

Despite best intentions, researchers don't always share findings with study participants

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Dr. Teresa Kelechi, associate dean for research in the College of Nursing at the Medical University of South Carolina, co-led the study examining whether and how study participants wanted to learn about trial results. Credit: Sarah Pack, Medical University of South Carolina

Researchers and the participants who enroll in their clinical trials do not always speak the same language, making it difficult to share trial results

with study participants.

As a result, most clinical trial participants are not told the results of the study in which they were involved, though most would like to know, and most researchers would like to tell them, report Medical University of South Carolina (MUSC) researchers in an article published in the *Journal of Clinical and Translational Science*.

Helping researchers to learn how to translate their findings for a lay public could make participants feel like respected partners in research and potentially increase the number of patients willing to enroll in trials.

Study participants deserve the right to hear those results and know their efforts made a difference, said the two National Institutes of Health-funded MUSC translational researchers who led the study: senior author Teresa J. Kelechi, R.N., Ph.D., associate dean for research in the MUSC College of Nursing, and lead author Cathy L. Melvin, Ph.D., a professor in the Department of Public Health in the MUSC College of Medicine. The study was funded by a special commission pilot project grant from the South Carolina Clinical & Translational Research (SCTR) Institute, the Clinical and Translational Science Awards hub headquartered at MUSC.

Translational research is about "translating" research breakthroughs into clinical practice, but it is also about translating research results into meaningful messages for members of the community, particularly those who made the research possible.

"So part of translation is not only translating from bench to bedside but also translating your findings back to the participants who made it work," said Kelechi. "At the end of the day, it's because of them that we're doing science."

Kelechi and Melvin interviewed and ran focus groups for past study participants to find out whether and how they would like to receive study results. The study also canvassed researchers to determine whether they were willing to share results and identify any barriers to doing so.

Of the 48 past study participants surveyed, almost 70% never received the results from the study in which they participated, though 75% would have liked to. The vast majority of researchers surveyed—95% - thought it was important, and even an ethical duty, to report findings to study participants.

If informed of findings, many study participants also expressed a willingness to share them with friends, health care providers and others with the same condition. As such, participants could become champions for research in the community, helping to disseminate findings while encouraging others to participate through their example.

Study participants expressed different preferences for how to receive study findings, based on their ages. Two groups of study participants were surveyed: teens/young adults and adults older than 50. The top preference for both groups was email, but older adults greatly preferred mailed letters, postcards, newsletters or calls to texts or social media, while teens/[young adults](#) expressed a strong preference against mailed correspondence or newsletters.

The researchers surveyed said they had received little training in communicating to a lay public through age-appropriate channels. Several of the surveyed researchers expressed a desire for more training through workshops as well as templates for a variety of communication documents.

"For me, this was an eye-opening experience," said Kelechi. "I've been doing research for 20 years but was unaware how much the research

community feels unequipped to report their findings to study participants. They want to give back, but that is not a skill set that they have, but it is one they want to develop."

To meet that need, Kelechi and Melvin have already developed a number of communication templates and are currently working to refine them further. They also would like to develop lunch and learns and an online module on the topic. At MUSC, researchers can also request recruitment consults and marketing assistance from SCTR via the electronic tool SPARCRequest.

Researchers were also unsure if they should communicate preliminary, partial or equivocal findings to participants. Melvin thinks they should. "Whatever the results are, researchers have a responsibility to share that information back to the participants," she said.

Funding can be another barrier for researchers. Most monies dedicated to communication in a grant are used to recruit patients, leaving little at the end of the study to cover the costs of disseminating the findings. Kelechi suggests that researchers buy postage and other supplies ahead of time to ensure that they have the necessary resources at the end of the study.

Kelechi and Melvin are confident that the gap in communication between researchers and study participants can be bridged.

"We have two groups of people who want the same thing, which is to share information with each other," said Melvin. "So, given the good will on both sides, I'm very optimistic and feel that there is a real opportunity for us to make a difference in this area."

More information: Cathy L. Melvin et al, Communicating and disseminating research findings to study participants: Formative

assessment of participant and researcher expectations and preferences,
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