Submitted: 04 Oct. 2021
Accepted: 17 Dec. 2021
Published Online: 24 Feb. 2022

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HOW TO CITE THIS ARTICLE: Suwasrawala SS and Ramamprasad A. Interventions for the Well-Being of Children With Disabilities During a Pandemic: Lessons From COVID-19. *Indian J Psychol Med*. 2022;44(2): 198–199.

ACCESS THIS ARTICLE ONLINE
Website: journals.sagepub.com/home/szj
DOI: 10.1177/02537176211072980

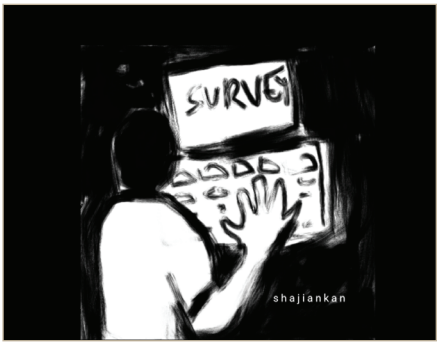
Safety and Ethical Concerns Associated with Conducting Online Survey Studies among Children and Adolescents

To the editor,

There is a surge in online survey studies during the COVID-19 pandemic. This holds for research conducted among children and adolescents too.[1] We want to highlight safety and ethical concerns associated with online survey studies, keeping in mind the vulnerabilities of this age group.

The link for the online study survey is often shared via email or social media platforms (e.g., WhatsApp). There is a possibility of these mediums being abused by certain people with malicious intent to introduce malware, ransomware, or virus into the digital devices (e.g., smartphones, laptops) used by children on the pretext of filling online surveys. Online predators or cyberbullies could use this information to further abuse and blackmail children. Most online survey studies either use email or web-based survey platforms (e.g., Google Form) to collect data. However, these might not be fully secure mediums for sharing personal and sensitive information and are prone to hacking or snooping. For example, the personal information collected on a personality test over Facebook was shared with a third party for individual profiling without participants' knowledge or consent.[2] The available literature suggests an increase in the use of internet media for online child sexual exploitation and abuse by perpetrators.[3] To minimize this risk, the researchers should employ alternative ways of responsibly sharing survey links with children (e.g., sharing survey links via teachers to students in a closed online group).[4] Additionally, using Health Insurance Portability and Accountability Act (HIPAA) compliant online forms (e.g., JotForm) to collect sensitive personal information might be a possible safeguard. HIPAA compliance means that the platform used for collection and/or storage of sensitive information fulfills the updated industry standards (including administrative, physical, and technical safeguards) deemed necessary for ensuring confidentiality and integrity, and availability of data.[5] However, HIPAA-compliant forms or web-survey platforms are not free for mass use, and researchers would need to buy them. This would increase the cost of an online survey study. Further, children should be made aware of potential online risks and ways or steps they could take to ensure digital safety. Both teachers and parents should talk with the children about their online experiences openly and promote digital literacy using child-friendly resources such as a handbook on cyber safety and security for children and adolescents.[6]

The process of taking online informed consent for these studies is inherently different from the one followed in traditional offline research.[7] Often, consent is obtained at the beginning of the online survey by providing formal paragraph-wise information about the study and making the participant (child) click on a button for providing consent on the same online survey platform before moving on to filling the rest of the online survey/study questionnaire. There is seldom any attempt to check whether the child has read and understood the information provided or to clarify any doubts they might have. Many children might not be interested in reading it and skip forward in a routine manner. The researchers should provide the participant information and consent-related information preferably in an age-appropriate, easy-to-follow format (e.g., audio-visual format, images, bullet points).[8] There should be an online



debriefing page at the end of the survey, and participants should again be given an option to withdraw their consent (as they are more likely by then to understand the nature of the data collected). The researchers should preferably mention steps (e.g., storage and back-up of data, de-identification and encryption procedures followed, etc.) taken by them to maintain anonymity and confidentiality of study responses, rather than simply stating the same to participants. Further, the possibility of an inadvertent accidental breach of data privacy should be acknowledged in the participant information section.

Moreover, research has suggested that many children might not understand or appreciate the importance of maintaining data privacy while sharing personal and sensitive information online.[9] This places greater responsibility on the researchers to ensure that all possible efforts are made to make them aware of potential risks and limits to data confidentiality, and also inform them about the possible steps they could take to maintain confidentiality and online safety (e.g., delete browsing history, not share information online that they are not comfortable with, using stickers to cover webcams when not using them, etc.).

The involvement of parental supervision (either directly or indirectly through parental supervision apps like Google Family Link, etc.) while children are filling online survey questionnaires is a potential solution to address some of the concerns mentioned above. Additionally, assent should be taken from children below 18 years, along with consent from a parent or the legal guardian.

The available literature also suggests that formal ethical clearance from review boards is sometimes skipped while conducting online survey studies during the COVID-19 pandemic.[10] This practice should be discouraged, and researchers should either apply for an ethics waiver or take ethical clearance prior to starting data collection.

Thus, there is a need for starting the process of discussion and consensus-building on how best to minimize the risks and maximize the benefits of conducting online research among children by involving different stakeholders such as researchers, parents, child social workers, and representatives from government agencies involved with the protection of child rights and welfare.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

Swarndeep Singh[1] and Rajesh Sagar[1]

[1] Dept. of Psychiatry, All India Institute of Medical Sciences, New Delhi, Delhi, India

Address for correspondence:

Rajesh Sagar, Dept. of Psychiatry, All India Institute of Medical Sciences, New Delhi, Delhi 110029, India. E-mail: rsagar29@gmail.com

Submitted: 31 Oct. 2021
Accepted: 13 Dec. 2021
Published Online: 18 Feb. 2022

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HOW TO CITE THIS ARTICLE: Singh S. and Sagar R., Safety and Ethical Concerns Associated with Conducting Online Survey Studies among Children and Adolescents *Indian J Psychol Med*. 2022;44(2): 199–200.

ACCESS THIS ARTICLE ONLINE
Website: journals.sagepub.com/home/szj
DOI: 10.1177/02537176211070430