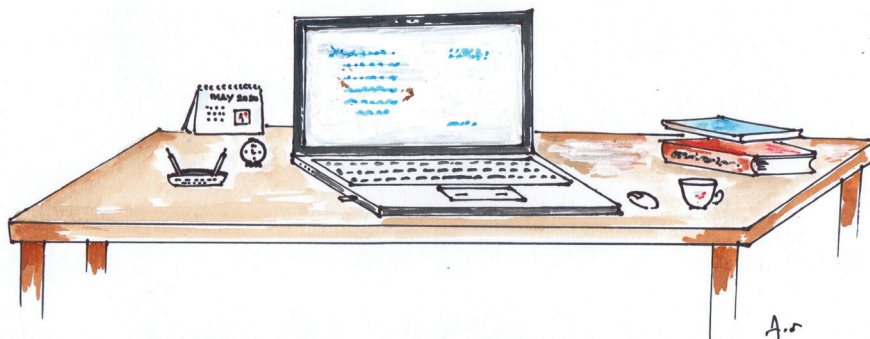# Ethical Considerations of Mental Health Research Amidst COVID-19 Pandemic: Mitigating the Challenges

During these difficult times of the coronavirus disease 2019 (COVID-19) pandemic, when routine clinical care has taken a back seat, it is not surprising to note that there is an almost complete suspension of research work (except those related to COVID-19). The same holds true for mental health research as well. However, times such as these call for greater prioritization of research. As the far-reaching mental health ramifications of the pandemic come to the fore, there is an urgent need to address these issues. A position paper published in *The Lancet Psychiatry* on 15th April 2020 suggests multidisciplinary collaboration and strategies to mitigate the mental health impacts both in the immediate context and the long term.[1] Various guidelines on research during an emergency such as the current pandemic suggest prioritizing research based on how essential it is, relevance to the current scenario, whether it is labor intensive, and the risk of harm vis-à-vis benefits.[2] Indian Council of Medical Research (ICMR) has a guideline for

conducting research during humanitarian crises and disaster, which has addressed the ethical concerns pertaining to an epidemic like the present one.[3] An editorial in the *Nature Medicine* summarized other concerns such as drying up of funds to support further research, to support trainees, and for continuing career development, and premature termination of existing studies. It has also called for supporting scientists and future health research.[4] For this piece, we would like to discuss the ethical challenges for a specific type of health and mental health research.

Use of Information Technology in Mental Health Research

Mental health research is predominantly based on face-to-face interviews. However, such in-person communications in the context of the current pandemic would be potentially hazardous for both the participants and the researchers. An alternative solution is to conduct tele-assessments, that is, assessment of participants by a member of the research team using information technology for communication. The modes of communication could be video or chat (on video or chat platforms like Skype), audio (on the phone), or text (e.g., surveys using Google forms). Internet-based research has been classified into observational, interactive, and survey/interview-based. While observational research is the collection of information that is publicly available, interactive research is in which an investigator contacts the participants for permission to view their web content.[5] The former type

of research is not particularly relevant in the Indian context (because of the lack of a public database), and the latter is not widely practiced in mental health. We would like to focus on the third type of research, that is, surveys and interviews, wherein the researchers share mailed surveys or links on social media and chat platforms, or conduct interviews on an online video platform (e.g., Zoom and Skype). However, this category of online research raises certain grave concerns related to privacy, participant recruitment, and informed consent.

Concerns of Privacy

Adequate provision to protect the privacy of the participants and the confidentiality of the data obtained is an integral part of any research involving human participants. A breach in privacy of either would pose a serious threat of exposure of sensitive and personal information or some illegal or embarrassing act.[6,7] The privacy and security threats of online video-meeting platforms (e.g., Zoom) are critical. Similar concerns also exist for social media networks (e.g., Facebook).[7] Although email communications have double-encryption, a large majority of the potential participants might not have a personal email address. Privacy threats exist in data storage and access too. Cloud could be a potential data storage space and uses double encryption. However, breach of privacy depends on the number of individuals with access to the space. Multiple researchers with access to the data repository would increase the odds of a breach in privacy and confidentiality. ICMR's ethical practice guideline discussed the measures to ensure the privacy of databases maintained in the electronic or digital format.[3] Telephonic interviews suffer from the problem of po-

tential impersonification of participants. All these concerns would magnify in the case of a vulnerable population such as those with mental health problems, as a breach of privacy would further increase their vulnerability.[3]

Concerns About the Recruitment of Participants

Recruitment through the internet could be done using either push or pull technology. The former involves recruitment through social media. In contrast, the latter involves sending direct e-mails or text messages or having a dedicated webpage or mobile application (to be installed by the participants) for recruiting the participants. Both the categories have several limitations. In an ideal scenario, recruitment should follow the principle of justice, that is, it should be fair, and every eligible participant should have an equal chance of getting selected for the study. However, internet-based recruitment suffers from self-selection bias, and there are definite disparities in the access to internet and the expertise in handling online matters, depending on the socioeconomic and the educational backgrounds.[8] Additionally, the existence of multiple online identities, the use of pseudonyms, and the difficulty in verifying the age and demographic data could pose further challenges in internet-based recruitment.

Issues in the Informed Consent

Informed consent requires the participants' voluntary involvement in the study after weighing the potential risks and benefits. Ideally, it is a process in which the participants are provided with information clearly and concisely and they would have the time to read the text and contemplate and have their queries answered prior to consenting.[9] Implementing this is difficult on an online or digital platform, which would at best have a didactic component.[10] Wrong assessment of a participant's mental health capacity is another potential difficulty in the context of mental health research.[11] The latest guideline for biomedical and health research (2017) by the ICMR allowed online

consent for "research involving sensitive data." The examples of such data cited were high-risk sexual behavior, use of contraceptives, behavior related to unsafe sexual practices, etc.[3] Therefore, informed consent obtained using online surveys, or even during a synchronous communication, for mental health research dealing with "non-sensitive" data (e.g., use of the internet during the lockdown and mental health impact of the lockdown) would be considered invalid. Moreover, the ICMR guideline identifies individuals who have mental illness as a vulnerable group and talks about empowering them to the maximum extent possible to enable them to make any decisions. Should the attempt of empowerment fail, legally authorized representatives (LAR) are to be contacted for consent.[3] Online process of obtaining informed consent complicates the application of both these aspects.

We would like to reiterate that these challenges are applicable to research among professionals as well. Online surveys using specific survey platforms or Google forms have become all the more relevant in the current context. Usually, these surveys are conducted in a specified group of professionals sharing a common characteristic (e.g., employees of a specific institute and members of a particular professional society), and in many instances, the researchers too belong to the same professional group. Despite the best intentions, it is almost impossible to protect the privacy and confidentiality of the respondents during such research. From age, demographic data, and professional affiliations, the participants' identities can be inferred even in the absence of definite personal identifiers (e.g., email ID and phone numbers). Informed consent is usually text-based and single-staged. Often, the researchers send these surveys multiple times, creating a subtle pressure on the prospective participant to respond. Sometimes, there is a direct incentive for participation (e.g., having authorship). All these are in direct contravention of the principles of informed consent.

The discussion would be incomplete without highlighting the role of the Ethics Review Boards, which, on the one hand, would have the task of ensuring

a full adherence to research ethics and, on the other hand, have to minimize inadvertent delay in project approval. A recent paper from China showed that the approval rate during the COVID pandemic was significantly lower than the usual times, suggesting hasty preparation of documents.[12] We believe the journals' peer reviewers too must give additional emphasis on the ethical aspects. Internet-based research, because of its aforementioned challenges, would require special attention.

The bottom line is that information-technology-based research presents serious challenges to participants' privacy, fair opportunities for recruitment, and the process of informed consent. Mental health research has additional distinctive concerns with regard to the vulnerable population of interest and the nature of the data.

Mitigating These Challenges and a Window of Opportunity

Amidst all the hardship, pain, and suffering, the COVID-19 pandemic has presented a unique opportunity to revisit digital-platform-based research and to reorient the research ethics. Many of the issues discussed above with respect to the mode of communication are akin to those described in the telemedicine practice guideline drafted recently by the Board of Governors of the National Medical Council, India.[13] A similar guideline focusing on ethical practice in digital-technology-based research on human participants would be an important and much-needed step in this direction. At the international level, the Association of Internet Researchers published their latest guidelines this year.[14] As the nodal agency of health research in the country, ICMR might like to take the lead in drafting such a guideline. However, we acknowledge the diversity across internet cultures, values, and modes of operation, and understand the limits of a single set of guiding principles. Nevertheless, it would provide a foundation for further work. As already mentioned, mental health research would have a substantial stake in this kind of research practice. Hence, the Indian Psychiatric Society (in collaboration with other profession-

al bodies involved in mental health research) might also consider publishing a guideline on the ethics of research based on online platforms.

As the world tries to adapt to life during and after COVID-19, an overhaul of the existing systems is inevitable. The field of research, which forms an integral part of any healthcare system, needs to adjust to these changes. A collective search for answers to the novel challenges one may encounter during the process of change is necessary to keep the system working effectively.

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References

1. Holmes EA, O'Conner RC, Perry VH, Tracy I, Wessely S, and Arseneault L. Multidisciplinary research priorities for the COVID-19 pandemic: A call for action for mental health science. *Lancet Psychiatr* [Online first]. DOI: https://doi.org/10.1016/S2215-0366(20)30168-1

2. Calain P, Fiore N, Poncin M, and Hurst SA. Research ethics and international epidemic response: The case of Ebola and Marburg hemorrhagic fevers. *Public Health Ethics* 2009; 2: 7–29.

3. Indian Council of Medical Research. *National ethical guidelines for biomedical and health research involving human participants.* New Delhi: Indian Council of Medical Research, 2017. Available from: https://www.icmr.nic.in/sites/default/files/guidelines/ICMR_Ethical_Guidelines_2017.pdf.

4. Ghebreyesus TA. Safeguard research in the time of COVID-19. *Nat Med* 2020; 26: 443.

5. Moreno MA, Goniu N, Moreno PS, and Diekema D. Ethics of social media research: common concerns and practical considerations. *Cyberpsychol Behav Soc Netw* 2013; 16(9): 708–713.

6. Buchanan E and Hvizdak E. IRBs and online surveys: Ethical and practical considerations. *J Empir Res Hum Res.* 2009; 4: 37–48.

7. Ohm P. Broken promises of privacy: Responding to the surprising failure of anonymization. *UCLA Law Rev* 2009; 57: 1701–1708.

8. Ameen S and Praharaj SK. Problems in using WhatsApp groups for survey research. *Indian J Psychiatr* 2020; 62(3): 327–328.

9. World Medical Association. WMA Declaration of Helsinki—ethical principles for medical research involving human subjects. *59th WMA General Assembly*, Seoul, Korea, 2008. Available from: www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

10. McKee HA and Porter JE. *The ethics of internet research: A rhetorical, case-based process.* New York, NY: Peter Lang, 2009.

11. Avasthi A, Ghosh A, Sarkar S, and Grover S. Ethics in medical research: General principles with special reference to psychiatry research. *Indian J Psychiatry* 2013; 55: 86–91.

12. Zhang H, Shao F, Gu J, Li L, and Wang Y. Ethics committee reviews of applications for research studies at 1 hospital in China during the 2019 novel coronavirus epidemic. *JAMA.* Published online March 23, 2020. doi:10.1001/jama.2020.4362

13. Ministry of Health & Family Welfare. *Telemedicine practice guidelines.* New Delhi: Ministry of Health & Family Welfare, 2020. Available from: https://www.mohfw.gov.in/pdf/Telemedicine.pdf

14. Franzke AS, Bechmann A, Ess CM, and Zimmer M. Internet research: Ethical guidelines 3.0. 2020. Available from: https://aoir.org/reports/ethics3.pdf