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UAMS Aims to Improve How Researchers Share Results with Study Participants

FAYETTEVILLE – More than \$180 billion are spent each year in the U.S. on medical and health research, with hundreds of thousands of people taking part. However, the results of those studies are often not returned to participants.

Researchers at the University of Arkansas for Medical Sciences (UAMS) are trying to change that. Chris Long, Ph.D. (senior research director in UAMS Office of Community Health and Research), Rachel Purvis, Ph.D. (assistant professor in the College of Medicine), and Pearl McElfish, Ph.D. (vice chancellor for the UAMS Northwest Regional Campus), are national experts in the ethics, need and methods for returning results to participants.

While researchers acknowledge that they should share results with participants, they admit they rarely do. In a 2016 study published in “Clinical Trials,” Long, McElfish and colleagues found that over 90 percent of participants want to receive results. But only 33 percent ever do.

A new study conducted by the research team showed that health researchers face several barriers to returning results, including financial barriers (lack of funding), systems barriers (lack of incentives or requirements to share results), skill-related barriers (lack of knowledge about how to share results with non-scientists) and ethical concerns (concerns that participants may misunderstand or misuse the results). Over 80 percent of researchers reported each one of these barriers applied to at least some of the health research studies they have conducted.

“Researchers generally express support for sharing results with participants,” Long said, “but in practice, they feel unprepared or unwilling to do so. Although the solution appears straightforward – just require federally funded researchers to offer the results to their participants – there are gaps in our knowledge that suggest a more deliberate approach might be better.”

To address these knowledge gaps, UAMS is testing the best methods for sharing results with participants and has established the UAMS Northwest Regional Campus as a nationally recognized research program in research dissemination.

The research team believes public and private research funders can play an important role in ensuring participants receive research results from the studies they participate in, and they have recommended that funders consider ways to increase the sharing of results beyond scientific journals and conferences.

For example, funders could require results-sharing plans as part of researchers' applications for funding, and they could require that a portion of grant funds be used specifically to share results with lay audiences and participants. At the same time, funders would need to increase grantees' skills and comfort with sharing results more broadly. For example, funders could provide tools and training, such as webinars with science communication experts, which would support grantees' efforts to share results with participants.

The research team's work suggests that funders, researchers and health research participants each have a part to play in improving the communication of research results.

“Collaborative research involving researchers, funding agencies and participants can produce an evolving set of evidence-based guidelines and tools for effective results sharing with participants, and will ultimately make health science more ethical and accessible to everyone” Long said.

The research team's new study can be found at this [link](#). Additional studies are currently underway as well.

UAMS is the state's only health sciences university, with colleges of Medicine, Nursing, Pharmacy, Health Professions and Public Health; a graduate school; hospital; a main campus in Little Rock; a Northwest Arkansas regional campus in Fayetteville; statewide network of regional campuses; and seven institutes: the Winthrop P. Rockefeller Cancer Institute, Jackson T. Stephens Spine & Neurosciences Institute, Harvey & Bernice Jones Eye Institute, Psychiatric Research Institute, Donald W. Reynolds Institute on Aging, Translational Research Institute and Institute for Digital Health & Innovation. It is the only adult Level 1 trauma center in the state. UAMS has 2,727 students, 870 medical residents and five dental residents. It is the state's largest public employer with more than 10,000 employees, including 1,200 physicians who provide care to patients at UAMS, its regional campuses, Arkansas Children's Hospital, the VA Medical Center and Baptist Health.

The UAMS Northwest Regional Campus includes 250 medical, pharmacy, nursing and health professions students, 50 medical and pharmacy residents, and 1,000 community-based faculty. The campus has nine clinics providing advanced health care. Faculty conduct research to improve community health. Visit www.uams.edu or www.uamshealth.com. Find us on [Facebook](#), [Twitter](#), [YouTube](#) or [Instagram](#).

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