

Ethical communication for medical research in the age of information

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Research process

Research design

- What is the purpose and benefit of using electronic methods?
- Which steps of the project can benefit from the use of electronic methods?
- · How will scientific validity be ensured?

Recruitment

- What measures will be taken to protect potential participants with vulnerabilities from additional risks associated with online communications?
- How will the privacy of research candidates be protected?

Informed consent

- Is the information presented online complete, accurate, and not overwhelming?
- How will participants be given appropriate information to match their individual literacy?
- Will participants be guaranteed a chance to ask questions to the researchers?
- How will researchers check that the participants have understood the information provided?
- How will the consent from the participant's legally authorized representative be obtained?

Data communication

 How will researchers handle data that are available but about which participants are unaware (eg, GPS data and data about their devices)

Dissemination / return of results

- How will sufficient medical, psychological and social care for the patients be provided?
- How often will progress and results of research be disseminated to participants?
- What local regulatory or legal requirements should be followed associated with this process?
- What is the potential impact on existing health care system and its sustainability?

Overarching perspectives

Access to research and online dialogue

- How will the security of communication be protected?
- · How will the digital divide be handled?
- · How will participants be authenticated?
- Will the possibility of miscommunication be considered?

Involvement of target population

- What is the strategy for "community" involvement?
- Are the online communication tools for each research process well accepted by the target "communities"?
- · How will the responsibility be shared?
- · How will the benefits of research be shared?

Independent review

- How will the research protocols be reviewed when the research is planned in a certain country and participants are recruited from foreign countries?
- Will the research be reviewed from the technical perspective of electronic methods?
- · Will privacy risks be accurately reviewed?

The five boxes on the left show the research process and the three boxes on the right show overarching perspectives related to the five processes. Each box



contains the main benchmarks for that issue or process. Credit: Atsushi Kogetsu and Kazuto Kato

Since its inception, the Internet has fundamentally changed all parts of human society for both good and ill, and medical research is no exception. The fast pace of change enabled by digital technologies means that ethical guidelines may not address all the issues that arise in modern research. To help solve this problem, researchers from Osaka University performed an ethical analysis based on the eight ethical principles for clinical research and they proposed an ethical framework and practical guidance for communicating with research participants through the Internet.

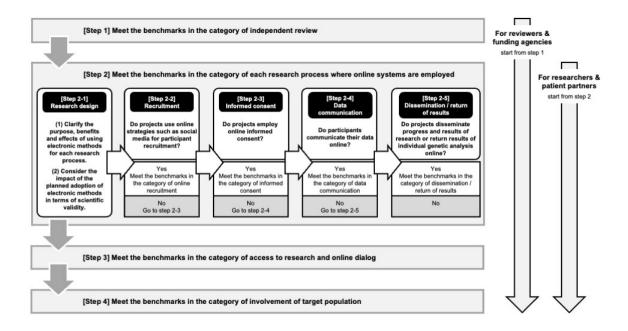
The ability to recruit study participants regardless of geography is a major advantage of electronic communications, such as for studies of rare diseases, where it is often difficult to find enough participants in a defined geographic area to ensure <u>scientific validity</u>. However, the ease and scale of electronic communications has also led to serious problems such as violations of privacy, duplicate registrations, and misinformation that existing ethical guidelines didn't anticipate.

"Currently, there are no comprehensive rules or guidelines for the various electronic methods used to communicate with research participants," says Atsushi Kogetsu, lead author of the study, "and that includes methods for collecting electronic informed consent and online recruitment." Hence, the authors performed an ethical analysis to determine what the issues are and how they relate to each other.

The analysis is based on the Emanuel framework, which consists of eight ethical principles for clinical research: collaborative partnership, social value, scientific validity, fair participant selection, favorable risk-benefit



ratio, independent review, informed consent, and respect for participants. For instance, the researchers found that although there are many advantages to online communications, it is important to consider how patient access to the Internet varies according to circumstances and culture, which could affect participant recruitment, leading to selection bias.



This guidance chart mainly consists of four steps. Step 1 is for independent reviewers and funding agencies, and steps 2, 3, and 4 are for reviewers, funding agencies, researchers, and patient partners. Credit: 2022 Atsushi Kogetsu and Kazuto Kato

"We also need to be careful how we present information to study participants," says Kazuto Kato, co-author of the study. "It's important to remember that the lack of nonverbal information when using some online tools can lead to miscommunication. We need to make sure that



information is complete and accurate but not overwhelming."

The proposed framework covers both the specific processes involved in medical research (from research design to the dissemination of results) and three overarching perspectives (access to research, community involvement, and independent review). It provides the practical steps independent reviewers, funding agencies, researchers, and patient partners can use to ensure all ethical guidelines are followed. The researchers believe the results of this study and its framework will improve future practice in medical research using the Internet.

The research was published in the *Journal of Medical Internet Research*.

More information: Atsushi Kogetsu et al, Framework and practical guidance for the ethical use of electronic methods for communication with participants in medical research, *Journal of Medical Internet Research* (2022). DOI: 10.2196/33167

Provided by Osaka University

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