

# The NCRM wayfinder guide to doing ethical research during Covid-19



The Covid-19 pandemic has brought about significant changes to social research practices. Social distancing and restrictions to travel and access to sites have disrupted research projects and brought about adaptations to methods, introducing multiple and interrelated ethical challenges. The pandemic has raised moral and ethical issues about society in general and has affected everyone involved in research studies – researchers and participants alike. This guide draws on recent literature and workshop discussions to unpack the complex ethical dimensions of conducting research during Covid-19 to provide insight, guidance and ideas.

## Ethical challenges

The continuation of social research during this time has required engagement with particular ethical challenges, compelling researchers to fundamentally rethink their research plans to consider the effect of the pandemic (and any changes to research designs) on participants.

Social research has the potential to contribute many vital insights, not least about life during a global pandemic<sup>1</sup>, yet meeting the ethical imperative to generate such insights brings ethical challenges of attending to important research questions and procedures while attending to participant groups' stresses and uncertainties in the pandemic. Many researchers have been ethically and morally committed to continuing research or responding rapidly with new projects, particularly in research with disadvantaged and marginalised communities disproportionately affected by Covid-19 and the social effects of the pandemic. This includes disabled people<sup>2</sup>, older people<sup>3</sup>, young people without homes<sup>4</sup>, and lone mothers with their children<sup>5</sup>. Equally, for Snow<sup>6</sup> maintaining oral history interviews with NHS patients, frontline workers and policy-makers during the pandemic was seen as a moral responsibility. In some cases, researchers feel a duty to their participants to continue research<sup>7</sup>, yet face the dilemma that such participation can risk putting them in an increasingly vulnerable position. In his participatory action research project with children, Cuevas-Parra (2020)<sup>7</sup> had to balance the increased agency and decision-making of his co-researchers that came with adapting remote methods with heightened safeguarding needs.

According to Malila<sup>8</sup>, researchers should be flexible and agile in their ethical approaches and decision-making, continually adapting to the dispositions of participants

and their circumstances. In doing so, they face the repeated challenge of adjusting their ethics protocol as their research design changes, and we have heard how getting or updating ethics approval has proved challenging for some, especially when ethics committees are having to respond to dynamic situations and the need to prioritise Covid-related research.

## Participant welfare

Researchers should prioritise participant wellbeing throughout the research process<sup>9</sup>, and the current crisis has required they reconsider ethical procedures in response to: (a) the effects of the pandemic, and (b) the effects of adaptations to research methods or modes. Enforced disruptions and gaps in research programmes have left researchers unaware or unsure about how much the pandemic may have affected participants, with the task of re-establishing trust and rapport without over-burdening them. Fell et al.<sup>10</sup> recommend researchers hold back on unnecessary sensitive issues that may be amplified by the pandemic unless they are essential to the research topic. Survey researchers have adopted methods to separate out pandemic-related questioning, such as using supplementary surveys<sup>11</sup> or sub samples<sup>12</sup>, partly to mitigate risks to data validity, but also providing participants with dedicated and reflective spaces to process their responses in an appropriate and ethically responsible way. Social distancing has typically denied us the opportunity to engage in the type of informal social interactions that can help determine a participant's predicament and feelings. Enabling the time and spaces for such 'small talk' remotely is a challenge, and the limitations of online communication restricts visual and communicative cues to participants' wellbeing<sup>13,2</sup>.

While some researchers may be able to draw on previous professional experience (such as in social work and counselling) to communicate appropriately with participants deeply affected by Covid-19, others have highlighted this as an area for which they have had little training.

## Online ethics

The significant shift of methods into online and digital spaces has introduced a range of ethical concerns. Issues around confidentiality and data security and data ownership have proven to be particularly grey areas for researchers we spoke to and, because of the fast-changing technologies, functionalities, licences and practices, up-to-date ethical guidance has not always been available.

Assessing risk to participants remotely is particularly challenging, with the potential for 'off-screen' coercion from third parties. Valdez and Gubrium<sup>14</sup> ensured vulnerable participants were provided with a 'safe place' to conduct video calls. After switching their methods online, we heard how one research team used Zoom breakout rooms to counsel any anxious or distressed participants privately and confidentially. Digital technology has also been used to mediate ethics procedures, with researchers using videos instead of participant information sheets and seeking verbal rather than written consent through online communications.

The pandemic has highlighted familiar concerns around digital divides and researchers have demonstrated an ethical responsibility to mitigating inequalities in both digital access and literacy, such as for those with disabilities and older participants<sup>3,2</sup>. Internet connectivity has also been a barrier. Survey researchers have notably shifted to using computer-assisted telephone interviewing (CATI) in communities in low- and middle-income countries where there is relatively widespread ownership and use of mobile phones<sup>15</sup>. Goldstein et al. (2020)<sup>4</sup> faced the challenge of conducting remote ethnographic research with homelessness in São Paulo without internet access by distributing disposable cameras and mobile phones for participants to capture their experiences during the pandemic.

## Positive benefits to participants

We have also seen how social researchers have explored methods with the potential for promoting participant wellbeing during the pandemic. Interactive

and reflective methods such as diaries (written, audio or video) and interviews with photo-elicitation have been seen to be particularly therapeutic and effective at promoting emotional wellbeing, as well as giving participants a 'sense of purpose' and a feeling they are contributing to documenting the pandemic<sup>16</sup>. Pacheco and Zaimağaoğlu<sup>1</sup> recommend participants adopt a positive outlook as they reflect on their own experiences. After turning to diary writing for their research with young people in the Middle East, Jones et al.<sup>17</sup> suggest their adapted methods provided participants with a space for self-expression. Researchers in lockdown have also shared their autoethnographies in supportive and collaborative projects<sup>18</sup> that promote reflection and a collective ethics of care.

## In it together

Relational and feminist approaches to research<sup>17,19</sup> remind us that the pandemic has affected everyone, leading researchers to consider their own social positions, roles and responsibilities in their relationships with the research topic and their research communities<sup>5</sup>. For some, the increased difficulties in gaining access to participants has underlined the role of gatekeepers and research partners in maintaining relations<sup>15</sup>. However, local researchers in low- and middle-income countries have highlighted how the pandemic has exposed historic and exploitative inequalities within the global research community, with a call for greater recognition and opportunities<sup>20,21,22</sup>.

## Looking forward

Uncertainties remain. As restrictions ease, they may continue to fluctuate and vary across regions. Ongoing discussion and collaboration with participants and research partners will be essential to ensure important research can continue effectively and safely. There remains a continued need for the research community to share coherent and up-to-date ethical guidance, support and resources.

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This guide was produced in 2021 by Andy Coverdale, Robert Meckin and Melanie Nind as part of a series produced from the Changing Research Methods for Covid-19 Research Project. We are grateful to participants in the knowledge exchange workshops for sharing their experiences.

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