

Protections needed for some people who say no to research, study concludes

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Although federal regulations provide protections for people who participate in research, protections are also needed for some people who decline to participate and may face harmful repercussions as a result, concludes an article in *IRB: Ethics & Human Research*.

In addition, the authors say that deception may be necessary and ethically justified as a means for researchers to protect decliners from those who might harm them because they chose not to enroll in a study. People in need of such protections include prisoners and others in vulnerable circumstances.

The article is based on findings from the authors' ongoing study, funded by the National Institute of Mental Health, of what influences prisoners to decide to participate in research. The authors realized it was difficult to ensure that prisoners were voluntarily enrolling in their study, rather than enrolling because they were afraid of negative consequences from prison administrators if they declined.

The first solution the authors devised was to talk with prison administrators about the importance of voluntariness. However, they found that such communication "may not reduce the perception of negative consequences for declining to enroll in a study."

The authors then concluded that deception was ethically justified to protect inmates who did not want to volunteer for their study. They protected these people by giving them the option to stay with the

researchers for as long as it would take participants to complete the study. The idea was to make it difficult for corrections staff to distinguish the participants from the decliners.

Four inmates asked for this option "These individuals asserted that they felt coerced by the staff of the facility to participate and believed that if they did not participate, they would be penalized," the authors wrote.

The authors proposed other options for protecting people who decline to volunteer for studies, including having the researchers say that these people did not meet the study's eligibility criteria. "All of the approaches designed to protect decliners obviously involve deception," the authors write. "In our view, the obligation to protect participants (and decliners) from illegitimate sanctions outweighs any obligations to disclose fully the bases for our decision to exclude an individual from a study."

While their study involved prisoners, the authors identified other populations who are vulnerable to harm if they decline to participate in research: students concerned that their grades will be affected if they don't enroll in their professors' studies and patients worried that the quality of their medical care will suffer if they do not enroll in their doctors' studies.

Provided by The Hastings Center

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