FTD DISORDERS REGISTRY®

FTD Disorders Registry Engagement of Minority Populations Report

DEMENTIA, MINORITIES, AND REGISTRIES

L YOUNGBORG, S HARLASS, S REDDY, L VINCENT, AND D HUGHBANKS-WHEATON

Engagement of Minority Populations

Abstract

Background. With recent studies suggesting that certain ethnic and racial minorities may be disproportionally impacted by dementia, an increasing number of organizations are exploring minority engagement in dementia research and education. This has led to a wealth of published literature on this important and timely topic. While such studies and guidelines offer strategies for engaging, recruiting, and retaining minority participants in general, there is a lack of published data specific to web-based health research. The aim of this report is, therefore, to explore best practices for minority engagement, with a special focus on digital and other remote strategies.

Methods. The project used a mixed methods approach (survey and qualitative interview) to explore the current landscape of minority engagement. Survey findings are presented as descriptive statistics. Qualitative data, including open-ended survey questions and responses recorded during follow-up interviews, were analyzed for common themes.

Results. Of the 36 organizations identified, 17 (47.2% response rate) participated in the survey, five of which also contributed information via qualitative interviews. When participants were asked to rate how challenging minority engagement is for their organization on a scale from 0 (not at all) to 100 (very), the mean response was 55.8 (SD=30.4). Perceived barriers to minority engagement included lack of awareness of research opportunities, lack of trust, different cultural beliefs, communication challenges, fear of health insurance discrimination, lack of insurance, legal status in the United States, and stigma.

Common practices for engaging diverse populations reported by the surveyed organizations aligned with those identified in the literature. They included: (1) partner with communities; (2) enlist dedicated staff and/or committees to prioritize inclusive engagement; (3) increase awareness of research and health-related information in minority populations; (4) ensure cultural competence of staff, messaging, and materials; (5) address language barriers; (6) select the appropriate modes of communication; (7) offer reassurances to foster trust; (8) communicate research progress and findings; (9) reduce participant burden; (10) consider and address stigma and negative consequences for study participants; and (11) ensure that technologies are user- and mobile-friendly.

Conclusion. This report outlines barriers to and suggested practices for minority engagement as identified in the literature and through solicited input from organizations across a variety of industries. The FTD Disorders Registry (FTD Registry) will translate the data collected via this minority engagement discovery into a multi-phased strategic plan for engaging, recruiting, and retaining a more inclusive and diverse population of individuals who are impacted by frontotemporal degeneration (FTD).

Introduction

Dementia describes a group of conditions characterized by difficulties with memory, language, problem solving, and other cognitive skills that affect a person's ability to perform everyday activities. Although dementia affects people of all races and ethnicities, recent studies suggest that certain minority populations may be disproportionately impacted. For example, numerous studies have demonstrated an elevated risk of dementia among African American and Latino populations despite variations in designs, sampling methods, and definitions of dementia. These studies consistently report that African Americans and Latinos have 2.0 and 1.5 times the odds of dementia, respectively, compared to non-Hispanic whites. Racial and ethnic differences in dementia risk may result from biological, behavioral, sociocultural, and/or environmental factors.[1]

The engagement of diverse communities in clinical research is important because it supports health equity and ensures that research discoveries are generalizable to all populations. Unfortunately, participation in research studies is lower among some racial and ethnic minorities, reducing the applicability of research results to these populations. Despite their underrepresentation in dementia and other research, studies show that individuals from minority populations, in general, are as likely as non-Hispanic whites to consent if they are offered the opportunity.[2, 3]

Patient research registries are uniquely positioned to bring the voices of minority communities to health disparities research. When registry participants share their experiences, they help research funding agencies, pharmaceutical companies, regulatory agencies, and patient organizations learn how to best serve their communities and focus on the issues that are important to them. Strategies for engaging diverse populations in registries are, therefore, essential to ensure that everyone is represented in this patient-centered research.

Although there is a wealth of published data regarding barriers and facilitators to diverse research participation in general, recommendations specific to web-based, patient registry research do not exist. Such registries are often national or global initiatives which may not have the local presence necessary to deploy the face-to-face recruitment strategies often cited in the literature. Community-based engagement strategies may also be less successful for rare disease registries since the studied condition may only affect a small percentage of any given community. The aim of this report is, therefore, to explore best practices for minority engagement, with a special focus on digital and other remote engagement strategies.

Methods

This project used a mixed methods approach (survey and qualitative interview) to explore the current landscape of minority engagement. A traditional [literature review](#) identified barriers and facilitators to engaging diverse populations. These findings guided the development of a Minority Engagement Survey. Aggregate data from the surveys, along with individual responses, were used to create a unique set of follow-up questions for each qualitative interview.

Participants

The project team identified individuals with a special interest or demonstrated expertise in engaging diverse populations as possible participants. Efforts were made to invite participants from a variety of industries, including advocacy, education, government, healthcare, and research.

Survey

A 38-question survey was developed to collect information on current minority engagement practices across several industries. The instrument included open- and close-ended questions regarding participant demographics, minority engagement barriers/facilitators, communication strategies, cultural competence training, partnerships, and willingness to discuss this topic further.

The survey was administered via SurveyGizmo (https://www.surveygizmo.com) between February 11, 2020, and March 12, 2020. Potential participants received an email invitation with a linked survey followed by two reminder emails. To improve the response rate, non-responders were given the opportunity to participate in a 9-question, abbreviated version of the original survey which was also distributed via SurveyGizmo.

Qualitative Interviews

Survey participants who indicated their willingness to discuss the topic further were offered the opportunity to schedule a 30-minute, qualitative interview with the project team. Invitations were sent via email with a linked Doodle Poll for scheduling. Discussion topics were based on aggregate data from the Minority Engagement Surveys along with personalized follow-up questions based on the participant's responses.

Analysis

Survey findings are presented as descriptive statistics. Qualitative data, including open-ended survey questions and responses recorded during follow-up interviews, were analyzed for common themes.
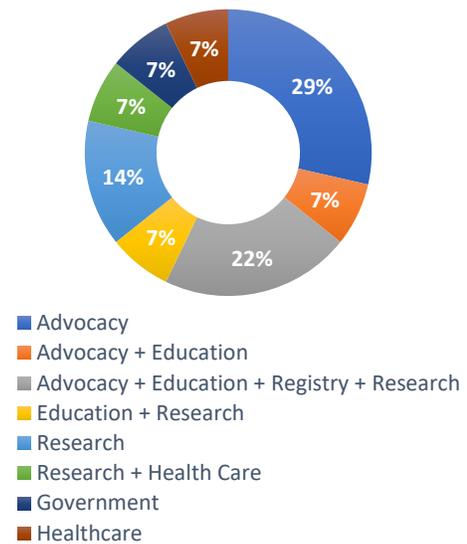
Results

Participant Demographics

Of the 36 organizations identified, 17 (47.2% response rate) participated in the survey. Fourteen submitted the original survey and an additional three organizations completed the abbreviated survey. Five of the survey participants also contributed data through qualitative interviews. Respondents represented a variety of industries with most self-identifying with more than one industry category (Figure 1, next page). Eight of the 14 respondents identified with advocacy (57.1%), seven with research (50.0%), five with education (35.7%), three with registry (21.4%), two with healthcare services (14.3%), and one with government (7.1%). For a complete list of organizations who contributed data, please see the "Participating Organizations" section at the end of this report.

Minority Populations Engaged

While some organizations reported a singular focus, most (88.2%) were working to engage two or more populations. Of the 17 respondents, 15 (88.2%) were attempting to engage with Latinos/Hispanics, 14 (82.4%) with African Americans, nine (52.9%) with Asian Americans, eight (47.1%) with American Indians/Alaska Natives, and eight (47.1%) with Pacific Islanders/Native Hawaiians (Figure 2, below). Five (29.4%) respondents also reported outreach to "other" underserved populations such as LGBTQ, elderly, rural, and disadvantaged communities. When participants were asked to rate how challenging minority engagement is for their organization on a scale from 0 (not at all) to 100 (very), the mean response was 55.8 (SD=30.4).
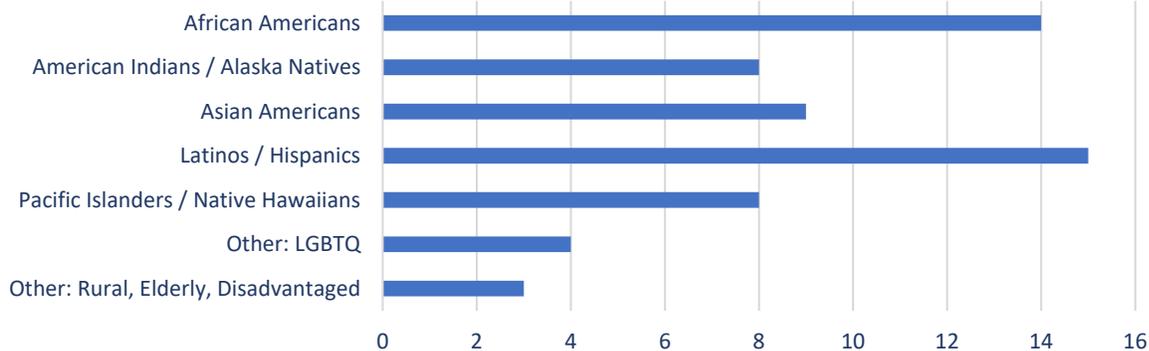
Figure 1. Distribution of Self-Identified Industry Categories (N=14)*

- Advocacy — 29%
- Advocacy + Education — 7%
- Advocacy + Education + Registry + Research — 22%
- Education + Research — 7%
- Research — 14%
- Research + Health Care — 7%
- Government — 7%
- Healthcare — 7%

*Note: N=original survey participants only

Organizations attempting to engage a larger number of minority populations (≥4) tended to report minority outreach/engagement as more challenging than those with more targeted engagement activities (mean = 70 compared to mean = 46, respectively); however, this did not reach significance. There were also no significant differences in challenge when stratified by targeted population.

Figure 2. Minority Populations Engaged (N=17)*

| Population	Count
African Americans	14
American Indians / Alaska Natives	8
Asian Americans	9
Latinos / Hispanics	15
Pacific Islanders / Native Hawaiians	8
Other: LGBTQ	4
Other: Rural, Elderly, Disadvantaged	3

*Note: Respondents were not limited to one response; N=original and abbreviated survey participants

Barriers to Engaging Diverse Communities

As identified in the literature, there are many barriers that can impact the engagement of ethnic and racial minorities. Many of these factors are widespread, while others are seen more frequently in certain minority populations.[4] Participants were asked the level to which the following barriers have impacted their organizations' efforts to engage minority communities (Figure 3, next page):

FTD DISORDERS REGISTRY®

Figure 3. Barriers to Minority Engagement (N=17)*
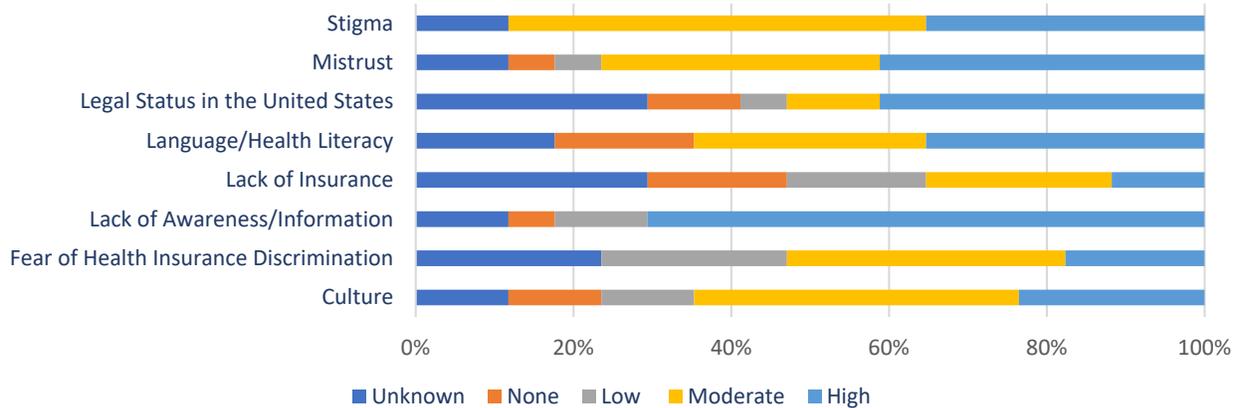
Note: Reported level to which organizations experiences minority engagement barriers by percentage of respondents; N=original and abbreviated survey participants

Cultural and Language Barriers. Cultural and language barriers can make it difficult to engage, recruit, consent, and retain racial and ethnic minorities in research. Examples reported in the literature include a lack of culturally competent, language-appropriate materials written at an appropriate reading level; reduced access to bilingual research staff; and/or differences in cultural beliefs about illness.[4, 5]

Among survey participants, four (23.5%) responded that cultural barriers had a high impact on their organizations' minority engagement efforts, seven (41.2%) reported a moderate impact, two (11.8%) a low impact, two (11.8%) no impact, and two (11.8%) replied unknown. Six (35.3%) respondents indicated that language barriers impacted their engagement efforts to a high degree, five (29.4%) to a moderate degree, three (17.6%) reported no impact, and three (17.6%) were unsure.

Health Insurance-Based Barriers. Lack of or inadequate health insurance can act as a barrier to research enrollment for many underrepresented populations. Some ethnic and racial minorities also report a fear of health insurance discrimination as a direct result of participation in research. For example, fear of discrimination from health insurance companies based on research-associated genetic testing is a commonly reported concern in African American research participants. African American and Latino communities may also share concerns about health insurance coverage for participation in clinical trials.[4, 5]

Two survey respondents (11.8%) reported that lack of health insurance highly impacted their organizations' engagement efforts, four (23.5%) reported a moderate impact, three (17.6%) a low impact, three (17.6%) no impact, and five (29.4%) were unsure. With regards to fear of health insurance discrimination, three respondents (17.6%) reported that this barrier impacted their organizations' minority engagement activities to a high degree, six (35.3%) to a moderate degree, four (23.5%) reported no impact, and four (23.5%) replied unknown.

Lack of Awareness/Information. Studies demonstrate that minority communities are often less familiar with the concept of research participation and have less access to information regarding research. This may be caused by a variety of factors including language barriers and reduced access to healthcare centers that offer research opportunities.[4, 5, 6]

Twelve (70.6%) survey participants responded that lack of research awareness and information had a high impact on their organizations' minority engagement efforts, two (11.8%) reported a low impact, one (5.9%) reported no impact, and two (11.8%) replied unknown.

Legal Status in the United States. According to the literature, Asian American and Latino immigrants often report concern that participation in research could impact their legal status and result in deportation.[4]

Seven (41.2%) survey respondents indicated legal status in the United States impacted their organizations' minority engagement activities to a high degree, two (11.8%) to a moderate degree, one (5.9%) to a low degree, two (11.8%) reported no impact, and five (29.4%) were unsure.

Mistrust. Mistrust appears to be a shared barrier across all ethnic and racial minorities. It often stems from the belief that institutions and pharmaceutical companies may put their own interests ahead of the participants' desires and needs.[5] Individuals from certain minority populations are also more likely to express concerns that study findings will only benefit non-Hispanic whites/research institutions (African Americans) or they fear medical experimentation (Latinos).[4]

Among survey participants, seven (41.2%) reported that mistrust issues had a high impact on their organizations' minority engagement efforts, six (35.3%) reported a moderate impact, one (5.9%) a low impact, one (5.9%) no impact, and two (11.8%) replied unknown.

Stigma. Stigma as a reported barrier to participation is often related to the disease of interest in the research study. For dementia research specifically, participants of all races and ethnicities may fear that volunteering for a trial and being labeled with a dementia diagnosis could result in stigma. A dementia diagnosis can also negatively impact employment, health insurance coverage, capacity to make important decisions, ability to drive, and independence.[3, 4]

Six survey respondents (35.3%) reported that stigma highly impacted their organizations' engagement initiatives, nine (52.9%) reported a moderate impact, and two (11.8%) were unsure.

Other. Three participants indicated that their organizations had encountered additional barriers that were not offered as a survey response. Such barriers included:

- Reduced coverage of certain regions in a national research initiative.
- Difficulty identifying effective communication channels for reaching individuals from minority populations who are affected by a specific disease.
- Lack of investment in community-based organizations related to a certain condition.

Recommended Practices for Engaging Minority Populations

In a review of the literature, 11 key themes emerged as recommended practices for engaging diverse populations. These included:

- Partner with communities.
- Enlist dedicated staff and/or 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 and address stigma and negative consequences for study participants.
- Ensure that technologies are user- and mobile-friendly.

As evidenced by aggregate data from the surveys and qualitative interviews, these themes were also reported by survey participants. However, strategies for achieving each thematic goal often varied by organization.

Partner with Communities. In the literature, many inclusive studies and programs utilized a community-based participatory research approach in which organizations and researchers collaborate or partner with local underserved communities. Most survey participants (76.5%) reported minority engagement strategies that aligned with this theme. Connecting with community partners was often seen as a necessary first step in understanding the needs and priorities of a specific community which then informed all additional engagement efforts. There was also an emphasis on demonstrating a continued commitment to communities once foundational connections were in place. According to one participant, "episodic engagement, or showing up when you need advice or you need participation, doesn't work. Maintaining durable relationships with communities over time is a best practice."

Many participating organizations reported strategies for connecting with communities at the local level. In these cases, engagement often took place via face-to-face interactions in the community setting. As one participant described, "people tend to feel most comfortable amongst their own, so engagement must happen on their own turf with professionals who understand them." Specific examples included:

- Partnering with community-based organizations (i.e. community clinics, churches, schools) to build capacity around a specific project or activity.
- Utilizing a community health worker model in which bicultural, bilingual health promotors were recruited and trained to educate and engage individuals within their own communities.
- Hosting focus groups to understand the priorities of individual communities.

FTD DISORDERS REGISTRY®

Some respondents also reported engagement strategies that can be accomplished via digital or other remote tactics. These responses, combined with examples from the literature, include:

- Integrating national organizations that are dedicated to serving diverse populations as community engagement partners.
- Inviting patient or participant partners from diverse populations to provide input via working groups or task forces that inform specific aspects of the program or research project.
- Hosting webinars/teleconferences to engage minority patients, caregivers, and other stakeholders in shaping patient-driven research priorities.
- Developing and administering surveys to integrate the perspective of minority populations into programs and research studies.
- Providing a platform for patients or participants who are representative of minority populations to share their personal stories via hosted online webinars, social media, emails, and newsletters.[7]
- Fostering conversation opportunities between potential participants and their trusted advisors, including health care providers, support service providers, and community leaders.[7]

Enlist Dedicated Staff and/or Committees to Prioritize Inclusive Engagement. Some participating organizations reported committees and/or full-time staff dedicated to diversity and inclusion. These organizations often felt that having focused individuals with the ability to move/commit resources and set metrics helped make diversity and inclusion a priority. As one respondent stated, "to have someone who is ultimately accountable and responsible for diffusing a vision and a strategy for diversity and inclusion throughout the entire organization is tremendous because it keeps the momentum."

Focused staff and committees were created to provide input in a variety of areas, including:

- Internal hiring.
- Diversity of researchers in research portfolio.
- Diversity of participants in supported studies.
- Minority engagement strategies.
- Research and/or educational materials.

Increase Awareness of Research and Health-Related Information. As discussed previously, individuals from racial and ethnic minorities are often less familiar with the concept of research and may have less access to information about research opportunities. Programs or research projects that support rare conditions may face the additional barrier of reduced disease awareness among minority populations and the healthcare providers that serve them. For this reason, increasing awareness of research and health-related information through targeted education initiatives can empower people from diverse communities to participate in clinical research and other health programs.

About half of the participating organizations described dedicated educational outreach initiatives. Many of these efforts were accomplished through face-to-face interactions in the community. Reported examples included:

- Recruiting and training health promoters to give small workshops and presentations in their own communities.
- Offering workshops, lectures, and other educational programing in partnership with community-based organizations.
- Facilitating conversations between minority communities and staff at university medical centers.
- Hosting educational conferences for a variety of stakeholders.

Some organizations also offered digital and other remote strategies for promoting awareness. These included:

- Recording public service announcements and posting to social media channels.
- Hosting educational webinars in many different languages.
- Offering web-based continuing education programs for healthcare professionals.
- Sending recruitment letters that describe health disparities and explain why participation in research is important.[8]

Ensure Cultural Competence of Staff, Messaging, and Materials. To reach more diverse participants, culturally relevant materials and culturally competent program staff are essential. Most participating organizations (70.6%) offered specific strategies to accomplish this goal. The process of "cultural tailoring" was often described as attempting to understand a specific community and then developing materials and messaging with a focus on cultural traditions, values, and norms. This is important because, as one participant noted, "[minority engagement] is geographically different. Diverse populations are not one-size-fits-all."

Some participating organizations partnered with community-based organizations or representative participant partners to co-develop culturally appropriate materials and messaging. One respondent encouraged programs to never create anything without community partners as they have messages, mediums, and methods that resonate well and can offer advice on areas to avoid.

Making efforts to increase staff diversity was often seen as a necessary first step in planning culturally competent programs. Training materials and additional tools were also used to ensure that existing program staff and research personnel were culturally competent.

Address Language Barriers. Language barriers contribute to the perceived lack of access to information among some minority communities. They can also make it difficult to obtain truly informed consent. Based on the literature and the surveyed organizations, the following are recommended practices to address language barriers:

- Enlist the help of bilingual study personnel or translators to communicate with participants.
- Translate all materials into the appropriate language.
- Ensure readability of patient education materials is no higher than sixth- to eighth-grade level per recommendations of the NIH and CDC.[5]
- Provide opportunities for community members to review, modify, and approve translations based on linguistic norms.

Several participating organizations also emphasized that direct translations or translations from the mainstream point of view were not enough. Local dialects and other important cultural nuances must be considered when translating materials for a certain community. As one respondent who described her organization's process as "trans-creating" stated, "we wanted native speakers to be able to read the Spanish materials and feel like it was written in Spanish, specifically for them – not that it was written in English and then translated."
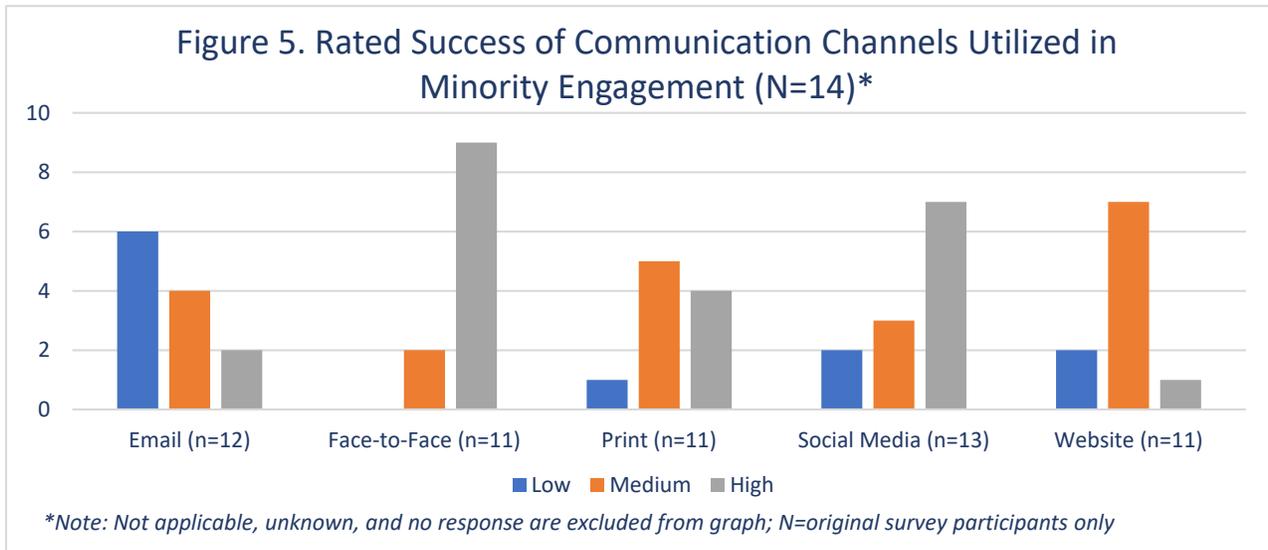
Select the Appropriate Modes of Communication. While planning minority engagement initiatives, most participating organizations carefully considered which modes of communication would be most successful in engaging specific minority communities. Sixty-two percent of participating organizations reported adjusting existing or creating new communication modes for minority engagement (Figure 4, at right).

Survey participants were also asked to share which communication channels their organizations used to engage minority communities and to rate their success level with each (Figure 5, next page). The highest levels of success were seen in face-to-face interactions with all organizations utilizing this channel (78.6% of responders) reporting medium

Figure 4. Percentage of Organizations Who Adjusted Existing or Created New Communication Modes for Minority Engagement (N=16)*

- Unknown: 19%
- No: 19%
- Yes: 62%

Note: N=original and abbreviated survey participants; one non-responder excluded from N.

to high success in reaching their targeted audience. Of those using social media, seven (53.8%) reported high success, three (23.1%) medium success, two (15.4%) low success, and one (7.7%) was unsure. However, many respondents indicated that they had varying levels of success across different social media platforms depending on the audience. For example, one participating organization found that Twitter was useful in engaging researchers, thought leaders, and policy makers while Facebook (closed Facebook groups and Facebook Live, specifically) was more effective for consumer-facing messaging. Other organizations reported success using WhatsApp and WeChat for communicating with Hispanic/Latino and Asian American communities, respectively.
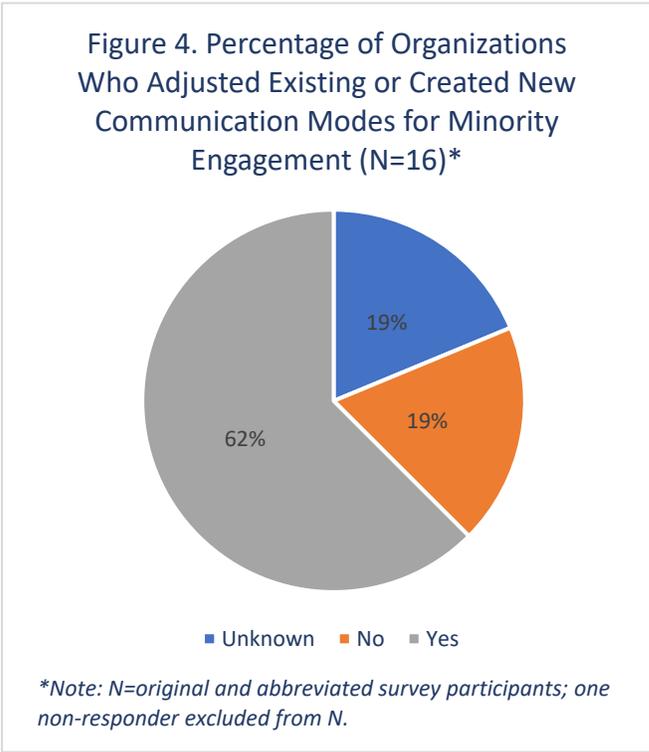
Among organizations utilizing email communications, two (16.7%) reported high success, four (33.3%) medium success, and six (50.0%) low success. The use of websites to engage minority populations was associated with high success in one case (9.1%), medium success in seven cases (63.6%), low success in two cases (18.2%), and unknown level of success in one case (9.1%). Of the organizations using print materials, four (36.4%) reported high success, five (45.5%) medium success, one (9.1%) low success, and one (9.1%) was unsure. However, print materials were often shared though face-to-face interactions in a community setting which may have contributed to their rated success. A few respondents indicated that their organizations used "other" communication channels, including radio (one participant) and telephone (one participant) with moderate to high success.

Figure 5. Rated Success of Communication Channels Utilized in Minority Engagement (N=14)*

*Note: Not applicable, unknown, and no response are excluded from graph; N=original survey participants only

Offer Reassurances to Foster Trust. In the literature, mistrust is often described as a universal barrier to minority engagement. Most of the participating organizations (76.5%) also reported this barrier impacting their engagement strategies at a moderate to high level. Creating opportunities to offer reassurances and build trust are, therefore, a vital component of successful minority engagement programs.

The following are trust-building strategies identified in the literature and/or utilized by participating organizations:

- Providing opportunities to learn and ask questions about the research process.[3]
- Providing verifiable assurances of human participant protection measures.[4]
- Communicating transparently regarding benefits and costs associated with research participation.[7]
- Addressing community concerns directly and honestly.[4]
- Offering timely responses to inquiries.[9]
- Partnering with trusted individuals from the community (i.e. leaders of community-based organizations, community healthcare providers, media personalities).
- Developing and maintaining durable relationships over time.

Communicate Research Progress and Findings. When people volunteer for research, they are often motivated by the desire to advance science for future generations. Consequently, many research participants care about their contribution and would like to know the outcomes of the study.[5, 9] Participating organizations reported the following strategies for disseminating research findings:

- Distributing patient-friendly summaries of relevant findings and updates throughout the research study continuum.
- Offering "participant portals" where study participants can login and view their personal data and in some cases, de-identified, aggregate data from the entire study population.
- Posting information on a registry's website regarding the research being done with the de-identified data.
- Hosting live events in the community or via webinar to present research findings and respond to questions.

Reduce Participant Burden. Competing time demands can be a major barrier to research participation, especially in the poorer and underserved segments of minority populations. The following are strategies for reducing participant burden as identified in the literature and/or as reported by participating organizations:

- Designing community-embedded research protocols in partnership with local organizations that service diverse populations.
- Providing financial support and vouchers.
- Using patient navigators to support people throughout the research process.[8]
- Integrating social and medical services in the research process.[8]
- Simplifying and reducing the length of the research consent process, screening and enrollment paperwork, and research protocols.[3]

Consider and Address Stigma and Negative Consequences for Study Participants. When individuals participate in research and are labeled with a diagnosis, they may face stigma. In dementia research, specifically, this label can also have implications for employment, health insurance coverage, power of attorney, and loss of independence. Research with a primary focus on dementia should, therefore, develop policies to mitigate potential negative consequences for those diagnosed with these conditions.[3]

Two of the participating dementia organizations mentioned difficulty connecting with some minority populations due to stigma. For example, one respondent indicated that the word for "dementia" in Spanish is also used to mean "you are crazy" or "you are demented." These organizations suggested addressing this barrier with educational initiatives led by trusted members of the community and culturally tailored materials that discuss stigma, specifically.

Ensure that Technologies are User- and Mobile-Friendly. Studies show that minority communities are not only more likely to own mobile phones, but they are also more likely than non-Hispanic whites to use their device for health specific information. This has important implications for web-based health research, such as online patient registries, since offering a mobile-friendly registry interface appears to circumvent the previously reported inequities in digital access by race and income ("the digital divide").[10] One of the participating registries recently integrated a user-friendly mobile App into their registry platform and many offer mobile-friendly platforms.

Discussion

With recent studies suggesting that certain ethnic and racial minorities may be disproportionally impacted by dementia, an increasing number of organizations are exploring minority engagement in dementia research and education. This has led to a wealth of published literature on this important and timely topic. While such studies and guidelines offer strategies for engaging, recruiting, and retaining minority participants in general, there is a lack of published data specific to web-based health research. Consequently, the FTD Registry aimed to explore the current landscape of minority engagement with a special focus on digital and other remote engagement strategies that can be efficiently translated into web-based research initiatives.

The FTD Registry's mixed-method approach assessed the multifaceted challenges of minority engagement across a variety of industries, including advocacy, education, registries, research, government, and healthcare. On average, the surveyed organizations found minority engagement to be moderately (mean = 55.8 on a scale from zero to 100) challenging. Organizations attempting to engage a larger number of minority populations (≥4) often found minority engagement to be more challenging than those with more focused engagement activities; however, this did not reach significance due to the small sample size.

Perceived barriers to minority engagement commonly cited in the literature include lack of awareness of research opportunities, lack of trust, different cultural beliefs, communication challenges, fear of health insurance discrimination, lack of insurance, legal status in the United States, and stigma. Although each barrier was experienced by a proportion of the surveyed organizations, lack of awareness/information, mistrust, and stigma emerged as the most substantial barriers. For some barriers, a large percentage of organizations (up to 29.4%) couldn't offer data regarding the impact on minority engagement efforts. This highlights the findings of the National Institute on Aging (NIA) which call for improved infrastructure and metrics to enhance data collection and utilization related to health disparities in Alzheimer's and related dementias.[3]

The qualitative data collected from participating organizations were consistent with minority engagement practices identified in the literature. The most commonly reported minority engagement practices were partnering with communities (76.5%) and ensuring cultural competence of staff, messaging and materials (70.6%). Many organizations also offered strategies for increasing education/awareness (47.1%) and addressing language barriers (41.2%). Other reported strategies included enlisting dedicated staff/committees to prioritize inclusive

engagement; offering reassurances to foster trust; communicating research progress and findings; reducing participant burden; considering and addressing stigma and negative consequences of study participation; and ensuring that technologies are user- and mobile-friendly. Although reported practices aligned with common themes, strategies for achieving each thematic goal often varied by organization.

When asked about specific communication strategies, many respondents (62.0%) had adjusted existing or created new modes of communication for minority engagement. Most organizations reported the highest levels of success with face-to-face engagement strategies which is consistent with data from the literature. Unfortunately, research registries and other web-based research initiatives are often national or global initiatives that may not have the local presence or capacity to launch in-person engagement events nationwide. Community-based engagement strategies may also be less successful for rare disease registries since the studied condition may only affect a small percentage of any given community. Although participating organizations also reported moderate to high success utilizing digital engagement channels such as social media and website, most platform-specific and population-specific data were anecdotal.

In summary, this project outlines barriers to and suggested practices for minority engagement as identified in the literature and through solicited input from organizations across a variety of industries. Although many digital and remote engagement strategies are reported, the success of these activities in patient registries cannot be inferred given the small sample size. Additional studies, including those with larger populations of web-based health research initiatives, are needed to better define best practices for specific minority engagement strategies in these research settings.

Next Steps for the FTD Disorders Registry

Frontotemporal degeneration (FTD) is a group of neurodegenerative disorders that affect the frontal and/or temporal lobes of the brain, the areas responsible for behavior, movement, and language. Since its launch in 2017, the FTD Disorders Registry has facilitated FTD clinical trial enrollment by providing high-quality, aggregate data, and by mobilizing a national base of potential research study volunteers.

The FTD Registry aims to equally serve the entire FTD community by cultivating the engagement and recruitment of underserved, disadvantaged, and/or minority populations. **As a first step, the FTD Registry will include a Race/Ethnicity field in the registration process to track our efforts in recruiting a representative study population.** The FTD Registry will translate the data collected via this minority engagement discovery into an iterative and continuously evolving multi-phased strategic plan for engaging, recruiting, and retaining a more inclusive and diverse population of individuals who are impacted by these disorders.

The Registry's plan includes a series of next steps that focus on each of the engagement categories. Activities to address each category have been divided into phases that include current status, short-term goals, and long-term vision. While a few of the short-term goals have been implemented, some have needed to be revised or postponed due to the coronavirus pandemic caused by COVID-19. Further ongoing analysis of recommended next steps will be made and adjusted as necessary in keeping with changes instituted by locales, researchers, patient advocacy groups, nonprofits, and other collaborating organizations.

The Registry will continue to seek engagement of minority populations as it promotes and encourages participation to advance research into the full spectrum of FTD disorders.

Participating Organizations

1. Accelerated Cure Project for Multiple Sclerosis
2. *All of Us* Research Program
3. Alzheimer's Association – National Headquarters
4. Alzheimer's Association – Northern California and Northern Nevada Branch
5. American Parkinson Disease Association (APDA)
6. Association for Frontotemporal Degeneration (AFTD)
7. Celiac Disease Foundation
8. COPD Foundation
9. Duchenne Registry
10. Emory University's Goizueta Alzheimer's Disease Research Center
11. Latino Alzheimer's and Memory Disorders Alliance (LAMDA)
12. Maya Angelou Center for Health Equity (MACHE)
13. NYU Center for the Study of Asian American Health
14. PKD Foundation
15. UC Davis Center for Reducing Health Disparities
16. UsAgainstAlzheimer's
17. Washington University's Hope Center for Neurological Disorders

References

1. Chen, Cynthia, and Julie M Zissimopoulos. "Racial and ethnic differences in trends in dementia prevalence and risk factors in the United States." Alzheimer's & dementia (New York, N. Y.) vol. 4 510-520. 5 Oct. 2018, doi:10.1016/j.trci.2018.08.009.

2. National Institute on Aging (2019) Alzheimer's Disease and Related Dementias Clinical Studies Recruitment Planning Guide. https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf

3. National Institute of Health and National Institute on Aging (2018) National Strategy for Recruitment and Participation in Alzheimer's Disease and Related Dementias Clinical Research. https://www.nia.nih.gov/sites/default/files/2018-10/alzheimers-disease-recruitment-strategy-final.pdf

4. S. George, N. Duran, K. Norris. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. Am J Public Health. 2014 Feb;104(2):e16-31.

5. MS Minority Research Network, Accelerated Cure Project. (2017). MS Minority Research Engagement Toolkit. https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Research/ResearcherToolkit2018.pdf

6. Erves JC, Mayo-Gamble TL, Malin-Fair A, Boyer A, Joosten Y, Vaughn YC, Sherden L, Luther P, Miller S, Wilkins CH. Needs, Priorities, and Recommendations for Engaging Underrepresented Populations in Clinical Research: A Community Perspective. J Community Health. 2017 Jun;42(3):472-480. doi: 10.1007/s10900-016-0279-2.

7. Brewster P, Barnes L, Haan M, Johnson JK, Manly JJ, Nápoles AM, Whitmer RA, Carvajal-Carmona L, Early D, Farias S, Mayeda ER, Melrose R, Meyer OL, Zeki Al Hazzouri A, Hinton L, Mungas D. Progress and future challenges in aging and diversity research in the United States. Alzheimers Dement. 2019 Jul;15(7):995-1003. doi: 10.1016/j.jalz.2018.07.221. Epub 2018 Sep 19.

8. Gilbert RM, Standaert DG. Bridging the gaps: More inclusive research needed to fully understand Parkinson's disease. Mov Disord. 2020 Feb;35(2):231-234. doi: 10.1002/mds.27906. Epub 2019 Nov 11.

9. Cocroft, Shelytia et al. Culturally Diverse Participant Registries to Facilitate the Recruitment of African Americans into Preclinical Alzheimer' Disease Studies. Alzheimer's & Dementia: The Journal of the Alzheimer's Association, Volume 14, Issue 7, P280.

10. Gliklich RE, Dreyer NA, Leavy MB, Christian JB (eds). 21st Century Patient Registries. EBook addendum to Registries for Evaluating Patient Outcomes: A User's Guide, 3rd Edition. (Prepared by L&M Policy Research, LLC under Contract No. 290-2014- 00004-C.) AHRQ Publication No. 17(18)-EHC013-EF. Rockville, MD: Agency for Healthcare Research and Quality; February 2018. www.effectivehealthcare.ahrq.gov.

Minority Engagement in Research
A Focused Literature Review on Dementia, Minorities and Registries

Introduction

1. **Prevalence of Dementia among Minorities**
   Although dementia affects people of all races and ethnicities, recent studies suggest that certain minority populations may be disproportionately impacted. For example, numerous studies have demonstrated an elevated risk of dementia among African American and Latino populations, specifically, despite variations in designs, sampling methods, and definitions of dementia. These studies consistently report that African Americans and Latinos have 2.0 and 1.5 times the odds of dementia, respectively, compared to whites. Racial and ethnic differences in dementia risk may result from biological, behavioral, sociocultural, and/or environmental factors.[11]

2. **Minority Participation in Research**
   The engagement of diverse communities in clinical research is important because it supports health equity and ensures that research discoveries are generalizable to all populations. Unfortunately, participation in research studies is lower among racial and ethnic minorities, reducing the applicability of research results to these groups. For example, African Americans represent 12 percent of the U.S. population but only make up 5 percent of clinical trial participants. Hispanics, who make up 16 percent of the U.S. population, represent only 1 percent of clinical trial participants.[12] Although these high-risk populations are currently underrepresented in dementia and other research, studies show that minority individuals, in general, are as likely as whites to consent if they are offered the opportunity.[16,17]

3. **Goals of Discovery**
   The Registry aims to equally serve the entire FTD patient/family/caregiver community by cultivating the engagement and recruitment of underserved, disadvantaged, and minority populations. To this end, the Registry will:
   a. Identify specific barriers to research participation.
   b. Outline 'best practices" for minority engagement identified in the literature and through solicited input from various entities that support minority inclusion research.

KEY POINTS
- African Americans and Latinos have 2.0 and 1.5 times the odds of dementia, respectively, compared to whites.[11]
- Participation in research studies is lower among racial and ethnic minorities.
  - African Americans represent 12 percent of the U.S. population, but make up only 5 percent of clinical trial participants.[12]
  - Hispanics, who make up 16 percent of the population, represent only 1 percent of clinical trial participants.[12]
- Studies show that, overall, racial and ethnic minorities are as likely as whites to consent if they are offered the opportunity to participate in research.[16]

Barriers and Facilitators to Engaging Diverse Populations

There are many barriers and facilitators that can impact the participation of ethnic and racial minorities in clinical research. Many of these factors are widespread, while others are seen more commonly in communities of certain races and ethnicities.[13]

BARRIERS	FACILITATORS
1. Mistrust 2. Lack of Awareness/Information 3. Cultural and Language Barriers 4. Stigma 5. Fear of Health Insurance Discrimination 6. Legal Status in the United States	1. Cultural Congruence 2. Benefits to Participation 3. Altruism (helping family or community) 4. Convenience of Participation 5. Low Risk of Participation

1. **Barriers**
   a. *Mistrust*. Mistrust is a shared barrier across all ethnic and racial minorities. It often stems from the belief that institutions and pharmaceutical companies may put their own interests ahead of the participants' desires and needs.[19] Certain minority populations also express concerns that study findings will only benefit Whites/research institutions (African Americans) or fear medical experimentation (Latinos).[13]

   b. *Lack of Awareness/Information*. Studies demonstrate that minority communities are often less familiar with the concept of research participation and have less access to information regarding research. This may be caused by a variety of factors including reduced access to healthcare centers that offer research opportunities and language barriers.[13,19,20]

   c. *Cultural and Language Barriers*. Cultural and language barriers can make it difficult for researchers to access, engage, recruit, consent, and retain racial and ethnic minorities in research. Reported examples include a lack of culturally competent, language-appropriate materials written at an appropriate reading level; reduced access to bilingual research staff; and/or differences in cultural beliefs about illness.[19,13]

   d. *Stigma*. Stigma as a reported barrier to participation is often related to the health condition of interest in the research study. For dementia research specifically, participants of all races and ethnicities may fear that volunteering for a trial and being labeled with a dementia diagnosis could result in stigma. A dementia diagnosis can also negatively impact employment, health insurance coverage, capacity to make important decisions, establishing a power of attorney, ability to drive, and loss of independence.[13,17]

   e. *Fear of Health Insurance Discrimination.* Some ethnic and racial minorities report a fear of health insurance discrimination as a direct result of participation in research.

For example, fear of discrimination from health insurance companies based on research-associated genetic testing results is a commonly reported concern in African American research participants. African American and Latino communities share concerns about health insurance coverage for participation in clinical trials.[13,19]

f. *Legal Status in the United States.* Asian American and Latino immigrants report concern that participation in research could impact their legal status and result in deportation.[13]

2. **Facilitators**

   a. *Cultural Congruence*. Research participation can be enhanced by using culturally diverse, bilingual research staff with culturally competent, language-appropriate research materials.[13]

   b. *Benefits to Participation*. Research participation is also improved when individuals can see a clear benefit to participating. Cited examples of perceived benefits that are relevant to registry research include learning more about personal health, receiving adequate information about the purpose of the study, and learning more information about other research/clinical trials.[13,19]

   c. *Altruism*. Individuals across all ethnic and racial backgrounds cite altruism as a strong motivator for research participation. Minority participants benefit from the knowledge that the study results may contribute to improved health and medical knowledge for future generations of their families and communities.[13,19]

   d. *Convenience of Participation*. Efforts that make participation convenient can help reduce barriers related to competing demands.[13] For registry research, specifically, this may include simplifying and reducing the length of the research consent process, screening and enrollment paperwork, and research protocols.[18]

   e. *Low Risk of Participation*. Studies that are perceived to have the least risk of discomfort or invasiveness, such as completing a survey or an education intervention, may also enable minority participation.[13]

Suggested Practices for Engaging Diverse Communities

1. **Increase Awareness of FTD and Research in Minority Communities**
   As discussed previously, individuals from racial and ethnic minorities may be less familiar with the concept of research and may have less access to information about research opportunities. They can also have different cultural beliefs about disease including reluctance to talk about illness and unique views about cause and treatment of disease. For this reason, increasing awareness and engagement through targeted outreach initiatives can empower people from diverse communities to participate in clinical research. Partners and key stakeholders in these efforts may comprise health care providers including primary care physicians, specialists, and nurses; health care organizations and system providers; advocacy organizations; and professional associations.[17]

2. **Engage Minority Communities**

    Many research studies with successful minority recruitment utilize a community-based participatory research approach in which researchers collaborate or partner with local underserved communities. Although this specific method is difficult to employ in a web-based, national registry, strategies exist to help engage minority communities nationwide. These may include:

    - Partnering with patient advocacy organizations that support dementia, as well as organizations that work with patients and health care professionals from minority communities.[15,19]
    - Using personal stories on dementia, caregiving, and research in creative ways, such as hosted online webinars, social media, emails lists, and newsletters. Featured faces and voices should be inclusive.[17]
    - Including patients who are representative of the target patient community as partners in research.[18,19]
    - Fostering conversation opportunities between potential participants and their trusted advisors, including health care providers, support service providers, and community leaders.[17]

    When engaging minority communities, it's important to plan tailored messaging by considering the following factors:[16]

    - Who may be in the best position to deliver messages that connect and build trust within the community?
    - What are the best channels to deliver messages to the community (social media, traditional print/radio/tv media, targeted mailing, etc.)? Should advocacy organizations or other intermediaries be involved?
    - In designing educational materials, what images, languages, literacy level, etc. are appropriate, interesting, engaging and effective?

3. **Offer Reassurances to Foster Trust**

    Because mistrust appears to be a universal barrier to engagement of minority communities, opportunities to offer reassurances and build trust are essential during recruitment and throughout the research process. This may be accomplished through:

    - Providing opportunities to learn and ask questions about the research process.[17]
    - Addressing community concerns directly and honestly.[13]
    - Offering timely responses to member inquiries.[14]
    - Providing verifiable assurances of human participant protection measures.[13]
    - Communicating transparently regarding benefits and costs associated with research participation.[15]

4. **Ensure Cultural Competence of Staff and Research Materials**

   To reach more diverse participants, culturally competent research staff and accurate, culturally relevant materials are key. To this end, studies may:
   - Require training in cultural competence for all research staff.[13]
   - Review all educational materials to ensure they are appropriate to the cultural context.[14,15,17]

5. **Address Cultural Differences**

   Numerous subgroups exist within the Latino (Hispanic) and Asian American populations. Research staff must consider when and how these subgroups need to be handled differently throughout the research study continuum. For example, all communications should be framed according to each subgroup's unique perspective and what is important to them culturally.

6. **Address Language Barriers**

   In some potential research participants from minority populations, difficulty understanding the study, its goals, and consent forms is a commonly reported concern. This may occur if the conversation or study materials are not translated into the participant's native language or if study documents are not written in lay language at an appropriate reading level. Even if a participant speaks English as a second language, many people may feel more comfortable and more confident listening to or reading recruitment materials, screening questionnaires, consent forms, and other study materials in their native language.[19] To address potential language barriers, study staff should:
   - Ensure readability of patient education materials is no higher than sixth- to eighth-grade level per recommendations of the NIH and CDC.[19]
   - Translate all research materials into the appropriate language.[15,17]
   - Provide opportunities for community members to review and modify or approve translations based on linguistic norms.[17]
   - Enlist the help of bilingual study personnel or translators.[16,19]

7. **Communicate Research Progress and Findings**

   When people volunteer for research, they care about their contribution and want to know how they have helped advance science. In fact, many people rank learning the outcome of a study as a top reason for participation.[14,19] Developing a summary of relevant findings and updates throughout the research study continuum in clear, lay language is an effective way to communicate results to participants.[19]

8. **Reduce Participant Burden**

   Competing time demands can be a major barrier to research participation, especially in the poorer and underserved segments of minority populations. Studies can reduce participant burden by simplifying and reducing the length of the research consent process, screening and enrollment paperwork, and research protocols.[17]

9. **Consider and Address Stigma and Negative Consequences for Study Participants**

   When individuals participate in research and are labeled with a dementia diagnosis, they may face stigma. This label can also have implications for employment, health insurance coverage, establishing a power of attorney, and loss of independence. Research with a primary focus on dementia should, therefore, develop policies to mitigate potential negative consequences for those diagnosed with dementia.[17]

10. **Ensure that Technologies are User- and Mobile-Friendly**

    Studies show that minority groups are not only more likely to own mobile phones, but they are also more likely than Caucasians to use their device for health specific information. This has important implications for web-based health research, such as online patient registries, since offering a mobile-friendly registry interface now appears to circumvent the previously reported inequities in digital access by race and income ("the digital divide").[18]

SUMMARY: SUGGESTED PRACTICES FOR ENGAGING DIVERSE COMMUNITIES

1. Increase Awareness of FTD in Minority Communities
2. Engage Minority Communities
3. Offer Reassurances to Foster Trust
4. Ensure Cultural Competence of Staff and Research Materials
5. Address Cultural Differences
6. Address Language Barriers
7. Communicate Research Progress and Findings
8. Reduce Participant Burden
9. Consider and Address Stigma and Negative Consequences for Study Participants
10. Ensure that Technologies are User- and Mobile-Friendly

References

11. Chen, Cynthia, and Julie M Zissimopoulos. "Racial and ethnic differences in trends in dementia prevalence and risk factors in the United States." Alzheimer's & dementia (New York, N. Y.) vol. 4 510-520. 5 Oct. 2018, doi:10.1016/j.trci.2018.08.009

12. American College of Cardiology. Clinical Trials Shed Light on Minority Health. CardioSmart Website. https://www.cardiosmart.org/News-and-Events/2013/04/Clinical-Trials-Shed-Light-on-Minority-Health

13. S. George, N. Duran, K. Norris. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. Am J Public Health. 2014 Feb;104(2):e16-31.

14. Cocroft, Shelytia et al. Culturally Diverse Participant Registries to Facilitate the Recruitment of African Americans into Preclinical Alzheimer' Disease Studies. Alzheimer's & Dementia: The Journal of the Alzheimer's Association, Volume 14, Issue 7, P280.

15. Brewster P, Barnes L, Haan M, Johnson JK, Manly JJ, Nápoles AM, Whitmer RA, Carvajal-Carmona L, Early D, Farias S, Mayeda ER, Melrose R, Meyer OL, Zeki Al Hazzouri A, Hinton L, Mungas D. Progress and future challenges in aging and diversity research in the United States. Alzheimers Dement. 2019 Jul;15(7):995-1003. doi: 10.1016/j.jalz.2018.07.221. Epub 2018 Sep 19.

16. National Institute on Aging (2019) Alzheimer's Disease and Related Dementias Clinical Studies Recruitment Planning Guide. https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf

17. National Institute of Health and National Institute on Aging (2018) National Strategy for Recruitment and Participation in Alzheimer's Disease and Related Dementias Clinical Research. https://www.nia.nih.gov/sites/default/files/2018-10/alzheimers-disease-recruitment-strategy-final.pdf

18. Gliklich RE, Dreyer NA, Leavy MB, Christian JB (eds). 21st Century Patient Registries. EBook addendum to Registries for Evaluating Patient Outcomes: A User's Guide, 3rd Edition. (Prepared by L&M Policy Research, LLC under Contract No. 290-2014- 00004-C.) AHRQ Publication No. 17(18)-EHC013-EF. Rockville, MD: Agency for Healthcare Research and Quality; February 2018. www.effectivehealthcare.ahrq.gov.

19. MS Minority Research Network, Accelerated Cure Project. (2017). MS Minority Research Engagement Toolkit. https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Research/ResearcherToolkit2018.pdf

20. Erves JC, Mayo-Gamble TL, Malin-Fair A, Boyer A, Joosten Y, Vaughn YC, Sherden L, Luther P, Miller S, Wilkins CH. Needs, Priorities, and Recommendations for Engaging Underrepresented Populations in Clinical Research: A Community Perspective. J Community Health. 2017 Jun;42(3):472-480. doi: 10.1007/s10900-016-0279-2.