

Study examines perceptions of benefits and risks of data sharing in dementia research

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Expectations for data sharing among scientists and returning research results to study subjects have evolved in recent years. A new study led by a Georgia State University researcher underscores potential barriers to

sharing data related to a relatively rare form of dementia known as frontotemporal lobar degeneration (FTLD).

In a new study [published](#) in *Alzheimer's & Dementia*, Associate Professor Jalayne Arias in the GSU School of Public Health examined the views of investigators who study FTLD as well as research participants.

The study found that researchers contend with a tension between making data widely available and protecting their career interests. Researchers also expressed concerns about protecting the privacy of study participants in the context of a [rare disease](#) with a strong genetic component.

Many study participants, Arias and her colleagues found, reported being motivated to enroll in a study to learn their genetic status. While they typically said they trust the research team, they reported varying levels of understanding of how their data could be shared.

"FTLD is a rare disease, so that heightens the value of data sharing for researchers," Arias said. "From the perspective of a study participant, the strong genetic component of the disease can motivate them to enroll in a study, but it also has the potential to make them more identifiable."

Arias and her colleagues conducted semi-structured interviews with 17 researchers and 17 participants for their study. The findings laid the foundation for broader study that is surveying 1,000 researchers nationwide who study Alzheimer's disease and Alzheimer's disease-related dementias.

Their work comes on the heels of a [2023 National Institutes of Health Data Management and Sharing Policy](#) that seeks to establish a foundation for equitable and effective sharing practices. Researchers are working to develop standards that are specific to their projects and

institutions, Arias said, but consistency among data sharing practices is lacking.

"Investigators may in theory value and appreciate data sharing, but in practice there may be barriers to sharing data," Arias said. "This study has helped unearth insights to help better understand barriers and the facilitators to [data sharing](#)."

More information: Jalayne J. Arias et al, Data stewardship in FTLD research: Investigator and research participant views, *Alzheimer's & Dementia* (2024). [DOI: 10.1002/alz.13719](https://doi.org/10.1002/alz.13719)

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