

FTD Disorders Registry (FTDDR) Minority Engagement Survey: Exploring Remote and Digital Strategies to Engage Minority Populations for Frontotemporal Degeneration (FTD) and Other Research

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Background

Engaging diverse populations in research supports health equity and ensures discoveries for all. Registries like FTDDR are often national or global initiatives without local presence for face-to-face recruitment. Although published data exists regarding barriers and facilitators in general, recommendations for web-based, patient registry research do not. **The FTD Disorders Registry Minority Engagement Survey explored best practices for minority engagement with a digital and remote focus.**

Methods

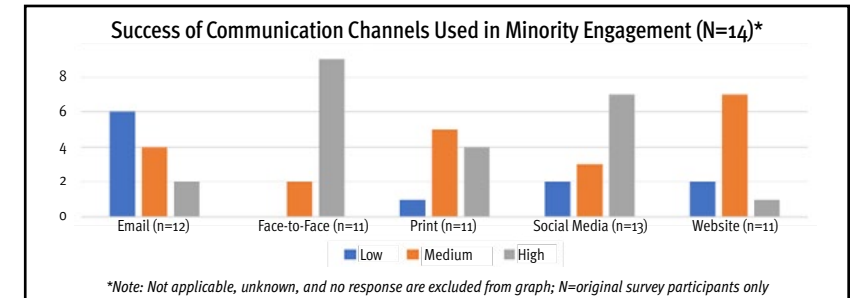
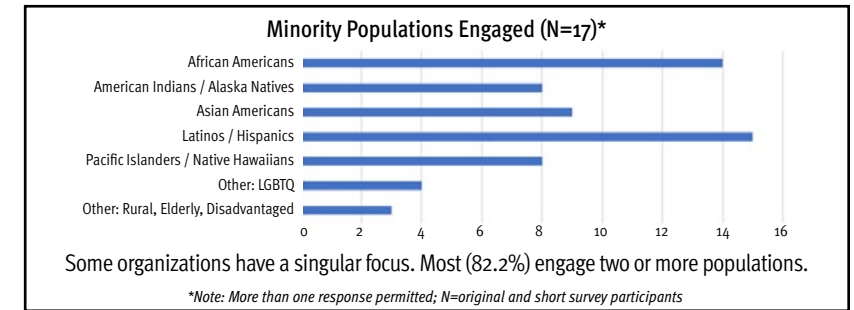
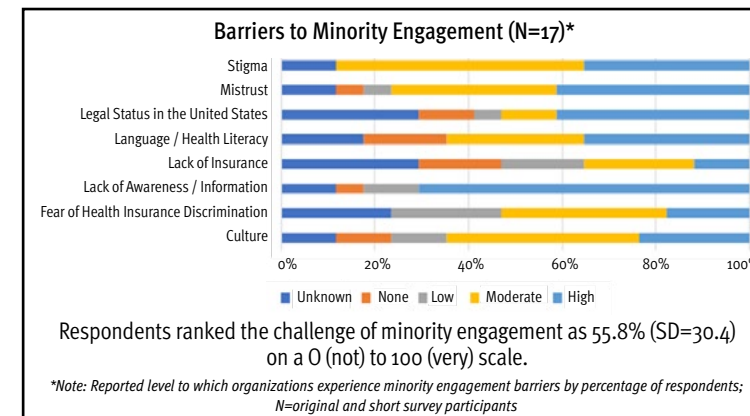
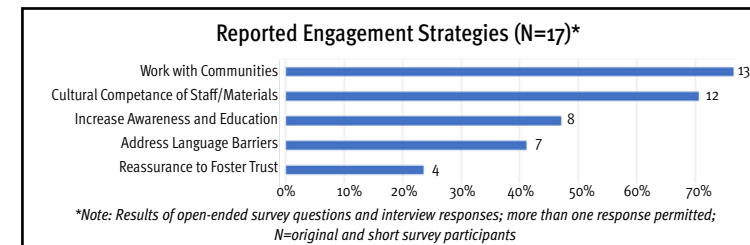
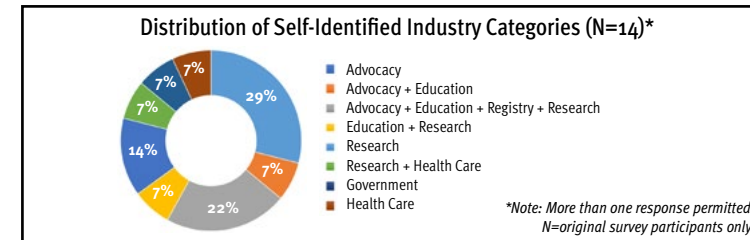
- A mixed-methods approach was used.
- Persons with an interest or expertise in engaging diverse populations within neuroscience or registries were identified among 36 organizations.
- A 38-item survey was created based on 11 themes from literature review.
- Open- and close-ended questions focused on participant demographics, minority engagement barriers/facilitators, communication strategies, cultural competence training, and partnerships.
- Non-responders received a 9-question, shortened version of the survey.
- Willing participants completed a 30-minute, post-survey interview.
- Results were summarized and analyzed for common themes.

Recommended Practices for Engaging Minority Populations

- Partner with communities.
- Enlist dedicated staff/committees to prioritize inclusive engagement.
- Increase awareness of research and health-related information in minority populations.
- Ensure cultural competence of staff, messaging, and materials.
- Address language barriers.
- Select the appropriate modes of communication.
- Offer reassurances to foster trust.
- Communicate research progress and findings.
- Reduce participant burden.
- Consider/address stigma and negative consequences for participants.
- Ensure that technologies are user- and mobile-friendly.

Results

- Response rate: 17 (47.2%) total; 14 full survey; 3 short survey; 5 interviews.
- 62% of organizations reported adjusting their existing or creating new communications modes for minority engagement.



Discussion & Conclusion

- Practices for minority engagement aligned with literature findings.
- Organizations attempting to engage more minority groups (≥ 4) reported a greater challenge than those with focused engagement.
- Digital and remote strategies included multiple targeted social media accounts (public and private) involving trusted community advisors.
- Interview questions yielded key insights such as:
 - Long-term relationships with communities versus episodic engagement.
 - Cultural tailoring of materials versus literal translations.
- Study limitations include small sample size and pre-COVID-19 data collection.
- **While additional studies are needed to better define best practices, FTDDR has outlined and implemented an internal multi-point action plan for our minority engagement in registry research.**