

Research with Vulnerable Populations During the Pandemic

These fall under two categories namely, considerations related to ongoing research and principles to consider if planning new Covid-19 human participant studies.

1. Ongoing Research

A lot of thought has been going into whether it is always appropriate to continue with existing data collection at this time. The following points for consideration raised by fellow researchers may help with this decision:

- ensuring the research does not compromise the public health response
- changing levels of vulnerability of participants and researchers due to the current situation, e.g. placing unnecessary burdens on mental health which may already be affected at this time, placing unnecessary burden on professionals involved in the Covid-19 response, added caring responsibilities, changes to working patterns, changes to work priorities.
- collecting meaningful data in the current context
- accessibility/inclusivity (e.g. people experiencing homelessness may not have access to the technology to take part remotely)
- providing appropriate support after the study, e.g. is normal support available at this time? Can we pick up on signs of distress remotely?
- ensuring confidentiality, e.g. when researchers and participants may be at home with other members of their household
- Additional anxiety generated by the use of online technologies (CRESR ethics group)

2. Covid-19 Project Considerations for Researchers Considering New Projects

These are strange times in relation to how we view the vulnerability of populations.

Everyone has heightened vulnerability in relation to Covid-19 and researchers need to acknowledge this, and the expectation is that:

The "All Other Research" route on Converis will be completed for Covid-19 related human participation studies as this allows full consideration of any issues. All Converis research ethics applications related to the effects of Covid-19 will be reviewed by senior staff researchers.

Research studies can have a significant impact on participants and researchers are asked to consider the following to help determine if this is the right time to undertake their particular Covid-19 related studies:

1. The declaration of Helsinki requires that research should do no harm to participants and they should benefit and this needs to be considered in relation to new Covid-19 related projects. Given that many of the population are experiencing heightened levels of anxiety related to their own susceptibility or that of their loved ones to Covid-19, increased stress levels due to loss of work and resulting financial pressures, stress due to working from home, home schooling and other caring responsibilities and so on, thought needs to be given to the impact that a survey relating to Covid-19 may have on such individuals.
2. Related to this is the question of how urgent is it that the research is undertaken now in the midst of the pandemic or could it be equally well done retrospectively when we have returned to 'normal'?

3. There may also be considerations about the quality of data likely to be collected under the current circumstances. Retrospective data may be of better quality.

If the decision is that a study is appropriate for now, care must be given to how research participants are obtained. These are some of the issues to be addressed but there may be others in particular contexts:

- a. Has permission been obtained to contact staff in particular organisations?
E.g. To contact NHS staff Health Research Authority permission is required, similarly permission is required to contact Social Care staff, prison staff probation staff and so on.
- b. Safeguards need to be in place so that especially vulnerable people are not targeted.
- c. There needs to be specific warnings in advance of undertaking the research if questions in a survey, interview, etc. may be anxiety provoking to alert individuals who are already anxious about Covid-19 not to participate.

This is not an exhaustive list, but the aim is to remind us as researchers that our first priority must be to protect our research participants.

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