or focus group takes place away from the participants' home, the researcher should ensure that the research participant has the financial means to get back home. Ensuring they are able to return home could be facilitated by offering to fund transport or similar.

The researcher should ask whether it would be acceptable to telephone or otherwise contact a participant who became distressed to see how they are. If acceptable, this needs to be done as soon as possible, so the researcher is able to provide any support requested, including contacting someone or an agency if it is the wish of the participant.

If the researcher continues to have concerns for the welfare and safety of the research participant, they should encourage them to speak to their GP, key worker or duty services in relevant local authority or NHS. If the participant refuses it may be a situation where confidentiality should not be maintained - and which will have been explained in the consent process - and advice should be sought from the researcher's line manager. It is important for researchers to be aware of KCL's Safeguarding policy (available here) and familiar with the details of any ethical approvals material which may contain details of agreed arrangements in certain locations or situations.

Closing the interview or focus group

The researcher should consider the interview topic sequence so that the interview does not end with the potentially sensitive topic. The researcher should check how participant(s) are feeling at the end of the interview or focus group, whether they have been obviously distressed or not. They should remind participants about the information about local and national support organisations, given before the interview or focus group and offer copies, if needed. Focus group facilitators should stay in the room or area until the last person has left, offering support, as needed.

Protecting the researcher from distress

Exposure to distressing experiences can have consequences for researchers and support is available from the principal investigator (PI), line managers and peers, as well as employee support schemes within KCL.

The PI or line manager and the researcher(s) should consider the potential impact of the subject matters discussed or raised in these interviews or groups on the researcher and others working on the study. It is advisable to

consider the number of interviews in any timeframe to avoid burnout, as well as the immediate support that should be available to the researcher.

Arrangements should be in place for researchers to know where they can go for an immediate debrief, if necessary, when sensitive subjects are being addressed. Regardless of this, if data collection is being carried out by a researcher working alone, the lone worker policy should be referred to: <https://www.kcl.ac.uk/hscwru/assets/policy/sspp-lone-working-policy-2020.docx>

For focus groups, where two researchers will normally be involved, they should allow time for an immediate debrief and to contact the PI or line managers for further support, if necessary.

Researchers working on projects involving sensitive subject matter should be offered regular debriefing sessions in addition to normal supervision. KCL also offers internal and external support through its Employer Assistance Programme: <https://www.kcl.ac.uk/hr/diversity/dignity-at-kings/support-services/staff-support>

Protecting others from distress

It is important to consider any others who may be impacted by the research. This applies particularly to anyone who transcribes recordings of interviews or group discussions or is present as an interpreter/translator or assistant with communication, but the principles may be applied to contact with others. Such individuals should be referenced in the ethics application and the nature of the project explained to them. They should also be alerted if there is a particularly distressing interview to be transcribed.

Throughout the research process, it should be remembered that, even if they have found certain aspects distressing, participants may also feel that the impact of sharing their experiences has been beneficial overall. Participants often report that their feelings have been validated by their experiences as a research participant.

Feedback

If you have any comments on the contents of this document, please contact the authors so that we can all learn from experiences and insights.

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