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Nothing about us without us: giving voice to persons with a diagnosis, family members and care partners through research participation

STATE OF THE ART

Opportunities for patients, caregivers and research participants to become advocates is important to promote research participation, develop person-centered research protocols and define clinically meaningful outcomes. Despite this importance, multiple barriers exist for patient engagement due to challenges related to cognitive impairment and communication difficulties.

METHODOLOGY

The ALLFTD study was established as a multicenter collaborative project to further research in the frontotemporal degenerations (FTD). As part of the study, the ALLFTD Participant and Family Engagement Board (Board) was created as a platform to advise principal investigators and study staff on participant and family priorities.

RESULTS

The Board launched in February of 2021 with the development of a charter and call for nominations from individuals currently enrolled in ALLFTD. Board members include two individuals living with a diagnosis of FTD, two care partners and one member of a family impacted by an inherited (genetic) form of FTD. Board meetings yielded contributions to an educational flyer and a recruitment email. To support the participation of members living with an FTD diagnosis, preparatory and follow up meetings were conducted, transcriptions and recordings were compiled for offline review and speech language pathologists were present at meetings to provide communication support.

CONCLUSION

To acknowledge personhood and dignity at each stage of the lived experience of FTD and related dementias, we must offer platforms that allow for amplification of the patient voice. Accommodations for individuals with communication challenges and cognitive impairment takes additional planning and resources to yield full participation, but can succeed!

