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Underrepresented and Underserved Populations in Neurological Research

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Abstract

Underserved and underrepresented populations have historically been excluded from neurological research. This lack of representation has implications for translation of research findings into clinical practice given the impact of social determinants of health on neurological disease risk, progression, and outcomes. Lack of inclusion in research is driven by individual-, investigator-, and study-level barriers as well as larger systemic injustices (e.g., structural racism, discriminatory practices). Although strategies to increase inclusion of underserved and underrepresented populations have been put forth, numerous questions remain about the most effective methodology. In this article, we highlight inclusivity patterns and gaps among the most common neurological conditions and propose best practices informed by our own experiences in engagement of local community organizations and collaboration efforts to increase underserved and underrepresented population participation in neurological research.

Keywords

Recruitment; community; underrepresented; underserved; research

Disparities in health care are largely driven by a high burden of adverse social determinants of health within affected populations, as well as other structural factors that influence health outcomes.[1] Social determinants such as limited access to education, unfavorable neighborhood environments due to poverty or crime, and economic instability, coupled with factors like structural racism translate into limited health care access, higher risk

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of disease, and greater prevalence of neurological conditions among underserved and underrepresented populations.[2] Social determinants also impact the natural course of progression of neurological diseases and their outcomes.[2]

Multiple neurological conditions disproportionately impact underserved and underrepresented populations. For example, although overall stroke incidence has declined in the past 50 years, disparities in stroke incidence and care between ethnocultural groups during this time have worsened.[3,4] Risk factors for stroke, including hypertension and diabetes, are also more prevalent among underrepresented and socioeconomically disadvantaged groups.[5] Epilepsy is associated with lower educational attainment, and socioeconomically disadvantaged individuals with epilepsy have greater barriers to therapy adherence and experience poorer outcomes.[6] Notable differences in rates of surgical intervention for epilepsy also exist between ethnocultural groups.[6] Socioeconomic disadvantage is highly prevalent among individuals with migraine, a condition which itself may contribute to increased risk of loss of employment and greater utilization of emergency care services.[7] This is not isolated to migraine, as many other neurological conditions adversely affect financial livelihood and employment with greater downstream consequences for those already socioeconomically disadvantaged. Finally, risk of clinical Alzheimer's Disease and Related Dementias (AD/ADRD) is 2-fold greater among African American individuals and 1.5-fold greater among Latino individuals compared with non-Latino White individuals.[8,9] Moreover, per U.S. census bureau estimates, by 2060, individuals of underrepresented populations aged 65 years or older will account for 45% of the U.S. population, with projections indicating an increase of 75% non-Latino White, 172% African American, 270% Asian and Pacific Islander, 274% American Indian and Alaska Native, and 391% Latino individuals.[10] These groups with the most substantial increases in the number of adults over age 65 will consequently be most impacted by AD/ADRD. Additional disparities in risk exist even among Latino and Asian and Pacific Islander individuals, given the tremendous heterogeneity encompassed by these categories.[11] It is also important to recognize that individual level risk for AD/ADRD may also differ from group level risk, with intragroup differences driven in large part by social determinants of health.

Research inclusive of diverse individuals from a variety of backgrounds and lived experiences is thus crucial to understand the numerous factors that influence disease risk and outcomes. Moving research findings into clinical practice inherently rely upon the assumption that the results of research will be translatable to the general population. Thus, lack of inclusivity of underserved and underrepresented populations significantly limits translatability of research into practice. In this article, we thus review (1) inclusivity patterns in research of highly prevalent neurological conditions and reasons for underrepresentation of certain groups; (2) reasons for lack of inclusion and underrepresentation of underserved communities in neurologic research; (3) previously suggested strategies to increase inclusivity and best practices informed by the literature and the authors' experience in the San Francisco Bay Area.

Inclusivity in Neurological Research of Highly Prevalent Neurological Conditions

Neurological research has historically failed to be inclusive of underserved and underrepresented populations. Here, we highlight inclusivity patterns in research within four of the most prevalent neurological conditions in the United States: stroke, epilepsy, migraine, and AD/ADRD.[12] Patterns of representation in less prevalent neurological conditions follow similar trends to those reviewed here.

Stroke

Research examining participation in National Institute of Neurological Disorders and Stroke (NINDS)-funded clinical trials demonstrated that Latino representation decreased (from 7.4 to 5.8%) in clinical trials over a 23-year period (1985–2008) and was well-below population levels.[13] During this same period, the U.S. Latino population percentage doubled from 6 to 12%.[13] A more recent meta-analysis of acute ischemic stroke trials from 2010 to 2020 revealed less than 50% of trials reported information about ethnocultural identity of participants.[14] Among trials that included this information, pooled proportions of African American individuals totaled 19%, 11% for Latino individuals, and 2% for Asian individuals (the remainder of individuals were White).[14] This representation in research is in contrast with the disproportionate incidence of stroke and stroke risk factors among Latino and African American individuals compared with other groups. Asian American individuals also have greater rates of intracerebral hemorrhage and poorer outcomes related to intracerebral hemorrhage compared with White individuals.[15] Landmark research trials in stroke that provided foundational evidence for current clinical practices further highlight a lack of inclusion of underrepresented and underserved populations.

Tissue plasminogen activator (t-PA) therapy is one of the cornerstones of acute ischemic stroke care. However, examination of the trials that led to the Food and Drug Administration (FDA) approval and widespread use of t-PA reveal a lack of inclusion of underrepresented populations in these studies. The pilot study conducted by Brott et al[16] examining the use of t-PA within 90 minutes included 74 patients, 85% of whom were White and 15% were African American. No other ethnocultural identities were represented among participants. There is also no information about whether included participants are from underserved or socioeconomically disadvantaged environments of residence.[16] The follow-up study examining a longer therapy window of 90 to 180 minutes also featured overrepresentation of White individuals (80%), with similar representation of African American individuals (15%) and a single Asian individual (5%).[17] No information on socioeconomic status or other sociodemographic characteristics of participants was reported. The much larger randomized, double-blind trial conducted by the NINDS and Stroke rt-PA Study Group that followed included participants who were 65% White, 27% African American, 6% Latino, and 1% Asian.[18] More recent research has revealed disparities in administration of t-PA in care settings and other disparities in stroke outcomes,[19] but the trials that served as foundation for expansion of t-PA into widespread clinical practice lacked inclusivity of underserved and underrepresented populations.

Endovascular treatment for acute ischemic stroke is one of the most significant recent advancements in stroke therapy. The landmark Multicenter Randomized Clinical Trial of Endovascular Treatment for Acute Ischemic Stroke in the Netherlands study, a multicenter clinical trial that established the efficacy and safety of intraarterial therapy, did not report the ethnocultural identity of any participants or any information about their sociodemographic characteristics.[20] The Solitaire with the Intention for Thrombectomy as Primary Endovascular Treatment trial that examined efficacy and safety of thrombectomy with stent retriever combined with intravenous t-PA included only 10% African American participants, <1% Asian participants, and 9% Latino participants.[21] Other landmark trials that demonstrated outcome benefits for endovascular treatment[22–26] show similar patterns of representation of ethnocultural groups and underreport sociodemographic characteristics of participants.

Epilepsy

Research examining participation in antiseizure medication clinical trials from 1988 to 2019 revealed significant underrepresentation of Latino and Asian individuals and an overrepresentation of White individuals.[27] Considering 39,576 participants across 230 studies, weighted racial and ethnic distribution revealed 76% White, 13% African American, 7% Latino, and 3% Asian representation.[27] Of note, representation of African Americans in studies between 2007 and 2013 was as high as 20%, sharply contrasting with 0% representation of Asian individuals. These trends changed between 2014 and 2019, where Asian individuals represented 4% of participants in studies and African Americans represented 8% of participants.[27] Beyond this, it is important to recognize that 75% of the individuals affected by epilepsy globally reside in low- and lower middle-income countries with limited to no opportunities for inclusion in research.[28] Clinical trials demonstrating efficacy of new antiseizure medications approved within the past 25 years also highlight a lack of inclusion of underrepresented and underserved populations in research.

Levetiracetam, initially approved by the FDA in 1999, has become one of the most widely prescribed antiseizure medications in the United States due to its favorable side effect profile. The efficacy of the medication was established partly through three randomized, double-blind, placebo-controlled clinical studies that enrolled a total of 904 patients.[29–31] White individuals constituted 95% of the total sample, while only 3% were African American, with 2% representation from other ethnocultural groups.[29–31] African American participants and other ethnocultural groups were only included in one of the three studies.[29–31] None of the studies provided any information regarding socioeconomic status or additional sociodemographic characteristics to assess whether participants were disadvantaged or from underserved neighborhoods. Clinical trials that demonstrated the efficacy of newer agents such as retigabine (2010), lacosamide (2014), and brivaracetam (2016) all show similar patterns of lack of inclusion of underrepresented and underserved populations.[32–34]

Surgical treatment for epilepsy was largely underutilized as a therapy until a landmark trial published in 2001,[35] followed by practice parameters in 2003 that recommended surgical treatment for drug-resistant temporal lobe epilepsy as a Level A consideration. Yet, this study did not include ethnoculturally diverse or underserved populations.[35] More than a decade later, the results of a second randomized clinical trial for temporal lobe epilepsy were published. Among the 28 participants included in this study, 76% were White, 15% were African American, and other ethnocultural groups only represented 8% of study participants.[36] No information regarding socioeconomic status or other sociodemographic characteristics was available for any of the participants, again raising questions about inclusion of patients considered disadvantaged or underserved.

Migraine

Migraine burden is substantial within the United States and globally. Up to one in six individuals living in the United States experience migraine or severe headache within any given 3-month period.[37] Numerous therapies have made migraine management highly tailorable, yet the research studies critical for demonstration of efficacy of these medications have lacked representation of underrepresented and underserved populations.

Botulinum toxin (Botox) is a highly effective medication for management of chronic migraine and is FDA-approved for this purpose. The first open-label, nonrandomized study to examine the efficacy of Botox for migraine included 106 individuals with no information about the ethnocultural identity or sociodemographic characteristics of any of the participants.[38] The first placebo-controlled, double-blind study examining Botox for migraine did include more information about participants than the open-label trial, however only 1% of participants were African American, 3% were Latino, and 1% were Asian.[39]

Other therapies for the acute and chronic management of migraine, in addition to prevention, have also continued to advance. For example, calcitonin gene-related peptide (CGRP) antagonists are newer therapies that are nonserotonergic and do not induce vasoconstriction, making them potentially more tolerable for individuals with preexisting conditions. However, clinical trials examining the efficacy of these medications have failed to be inclusive. The randomized, double-blind, placebo-controlled, multicenter trial of telcagepant for migraine prevention included 656 individuals, 90% of whom were White.[40] African Americans constituted 8% of trial participants and all other groups <3%. No information about sociodemographic characteristics of any of the participants was available.[40] Randomized controlled trials which have demonstrated proof of efficacy for additional CGRP receptor antagonists MK-3207,[41] BMS-927711,[42] and BI44370TA,[43] show similar trends in inclusivity.

Alzheimer’s Disease and Related Dementias

Recent examination of AD/ADRD imaging research over a 30-year period revealed significant overrepresentation of White individuals (>80% of all study cohorts) and underrepresentation of African American (<12%), Latino (<5%), and Asian participants (<2%).[44] Similar trends of representation are present in other observational research studies with even less representation in clinical trials within the AD/ADRD field. The recent development of disease-modifying therapies with FDA approval for the treatment of AD highlights the need for greater inclusion of underrepresented and underserved populations within AD/ADRD research.

Lecanemab is the most recent disease-modifying therapy for AD to receive FDA approval. The 18-month, multicenter, double-blind, phase 3 trial that examined the efficacy of lecanemab in individuals with symptomatically early AD included 1,795 individuals, of whom 74% were White, 16% were Asian, 12% were Latino, 2.4% were African American, 3% were from other ethnocultural groups, and no information was provided regarding the socioeconomic status of any participants.[45] Prior to the recent approval of lecanemab, the FDA also approved aducanumab (2021), a disease-modifying therapy directed against β-amyloid. The two randomized phase 3 clinical trials examining aducanumab among individuals with symptomatically early AD included 3,285 individuals across 20 countries, yet <1% of participants were African American, 3% were Latino, and 9% were Asian (largely from outside the United States).[46–48]

A challenge highlighted by examination of the multiple clinical trials and research studies across different neurological conditions is the frequent lack of reporting of ethnocultural identity,[49] and other social determinants of health characteristics like housing stability and neighborhood environment.[50,51] Absence of this information creates a barrier to understanding whether underserved and underrepresented populations are truly included in neurological research and whether research populations are truly reflective of the population at large.

Reasons for Lack of Inclusion of Underserved and Underrepresented Populations in Neurological Research

Factors influencing lack of inclusion of underserved and underrepresented populations in neurological research can be divided into individual-level, investigator-level, study-level, and system-level barriers. Individual-level factors, often fueled by historical and ongoing medical discriminatory practices and poor quality clinical care, include mistrust of physicians and research,[52,53] fears of personal information release without approval,[54] incomplete understanding of risks and benefits of research trials,[53] logistical barriers related to transportation and availability to participate in research visits,[53] and individual concerns about negative effects of exposure to a therapy.[55] Family composition and size can present a barrier when large families have multiple individuals who seek an active role in decision-making around research involvement.[56] Additionally, some underserved and underrepresented groups hold beliefs that the development of neurological diseases is part of the normal aging process or unavoidable,[57] as they often have not been exposed to education about this topic, though this is just one factor. Individual-level barriers like mistrust of physicians and research can set the stage for less robust participation but lack of inclusion is then further amplified by investigator-level, study-level, and system-level barriers (Table 1).

Geographical location of study sites, particularly academic institutions, limits inclusivity,[58] even though these sites may be located in urban settings where the population is more diverse. They are still frequently inaccessible to underrepresented and underserved communities. Eligibility criteria that disproportionately exclude individuals with comorbid conditions,[59,60] requirement of a study partner with obliged study visit attendance,[59,60] and lack of flexibility in visit scheduling have all been reported as barriers to inclusion.

Neurological research studies can also be burdensome to participants and introduce physical risks and opportunity costs.[61] Many studies require multiple day visits, requiring a participant to make complex travel arrangements and navigate transportation challenges or dangers repeatedly. The travel to many research sites can be lengthy, particularly for those who have fewer transportation options. Lack of cultural inclusivity among research staff and inadequate accommodations for non-English speakers also significantly limit representation of the underserved and underrepresented.[62] Language used in many patient-facing materials that communicates key information about research studies is often challenging to understand,[62] regardless of the language it is written in, and materials frequently are not culturally inclusive. Researcher biases and stereotypes toward underserved and underrepresented communities also undermine efforts at inclusion.[63] Finally, access to general medical care and neurological care is more limited for underrepresented and underserved populations. Less engagement with primary care providers and specialists affects an individual's likelihood of receiving a timely and accurate diagnosis of a neurological condition and reduces exposure to opportunities for participation in research.[64] These system-level, study-level, and investigator-level barriers can lead to the development of individual-level barriers. A comprehensive approach, therefore cannot simply emphasize individual-level barriers like mistrust of research without also acknowledging and examining system-level barriers like discrimination in health care and lack of access to care through neighborhood segregation policies that have directly contributed to the development of individual-level barriers.

Suggested Strategies for Increased Inclusion and Areas for Improvement

Numerous best practices and suggested strategies have been put forth to improve inclusion in neurological research. Best practices have emphasized building sustainable relationships with communities, strategic selection of research sites in more accessible locations (whether through transportation to institutional environments or establishment of sites in communities), creation of diverse research teams that engage participants, appropriate compensation for research participation, cultural inclusivity training of research team members, design of research studies with more inclusive eligibility criteria, and partnership with community leaders, organizations, and physicians.[64–67] Recruitment and retention strategies previously suggested for underrepresented and underserved individuals include dedicated, well-supported community outreach efforts and strategic advertising, as well as consistent follow-up communication and maintenance of relationships with the community.[66] Working with primary care in local communities to keep providers informed of research opportunities, allocated funding for research sites within the community with capacity to engage the underserved and underrepresented, and reducing participant costs of transportation and participation are also potential strategies.[64] Designing research studies in a manner that considers previously identified barriers to eligibility and participation (i.e., exclusionary criteria) with input from the community at the onset of study design also has been suggested.[65]

Strong collaborative and equitable relationships with community-based organizations and continued presence within the community have been repeatedly highlighted as foundational in improving inclusion of underrepresented and underserved populations in research. Absent or underdeveloped relationships with communities reinforce mistrust and other barriers, leading to continued patterns of underrepresentation. There is a paucity of quantitative research combined with qualitative research examining how engagement and relationship building with underserved and underrepresented communities should be approached. Existing research on engagement methods leaves questions about what constitutes the most effective or efficient approach.

Experiences from Our Community Engagement Efforts

Building relationships with community stakeholders is foundational for improving inclusivity since relationships between community partners and researchers have numerous downstream long-term benefits that can effectively mitigate barriers limiting the enrollment of underrepresented and underserved populations in research. To highlight opportunities and challenges with community engagement efforts, we share our own experiences in building relationships with communities in predominantly African American communities in the San Francisco Bay Area. The San Francisco Bay Area is home to diverse neighborhoods with individuals who represent a variety of ethnocultural identities and sociodemographic backgrounds. We emphasize engagement within communities that are predominantly African American and socioeconomically disadvantaged, as individuals from these communities are the least represented in our research cohorts.

Our community outreach program at the University of California San Francisco Memory and Aging Center engages communities around the San Francisco Bay area with goals of (1) educating individuals about brain aging and neurodegenerative disease, (2) improving access to clinical care for individuals with cognitive concerns, (3) recruitment of community members into research studies, and (4) supporting healthy cognitive aging through creative arts and physical activity-based experiences. We also organize educational lectures and host brain health-promoting recreational activities that support social connection and community building (e.g., bingo and group art). We have engaged with 17 different community-based organizations to date, including organizations that focused on community strengthening through social initiatives, organizations focused on serving spiritual needs, organizations focused on providing health education and services, and those focused on serving the needs of the elderly. The median percentage of the population living below the poverty line according to U.S. Census Bureau data within these communities ranges from 7.5 to 15.85%.

Key domains and suggested best practices based on our efforts to enhance community building are presented in Table 2. Typically, multiple points of contact are needed with organizations and it often takes between 1 and 4 months before a first collaborative event is hosted. Community organizations generally prefer to build our events into their larger programming and scheduled activities, and events are particularly well-received by community members when there are more opportunities for active participation (e.g., group games coupled with lectures).

In general, reasons behind interest in research participation among community members include the desire to advance science for the benefit of others, desire to receive the information provided from research about one’s cognitive testing performance, and interest in learning more about the experience of participating in a research project. Hesitations about research participation include lack of time to participate in required research tasks, logistical barriers to participation (e.g., inadequate transportation), concerns about sharing health information for research purposes, and mistrust of the larger medical system. Community partners highly valued bidirectional, open communication with us, and we learned early to avoid general assumptions about organizations and how to partner with them most effectively (Fig. 1).

Suggestions for Building Sustainable Relationships with Underserved and Underrepresented Communities

Building relationships with community stakeholders has repeatedly been suggested as a best practice, yet the specific practices and methodology for relationship building are nebulous, making it challenging to undertake and reproduce on a larger scale. The community–researcher relationship plays a pivotal role in improving representation of underserved and underrepresented in research. Based on our experiences, we offer suggested practices to build partnerships with the community, increase presence in the community, and facilitate inclusion of underserved and underrepresented populations in neurological research.

Carefully Consider Timelines for Engagement and Relationship Building

Planning adequate time for engagement and relationship development with the community is essential. Researchers operating within the confines of a strict timeline driven by financial constraints imposed by grant funding limits can formulate engagement strategies that are too short and pressured for building a meaningful relationship.[68] Community-based organizations may be unable to partner with researchers within these timelines due to competing priorities or unfavorable circumstances. This disposition, however, may not represent a lack of interest or willingness to partner on behalf of the community organization. Expressed lack of interest by researchers in building a relationship outside of a predefined timeline can be damaging and reinforce community mistrust.[69] From our experience, multiple months and up to a year may be required before certain organizations are able to participate in collaborative events. Additional time beyond this is then needed for community participants of collaborative events to consider the prospect of participating in a research opportunity. Considered in the context of an observational research study funded for 5 years or a clinical trial funded for 3 years, it would be highly unlikely to build relationships that would translate into recruitment of substantial numbers of underserved and underrepresented individuals from a community without a preexisting relationship. Ideally, relationships with community partners should be considered a long-term investment that must exist longitudinally, and outside of the confines of research funding timelines. This approach requires a shift in allocation of resources and priorities of funding bodies and institutions to allow opportunity for early career researchers especially to participate in this work. The standard method of assessing researcher productivity and success through manuscript publication and grant funding often fails to encapsulate the scope and impact of this work.[70,71]

Persistence and Flexibility are Essential in Relationship Building Efforts

Researchers must demonstrate persistence and flexibility in building relationships which are centered in trust. Community partners may be delayed in response times to inquiries or requests. Leadership within community organizations can change unexpectedly, creating a need to restart efforts with a new liaison at an organization. Community organizations may need reminders of prior conversations and plans as well as regular check-ins from researchers seeking partnership. The dynamic nature of many community organizations also leads to unexpected schedule changes and last-minute conflicts. We found this to be true in our efforts; for the number of successful collaborative events and successful points of contact we had with community-based organizations, there were often multiple rescheduled events, meetings, and plan adjustments. Organizations we engaged required repeated points of contact with our team before being willing to host a collaborative event, often requesting we meet multiple individuals within leadership with various decision-making capabilities at the organization. Flexibility on behalf of researchers is thus necessary to be able to adapt to needs and requests of the community partner as conversations continue and the relationship continues to develop. Lack of flexibility on behalf of researchers and expectations placed on the community organization are often embedded within larger underlying power dynamics, where the community is frequently in a disadvantageous position due to a one-dimensional relationship established by researcher actions.[72] Finally, seeking to understand the needs of community organizations through persistent but respectful efforts is essential to establishing bidirectional relationships where partners feel there is reciprocity.

Avoid Reinforcing Traditional Power Imbalances Created in Academic–Community Partnerships

Intentionality in approach to partnership can help to avoid reinforcement of power imbalances that often arise in partnership with community. These power imbalances arise from researchers' approach toward relationship building that imposes dynamics where communication is not bidirectional, interactions are transactional, and community feels obligated to comply with requests. Partnerships that recognize and emphasize community strengths can shift the power balance.[72] Special attention to how information is communicated within communities, specifically bidirectional communication that allows communities to voice their needs, shared decision-making, and researcher acknowledgment of community expectations all can help disrupt traditional power dynamics.[72] We deliberately ask community partners how they wish to collaborate and seek to integrate our efforts into already existing programming that organizations deliver to community members. Many of our educational lectures are embedded into larger, already successful educational series focused on health that are hosted by community partners, though we also have received requests for programming that spotlight our educational and recreational activities. We deliver educational materials that avoid challenging technical jargon and, when more complicated language is present, make deliberate efforts to make it understandable. By hosting on average at least one collaborative event every week for the past 2 years, the level of contact we have with community organizations and community members facilitates repeated opportunities for them to express their needs and thoughts about partnership, allowing us to tailor our approach accordingly.

Engage a Diverse Group of Potential Partners that Serve a Variety of Community Needs across a Geographic Region

Partnerships with different types of community-based organizations can be highly valuable.[73] Within the context of research participation by African American individuals in neurological research, significant attention has been given to partnership with faith-based community organizations and leaders,[74–76] however, we have found that other community-based organization types were also highly collaborative, particularly senior services' organizations. A critical component of effective community relationship building involves becoming knowledgeable about which community organizations are best positioned to engage in collaboration and then leveraging this knowledge. Working with only a single type of community organization is less fruitful to researcher and community alike. To engage more African American individuals and communities with a greater percentage of the population living below poverty level and eliminate geographical barriers, we traveled to multiple neighborhoods within a 12 square mile radius of our campus to engage underrepresented and underserved communities in our region.

Understand the Yield from Partnership Efforts

Not all attempts at formation of a community partnership are successful. Not all individuals who attend collaborative events hosted with community partners will be interested in participating in research. Scarcity of quantitative research examining how community partnerships directly translate into number of potential research participants makes it challenging for researchers to estimate the volume of work they need to perform within communities. Only a small proportion of all participants at our events expressed interest in research participation. A significant volume of collaborative work with community organizations can increase chances of engaging a greater number of individuals who will ultimately be interested in research participation. Although many researchers will identify participants enrolled into research from the community as a primary outcome of interest, it is important to also emphasize that many valuable unmeasured outcomes from the work also exist (e.g., knowledge gained by community individuals, changes in perceptions of research by community stakeholders, and durable long-term relationships).

Build a Sizeable "Footprint" in the Community through Sustained Presence

The importance of sustained presence in communities of interest cannot be understated. Sustained presence in a sizeable, but intentional, catchment area increases face-to-face time with community partners and community members alike, leading to increased trust and stronger relationships that can facilitate greater interest in research participation. We were informed from multiple community-based organizations and community members that they were made aware of our outreach and engagement efforts by other organizations in the community, leading to increased reassurance about our efforts and willingness to dialogue and collaborate with us.

Conclusion

Improving representation of underserved and underrepresented populations in neurological research is attainable through deliberate, sustained efforts to address individual-level, researcher-level, study-level, and system-level barriers. These barriers include but are not limited to individual-level mistrust of physicians and research, researcher biases and stereotypes, study-level exclusionary eligibility criteria, and less access to neurological care that limits exposure to research opportunities in a systemic fashion, among others. Increasing diverse inclusion in research is ethically responsible considering the disproportionate rates of disease and risk factors among certain groups. Relationship building and partnership with community-based organizations is the foundation of addressing many of these barriers, but researchers must be mindful of their approach to engagement and collaboration. Generous timelines for relationship building not limited by funding cycles, flexibility and persistence in efforts, avoidance of power imbalances, reciprocity of communication, engagement with different types of potential partners, and sustained presence are all key to successful relationship building. Following data-driven practices for engagement with communities can lead to successful collaboration and partnership that translates into research participation, but additional quantitative and qualitative research is needed to comprehensively understand all components of recruitment and retention of underserved and underrepresented populations into neurological research.

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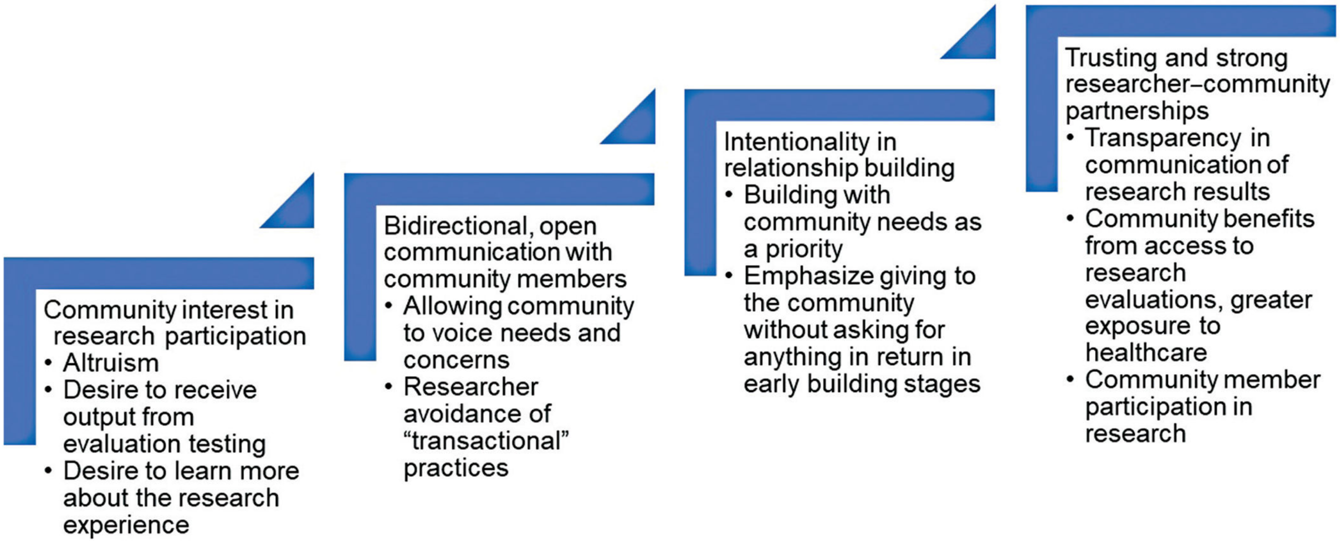

Community interest in research participation
- Altruism
- Desire to receive output from evaluation testing
- Desire to learn more about the research experience

Bidirectional, open communication with community members
- Allowing community to voice needs and concerns
- Researcher avoidance of “transactional” practices

Intentionality in relationship building
- Building with community needs as a priority
- Emphasize giving to the community without asking for anything in return in early building stages

Trusting and strong researcher–community partnerships
- Transparency in communication of research results
- Community benefits from access to research evaluations, greater exposure to healthcare
- Community member participation in research

Fig. 1.

Stepwise process of trusting researcher–community partnerships.

Table 1

Summary of individual-level, investigator-level, study-level, and system-level barriers that impact research participation

Barrier level	Specific barriers
Individual	- Mistrust of physicians, researchers, and institutions - Fear of loss of personal information through nonconsensual sharing by researchers - Incomplete understanding of research risks and benefits - Transportation barriers - Limited availability for research visits - Fears of negative side effects from exposure to therapy - Conflicting family views on research participation - Personal beliefs that development of disabling neurological disease is unavoidable or part of normal aging
Investigator	- Principal investigator and research team do not have experience in cultural inclusivity or have not been trained in this area - Inadequate accomodations for non-English speakers (e.g., lack of multilingual staff, lack of materials in various languages, etc.) - Researcher biases toward underserved and underrepresented individuals
Study	- Inaccessible or very difficult to access study sites - Exclusionary eligibility criteria that disproportionately impact underrepresented and underserved populations - Requirement of study partner with obliged visit attendance - Lack of flexibility in study visit scheduling - Lengthy, multiple day visits
System	- Limited access to quality general medical care and neurological care for underserved and underrepresented individuals - Historical and ongoing medical discriminatory practices and medical mistreatment of underserved and underrepresented individuals

Table 2

Key domains and suggested best practices with community-building, health care-based, senior services, and faith-based community organizations

Theme	**Suggested best practice**	**Experiences from our efforts**
Time investment in relationship building efforts	Carefully consider timelines for engagement and relationship building	- Time from first point of contact to first collaborative event with a community organization varies widely across the different types of community organizations - This time period is also just to first collaborative event. Maintenance and strengthening of relationships requires additional collaborative events and points of contact
Troubleshooting relationship building efforts	Persistence and flexibility are key	- Repeated points of contact are needed with organizations of all types prior to hosting a first collaborative event - Different organizations require tailored approaches to collaboration
Relationship dynamics	Avoid reinforcing traditional power imbalances	We synthesize our collaborative events with programming and activities already established by community organizations rather than imposing upon organizations
Community partner characteristics	Engage partners that serve a variety of community needs	We have engaged four types of community organizations to date that emphasize 1. general community building 2. health care 3. older adult needs 4. spiritual needs
Measuring outcomes	Understand yield from collaboration efforts can vary	- We measure traditional outcomes like number of collaborative events held, number of participants at events, and number of participants who expressed interest in research participation, but also expand beyond this - Many additional outcomes not typically appreciated are also achieved (e.g., increased knowledge for community members, brain health benefits from participation in collaborative events, etc.)
Scaling relationship building efforts	Build a sizeable “footprint” in the community through sustained presence	Participating in very frequent events has allowed us to build presence in the community through significant face-to-face time with community members