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Lived Experience Panel



Voices of the Lived Experience Panel: Health Equity in Dementia Care and Research

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Executive Summary

This report summarizes the overarching themes that emerged during four meetings of the NIA IMPACT Collaboratory's [Lived Experience Panel](#), the [Health Equity Team](#), and the [Engaging Partners Team](#). The goal of these discussions was to learn about Lived Experience Panel members' experiences and insights related to health equity in dementia care and research practices. Panel members shared their own experience living with dementia or mild cognitive impairment while others spoke as care partners or proxies. The results in this report are not a comprehensive review of these topics; rather, this report documents a conversational process among panelists. Extensive direct quotes are used throughout the report to enhance the readers' experience of this process as a dialogue. In all, this collaborative work identified six discussion themes listed below, that reflect panelists' experiences and feelings related to health equity, dementia care, and research. Our discussions emphasized the costs to patients and families for inequitable dementia care and research. Two major concepts emerged. The first is that people living with Alzheimer's Disease and Alzheimer's Disease Related Dementias (AD/ADRD) and their families have different experiences from one another. The second is that there is a need for a broad and inclusive plan to understand and address weaknesses within the systems of care in the United States, which are often fragmented and lack accountability for health equity.

Theme 1	Definitions, and Finding Consensus
Theme 2	Like Being a Tourist in the United States
Theme 3	You Don't Know What You Don't Know. Missed Opportunities
Theme 4	Equitable Implementation and Systems of Accountability
Theme 5	More Customization, Less Cookie-Cutter Guidelines
Theme 6	Informing the Dementia Research Mission

Key Takeaways

Lived Experience Panel members emphasized the following during our sessions:

- Health equity and related concepts such as underserved groups, can mean different things to different people. There should be agreement on terms, to help understand and achieve health equity.
- The phrase "underserved groups" should refer to people who have been historically excluded and have not received the same resources.
- The term diversity should refer to race, ethnicity, culture, gender identity, and sexual orientation, as well as diversity related to place and type of cognitive impairment (e.g., vascular, Alzheimer's, Lewy Body, frontotemporal, etc.).



- Living with dementia and interacting with systems of care can be overwhelming. Many factors like diagnosis, age, race, culture, preferred language, income, insurance status, where you live, and where you are from can contribute to unequal access to high quality care and research opportunities.
- Although the field of dementia care and research is growing, not knowing where to go for information, assistance, and care can mean missed opportunities to meet needs.
- Dementia care and research should focus on ensuring that all people receive the same type of care regardless of who they are. Systems of care should provide resources and support to include people who have historically been excluded.
- Dementia care should be tailored to the person and their family. Care guidelines should use a team approach that follows people throughout their journey.
- Access to and participation in Alzheimer’s research varies greatly. Rules for study eligibility can increase or reduce research participation.
- Terms such as “culturally tailored” and “under-represented” could be changed to “culturally responsive” and “historically excluded” respectively to better reflect community values and lived experiences.



About NIA IMPACT

The [National Institute on Aging \(NIA\) IMbedded Pragmatic Alzheimer's disease \(AD\) and AD-Related Dementias \(AD/ADRD\) Clinical Trials \(IMPACT\) Collaboratory](#) (U54AG063546) was established in 2019 to build the nation's capacity to conduct embedded [pragmatic clinical trials](#) (ePCTs) of non-pharmacologic interventions within health care systems to improve the care of people living with Alzheimer's disease and Alzheimer's disease-Related Dementias (AD/ADRD). The IMPACT Collaboratory does this through a coordinated effort between [IMPACT's leadership](#) and topic-focused [Cores and Teams](#) to:

- Develop and disseminate best practice research methods
- Support the design and conduct of embedded pragmatic clinical trials (ePCTs), including pilot studies
- Build investigator capacity through training and knowledge generation
- Catalyze collaboration among community partners, healthcare providers, and investigators
- Ensure research includes culturally tailored interventions and people from diverse and under-represented backgrounds

Ten topic-specific [Cores and Teams](#) work with the [Administrative Core](#) and funded investigators to accomplish the mission of the IMPACT Collaboratory. These [Cores and Teams](#) are made up of experts in their fields who work together under the direction of IMPACT leadership to develop and share best practice research methods, support the design and conduct of ePCTs, and provide guidance to IMPACT members and researchers.

About the Alzheimer's Association®

The [Alzheimer's Association](#) is a worldwide voluntary health organization dedicated to Alzheimer's care, support, and research. Its mission is to lead the way to end Alzheimer's and all other dementias by accelerating global research, early detection, and maximizing quality care and support. Its vision is a world without Alzheimer's and all other dementias.

About the Lived Experience Panel

The [Lived Experience Panel](#) (LEP) reflects a coordinated effort between the National Institute on Aging IMPACT Collaboratory and the Alzheimer's Association. Established in 2021, the Lived Experience Panel is a group of 9-12 people living with cognitive symptoms or caring for people living with dementia. Panel members help inform research priorities and challenges by sharing their thoughts and experiences with researchers from IMPACT's cores and teams in ongoing panel meetings. The Lived Experience Panel meetings cover different topics that may span more than one meeting. Generally, each topic area is introduced with a simple presentation by IMPACT research team members, followed by a discussion with panel members to capture their thoughts and feedback on the topic presented.



The diverse community of members participate in panel activities for one to two years. New panel members are added as previous panel members complete their participation period. Members are selected through an outreach and application review process. The current panel is made up of nine people reflecting various perspectives, including:

- Person living with dementia (PLWD): The panel includes those with a documented diagnosis of early-stage Alzheimer’s, Mild Cognitive Impairment (MCI), or other early-stage dementia.
- Care partner: The panel includes care partners/caregivers representing their own experience caring for a person living with dementia.
- Proxy: The panel includes care partners/caregivers representing the perspective of one or more persons living with dementia with middle or late-stage dementia or who are deceased.

The types of dementia represented by panel members include Alzheimer’s (6 members), Vascular dementia (2), Dementia (not otherwise specified) (1), Lewy Body dementia (1), Parkinson’s disease (1), Frontotemporal dementia (2), Mild cognitive impairment (1). Some panelists represented more than one type of dementia. The panel included people with the following characteristics and identities: Female (9), Male (2), Asian-American (1), Black or African-American (3), White (7), Latina (2), and LGBTQ+ (2).

About the Engaging Partners Team

The [Engaging Partners Team](#) (EPT) focuses on engaging community partners—including patients, care partners, clinicians, administrators, healthcare system leadership, community-based organizations, and public health entities—in all aspects of the development and conduct of embedded pragmatic clinical trials (ePCTs) among people living with dementia and their care partners. Team members create and share guidance and training materials on working with community partners during ePCTs, and support IMPACT researchers in developing strategies for meaningful collaboration with community partners throughout the research lifecycle.

About the Health Equity Team

The [Health Equity Team](#) (HET) contributes to the overall mission of the National Institute on Aging (NIA) Imbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) by developing and implementing strategies to address health equity in ePCTs and to ensure the IMPACT Collaboratory is a national resource for all Americans living with dementia and their families.¹



The Lived Experience Panel Report

Summary reports are written by the IMPACT core or team that facilitates the meetings for each topic area and reviewed by members of the Lived Experience Panel before being published and shared with the public. All reports are available on the [IMPACT website](#).

Introduction to this Report

This report summarizes feedback and insights from the IMPACT Collaboratory Lived Experience Panel on the topic of health equity in dementia care and research. The information was gathered through a series of conversations between the Lived Experience Panel, the Health Equity Team, and the Engaging Partners Team between late 2022 and early 2023.

Overview

Health equity related to dementia care and research is a central focus of the IMPACT Collaboratory. It is a key consideration in developing care and research practices on behalf of people living with memory loss, mild cognitive impairment, Alzheimer's disease and Alzheimer disease-related dementias (AD/ADRD). A range of topics were discussed in these meetings including the meaning of health equity, first- and second-hand experiences with inequity in dementia care and research, and possible solutions to prevent inequities. Additionally, members were asked to provide feedback on best practices to improve community engagement in research. The methods for obtaining feedback and insights are listed below, as well as the key themes that emerged from the facilitated discussions.

Methods

While the goal of this collaboration was to hear panel member perspectives about health equity considerations with ePCT research, the Health Equity Team created broad discussion prompts to collect feedback on health equity more generally, and beyond research.

A series of three 90-minute video conference meetings were held between October and November 2022 with members from the Lived Experience Panel, the Engaging Partners Team, the Health Equity Team, the Alzheimer's Association, Administrative Core, IMPACT Collaboratory leadership, and NIA Program Officers. A fourth meeting occurred a few months later, for the panel members to provide feedback on a draft of this report. Meetings were facilitated by Health Equity Team members with some portions (welcome, introductions, and closing) facilitated by the Engaging Partners Team. Agendas and meeting materials such as published articles and IMPACT Collaboratory materials were sent to panel members before meetings and were light in content to focus primarily on the contributions of the panel members.

Ahead of Meeting 1, the Health Equity Team supplied background materials ^{2,3} to the panel members and other attendees. These materials provided context for conversations about the impact of dementia health disparities (epidemiology, evidenced-based care, and economic costs), and definitions related to health equity and disparities. Members' openness to share their life experiences increased over the course of multiple meetings. By the last meeting, members shared additional examples of inequities and provided more detailed descriptions of experiences shared in prior meetings.



Meeting 1 took place on October 18th, 2022, and included introductions, background on the HET (mission, and collective work), and a facilitated conversation using two discussion prompts. The conversation began with defining terms typically used in health equity discussions, and the importance of health equity in dementia care, in general.

Panel members were asked to give feedback on the background materials^{2,3} provided, to share their understanding of the term health equity, and to describe any inequitable experiences that they or their family members had in their dementia care journey. There was a robust conversation using the following prompts:

- 1) What do we mean by health equity?
 - a. Why is this important in Alzheimer's care?
- 2) What experiences of discrimination in dementia care are you aware of?
 - a. What effect did these experiences of discrimination have on you or someone else?

As panel members shared their experiences, the meeting facilitator reflected what they heard back to the panel members, and then asked for other comments, leaving plenty of time for people to speak up. Some members used the chat function to contribute to the conversation.

Meeting 2 was held on November 7th, 2022, and included introductions, a complete review of the previous meeting's discussion, and a facilitated conversation about the panel members' experiences with the healthcare system. Additionally, they were asked to share their thoughts on best practices to incorporate health equity into research study design. Panelists were asked to respond to the following prompts:

- 1) What are your experiences with the healthcare system that highlight inequities?
- 2) Provide feedback on "6 Best Practices for Community Partner Engagement: Integrating Health Equity into ePCTs for Dementia Care."⁴
- 3) For feedback on the Best Practices document, the facilitator specifically asked:
 - a. What do you think about the 6 best practices described in the document?
 - b. What's missing?
 - c. Does it seem like a reasonable set of guidelines?
 - d. How do we best disseminate this or advertise this to the different people who are doing research so that they can engage community partners in the best and most equitable way?

Meeting 3, held on November 14th, 2022, was the group's final conversation before drafting this report. It included introductions, a recap of the previous discussion and possible solutions and next steps. Lastly, there was a facilitated discussion on the Best Practices for Community Partner Engagement document. Members were asked for suggestions on ways to engage



people living with dementia in the research process, and ways that the Lived Experience Panel can inform the research mission of the IMPACT Collaboratory. The following prompts were used:

- 1) Request for feedback on “6 Best Practices for Community Partner Engagement: Integrating Health Equity into ePCTs for Dementia Care”⁴
- 2) If you could radically reimagine your experiences, what would it have looked like or what would it look like moving forward?
- 3) What are some solutions and better ways to engage people with lived experience, like yourself, in the research process?

All meetings were recorded and auto-transcribed using Zoom Video Communications® software. Health Equity Team members reviewed all recordings, transcriptions, chat messages, and debriefing notes, and combined these sources into a meeting summary. Once this was done, the key themes that emerged were reviewed and refined by the Health Equity Team.

The draft report was then sent to the Administration Core and Engaging Partners Team for comments. A second draft, incorporating those comments, was then shared with panelists ahead of the fourth and final meeting so they could share feedback.

During **Meeting 4**, which was held on March 31, 2023, the panel members discussed the draft report and were invited to be listed as co-authors. The draft report was shared two weeks ahead of the meeting to allow time for review and reflection. During this final meeting, the facilitator closely reviewed each section of the report, asking for feedback from panel members at each step. The following prompt was used throughout, “Share your thoughts, including whether the summary of that section correctly captures your input.” Written responses to the report were also encouraged. Panel members expressed their appreciation and reported that they felt seen and heard throughout the report. An in-depth description of panelists’ feedback is recounted in the “Feedback from the Lived Experience Panel” section of the report.

Six key themes emerged during the meetings which are reflected in the following section.

Themes

Theme 1	Definitions, and Finding Consensus
Theme 2	Like Being a Tourist in the United States
Theme 3	You Don’t Know What You Don’t Know. Missed Opportunities
Theme 4	Equitable Implementation and Systems of Accountability
Theme 5	More Customization, Less Cookie-Cutter Guidelines
Theme 6	Informing the Dementia Research Mission



Theme 1. Definitions, and Finding Consensus

Questions arose around definitions of concepts during the first meeting, such as “What is meant by underserved (groups)?” Panel members expressed the desire to understand concepts and terms introduced in the background materials ^{2,3} and to ensure that everyone was on the same page about terms such as health equity and underserved groups. As stated by one panel member, *“Without consensus on what is meant by health equity, or what health equity looks like, we may not know how to achieve health equity because equity could have many dimensions”* (PLWD).

Members provided their own definitions of the term “underserved” as referring to situations in which certain groups of people living with dementia and their care partners experience negative consequences and lack of inclusion with regard to patient care, access to resources, and quality of life, based on who they are. One member noted that *“being underserved is a historical pattern where particular groups do not receive or have access to the same resources (as others),”* while another member added that *“underserved (groups) gives more of an opportunity for a group to slip through the cracks rather than be included ...”* (Proxy).

Members understood that *“equity may mean different things across the Lived Experience Panel members, and inequities have different dimensions”* (PLWD). They recognized the degree of diversity in their own group and the IMPACT team: *“We all have different experiences, different experiences with the healthcare system, different family experiences”* (Care Partner). They also acknowledged that discussions of health equity can be broad, and there are many different aspects of equity, including the diverse types of cognitive impairments represented by the panel members, (e.g., dementia, Alzheimer’s, related dementias, mild cognitive impairment, etc.).

Theme 2. Like Being a Tourist in the United States

A commonly reported experience among panel members was a feeling of helplessness as they try to understand their condition or that of their family member. They described the journey to diagnosis and the next steps as a confusing and often unknown path. They described a consistent struggle to orient themselves and navigate the next steps for care and support. The members were open in describing the health inequities they experienced, which occurred throughout the course of the disease—before the diagnosis, soon after the diagnosis, and beyond.

Rich examples of health inequities and contributing factors were presented during the meetings. The first factor introduced by the group centered around unfair treatment by healthcare providers because of their memory-related diagnosis or that of their family members. In other words, a central reason for the differential treatment or care was the fact that the person had a memory diagnosis (or memory complaint) in the first place. As a result, they did not receive the proper diagnostic evaluation or information on what to do following the diagnosis. A member expressed frustration with having to see several doctors for his post-diagnostic care and having to take a great deal of time to *“get the doctors up to speed”* about his condition (PLWD). Another member described the experience: *“I felt like being a tourist in the United States and in the worst way possible”* (Care Partner), as she made many attempts to get a diagnosis for her



mother and realizing that getting the right care for her mother's condition and neuropsychiatric symptoms was foreign and unreachable, especially in a rural community.

Across the meetings, additional factors that added to inequities in dementia care were identified including age, income, insurance status, socioeconomic status, lack of social support, geographic (rural) area, language, nativity, culture, and citizenship status. For example, one member described how her mother was unable to receive care for frontotemporal dementia in a rural part of the country. She believes that her mother experienced *"the prejudice of poverty as a Medicaid patient"* (Care Partner) such that her care was substantially delayed until her symptoms worsened, leading to hallucinations and combativeness. Another member reinforced that inequities can emerge due to rural inequities wherein *"a small, rural community may have only one neurologist who is located 60 miles away"* (PLWD).

Members cited ageism on the part of healthcare providers as a reason for not obtaining a timely diagnosis or lack of disclosure of the diagnosis to the person or care partner. One member described that she was diagnosed with mild cognitive impairment at the younger age of 45. She recounted how several neurologists dismissed her cognitive symptoms because of her younger age and wanted *"to think it's anything but dementia."* The panel member noted that because *"I did not look like what people think of when they think of Alzheimer's and dementia,"* she was not diagnosed earlier which also delayed her access to medications (PLWD).

Similarly, another member reported that ageism played a role in delaying her mother's diagnosis due to the mother's older age; the healthcare provider refused to engage in a conversation with the mother and daughter about memory problems because of the mother's older age, and thus, *"the diagnosis was brushed aside."* The member later found out that the diagnosis had been clearly stated in the medical record, but the provider insisted *that "these things are to be expected"* given her mother's late age. As a result of the provider's avoidance of *"having the difficult conversation,"* the panelist felt strongly that her mother was ignored and was not offered proper services or treatment options (Proxy).

Racial, ethnic, and socioeconomic considerations emerged as important factors in dementia care inequities. Support groups play an important role in information and resource sharing that is often lacking from providers, but these key spaces remain inaccessible to members from underrepresented groups. As one member described, *"As an African American, very few of us are even involved in early Alzheimer's support. So, imagine that is a whole lot more missed opportunities for us because there are many of us that seek out those resources and seek out the support groups (yet don't receive them)"* (PLWD). Another member talked about her ability to avail herself of support groups (and other resources) because of her life experiences that included growing up in predominantly White places, thus making it a bit more comfortable to attend support groups: *"But I think it's important to say because me being an Asian woman, and my ability to feel comfortable enough to sit in support groups, is a privilege that I acknowledge because of my lived experiences, and because of the different spaces that I've had to be in professionally, personally, ... that I recognize the benefit of being uncomfortable in that moment, outweighs what I might miss in terms of resources. And that's the inequity ... people shouldn't*



have to work so hard to find support. People shouldn't have to work so hard to have access to the stories and the experiences that we can all benefit from, regardless of what we look like, where we come from" (Care Partner). One member expressed concern that it did not register with her at the time that inequities due to her mother's race could have played a part in her mother's dementia care, although she suspected these did occur: *"I've said this so many times, I won't take up time to repeat it. It never occurred to me that my mother might not be receiving the best care possible due to her race or sex or whatever. I was so busy with researching and caring that it just did not occur. In retrospect, I still can't come up with examples of times I suspected that might have been the case. Of course, it's possible, but my mind was so full of other things the thought never occurred"* (Proxy). Another member shared her family's dismay with the physician's refusal to account for the family's cultural care preferences: *"He threatened to put my mother in a nursing home if I and my sister did not do so"* even when they specifically said that this was not a decision that her family would tolerate as a treatment option given their familial culture (Care Partner).

With regard to socioeconomic status, a member added that if support groups are comprised mainly of people with college degrees, this may exclude others from finding resources: *"... one particular support group collected demographic information on those involved. Out of 60 people, seven people had a high school diploma or less ... more than 50% of the people in our support group had a master's degree or above. If all these opportunities or resources are found in the support groups, then what about those that are less educated ... so socioeconomic status (can cause) missing out on even more opportunities ..."* (PLWD).

Another type of inequity cited by members was a lack of social support. One member took on the responsibility of caring for her mother as a young woman who had *"not quite figured out her career,"* and was still caring for her young children. She took on the care responsibility because *"no one in her family stepped up ... and family members did not want to acknowledge what was happening."* Her other family members were *"just not an option"* to help in the caregiving. She noted that in many families, one person, usually a female member, is left to *"walk with their loved one"* (Care Partner). Another member added that *"individuals who lack social support from families should also be considered "underserved."* For example, he brought up that if someone comes from a *"dysfunctional family or does not have daughters to care for them ...,"* this could be another dimension leading to health inequity and being underserved. Beyond lack of family support, he noted that being *"underserved"* could mean lacking access to supports such as unpaid care, transportation, and other logistical resources (PLWD).

Theme 3. You Don't Know What You Don't Know. Missed Opportunities

Members addressed their initial lack of information about dementia, where to go for help, what research opportunities were available to them, etc. Members echoed their confusion about where to go for information and assistance if, *"You don't know what you don't know"* (Care Partner). Understanding symptoms, diagnosis, treatment, and care was done with a lack of information. As one member put it, at the time of her mother's diagnosis, she did not know *"what best care looks like"* for someone with dementia and she feels that she still does not know. She added that her priorities and understanding of what her mom needed were self-



generated because she never received guidance on what her mom's needs were, or how to care for her (Care Partner). In retrospect, she wonders about the ways her mother's care might have looked different if the family had access to resources, money, and internal capacity.

I did as much as was possible for me to ensure that mom was well, that she had access to all of her medical appointments, that she had good sleep, food, ... I don't know what something different looks like when there is availability of resources ... when there is no issue with finances, there is no issue with time, there is no issue with internal capacity of understanding and knowing all of these pieces ... We need a care team to follow us, to be with us, to become part of our journey that has different levels of expertise that we don't necessarily have already. We come with assets, yes. We come with the love that we have for our family, care recipient, yes, but we also need so much more.

(Care Partner)

Another perspective related to not receiving the right care was when care was “misaligned” with the disease trajectory, and the needs and preferences of the person living with dementia, and/or the care partner. Examples of misaligned care included participating in support groups but “*not feeling represented since most participants had family members (living) in a facility*” (Care Partner). Another member acknowledged that although her mother finally received specialized memory services when she “*became a part of a memory care clinic ... but only a few months before [her mother] passed ... which was too late.*” A member noticed that there is more information directed towards caregivers than people living with dementia like him. Consequently, when he asks for information from different providers, “*they don't have answers that work*” (PLWD).

Thus, realizations of missed opportunities emerged—whether missed opportunities to take advantage of a new drug, a specialized treatment program, a financial benefit, or simply to see a qualified physician for a diagnostic assessment. As one member put it, she felt “*cheated and as if [she] let [her] mama down by not knowing what was available.*” She pointed out the dilemma of “*how do you find out what is available if you don't know to ask, 'What's available?'*” Getting access to the best care was an ongoing pressure for her—something she hid from her mom as she “*felt ignorant about [the situation],*” although in retrospect she feels she “*did the best I could*” (Proxy).

Theme 4. Equitable implementation and Systems of Accountability

A recurring theme was the idea of “equitable implementation.” Members provided details about how dementia care was implemented unequally—including variations in the information provided and inequitable access to resources—which made one member feel as if she was “*slipping into nothingness*” (Care Partner). As another member recalled, the combined effects of health inequities due to the diagnosis, living in a rural town, and being low-income, produced excessive burdens in her quest to secure the right care and support for her mother. She acknowledged that even though her mother received care from a team, the implementation was



“up and down in quality” as the “geriatric doctors kept leaving the practice, and clinical care was all over the place,” if my mother was here today, she would say, ‘I had the best care on the planet.’” She believed that is only because she *“made it a point to not let her see the pressure I felt to make sure that she got the best care ... [I] was “winging it” ... and “flying by the seat of (my) pants”* (Proxy).

Members believed that there should be a specific focus on “equitable implementation” and “systems of accountability” for dementia care. One member added that research should also be framed in terms of systems of accountability (Proxy). As an example, one member shared that her mother would have been diagnosed with dementia even later if she and her spouse, who is a medical doctor, did not live near a large research university (Care Partner) with strong connections to ensuring systems of accountability. Examples of systems of accountability provided by panel members included: establishing a team approach to care and sharing knowledge and information about support services—as part of treatment goals (Proxy).

Theme 5. More Customization, Less Cookie-Cutter Guidelines

Members expressed frustration with the general, post-diagnostic guidance they received from their healthcare providers. They encouraged a more tailored, individualized approach to information sharing and recommendations. As one member stated, *“No two cases are the same, therefore identifying best practices is complex”* (Care Partner). There was a general agreement that despite years of experience and advocacy, the treatment and care guidelines available to people living with dementia and their care partners are much the same today as they were a decade ago. They expressed frustration with the practice of referring newly diagnosed people and their care partners to the Alzheimer’s Association for information on what to do next. Panel members described this as out of touch with current realities. This was seen as no longer enough, and too overwhelming to rely on the Alzheimer’s Association as the *“first stop”*² (Care Partner).

Members provided recommendations for more tailored support and information for newly diagnosed people and their care partners. One such example was a checklist of post-diagnostic tasks or steps provided by physicians that can be “customized” and which should include a team of providers to include social workers, neurologists, etc. (Care Partner). Another member advocated for a *“team care approach” wherein people could be paired with a “group of people that we can walk this journey with”* at the time of diagnosis and over the disease course as needs changed. This was compared to situations where individuals are *“just left to drift in this big sea of nothingness”* after the diagnosis (Care Partner).

One member provided an example of an informational binder given to him by a physician assistant. The binder was customized for people living with cognitive impairment and provided information that was not overwhelming, and which made a difference in his post-diagnostic care (PLWD). Another member added that he did not care about the biology of the disease as much as for direction about finding resources after obtaining his diagnosis. He recommended that a flow chart or decision tree with options based on language, religion, etc. could be helpful for people receiving a diagnosis of dementia (PLWD).



Theme 6. Informing the Dementia Research Mission

A major role for Lived Experience Panel members is to inform the research mission of the IMPACT Collaboratory. Panel members were asked about their perceptions of dementia research, and to give feedback on the [Best Practices for Integrating Health Equity into Embedded Pragmatic Clinical Trials for Dementia](#).⁴ Specific focus was placed on the stakeholder engagement section of the document. Members' responses to these queries were much less detailed than those noted in the prior themes except for one notable area: The sole focus of members' discussion revolved around research study participation and the practices that can increase or decrease participation.

Panel members had significantly different levels of previous experience with study participation. One member living with dementia cited that finding research projects to participate in has been difficult for him, and many require a study partner (PLWD). Another member cited his satisfaction with participating in fifteen studies (PLWD). Another member discussed participation in a Latinx-specific group where the members were well-versed in research participation (Care Partner).

Members described a number of factors that limited their awareness of and involvement in research efforts. They reported that they had been excluded from participation due to their age, diagnosis, illness stage, or other criteria. As one panel member put it,

As a person living with dementia, I have been excluded from research even after completing a very long application for not being at the right dementia stage, being too old, too young, or not being Hispanic. It's kind of aggravating. (PLWD)

One member living with dementia found it difficult to qualify for existing studies and noted that as an African American—a population that is underrepresented in dementia research—there is a high likelihood of being excluded from participation due to pre-existing conditions (PLWD).

Some members believed that if they were not connected to groups such as dementia support groups, that they *"would be unaware of research studies"* (PLWD).

Members provided suggestions for ways to increase access to research. One member recommended that recruitment should be done in less threatening ways by investing in building relationships and trust and by offering study information in multiple languages. Additionally, the panel member suggested offering compensation to study participants as well as to medical and social service practitioners who share information about study participation with their patients. As she stated, *"In the past, I had mentioned that researchers truly do need to connect with the communities and cannot just expect to helicopter in and expect to have willing participants"* (Care Partner). Another panelist noted that *"seeing diversity among researchers themselves (is important). The research community should reflect the diversity of those affected by dementia"* (Proxy).



Research participation in dementia-related studies was compared to participation in other studies. A few members shared that they were participants in other studies with a cancer or health focus, unrelated to dementia. A member stated that they *“always wondered if cancer research and supports took this long to get to where they are now”* (Care Partner), while another member raised concerns about reimbursement inequities to dementia care funding, *“I wonder, if in the case of cancer, there (is) more money available for clinics, etc., because of the number of therapies available so there (are) revenue streams. Not the case in Alzheimer’s since there isn’t any therapy or revenue-generating opportunity”* (PLWD).

One member remarked on her dissatisfaction with some of the terminology used to describe IMPACT’s objectives. She made two specific suggestions related to the terminology used when describing the IMPACT objective ‘Ensuring research includes culturally-tailored interventions and people from diverse and under-represented backgrounds:’ 1) Change “culturally-tailored” to “culturally responsive:” *“I personally do not feel there is enough said when one says, ‘culturally-tailored’ and feel more strongly about stating it as ‘culturally responsive’ with the hopes that those using this (objective) as reference actually carry out practices that respond to those in that cultural community rather than bring a Euro-centric, standardized/sterile model that then they ‘tailor’ to ‘fit;”* and 2) Change the term ‘under-represented:’ *“Rather than using the phrase ‘under-represented backgrounds,’ call it what it is, ‘historically excluded backgrounds”* (Care Partner).

Discussion

Our discussions on health equity about people living with dementia and their care partners underscore the human costs of inequities in dementia care and research. Overarching concepts woven throughout the three sessions include the **fundamental diversity of human experience associated with AD/ADRD** and the **need for a broad and inclusive framework to understand vulnerability within healthcare systems** that are often fragmented and lack systems of accountability for health equity.

Underserved populations are more likely to experience inequities in dementia care and research based on a range of factors and individual characteristics, including race and ethnicity, age, income, insurance status, socioeconomic status, lack of social support, geographic (rural) area, immigration and citizenship status, and preferred language. These individual characteristics, as well as systemic racism, place people living with dementia and their families and care partners at risk of *“falling through the cracks,”* thus generating inequities in access to and quality of care. Problems with quality and access begin with delays in diagnosis and a lack of clear provider communication about the nature of the disease and the availability of community resources to people with dementia and their families.

Reflecting on their own lived experiences, Lived Experience Panel members emphasized the heterogeneity of diseases that fall under the rubric of Alzheimer’s Disease and Alzheimer’s disease related dementias (AD/ADRD), as well as the changing needs of people with dementia and their families in response to the unfolding disease process over time. The role of time resonated with members and how it contributed to or alleviated inequities across stages of the



disease. Our healthcare systems often fall short because they fail to adequately respond to these changing needs, creating inequities and gaps in care and services that result in suffering and stress for people with dementia and family caregivers. Inequities can be further amplified by physicians and other healthcare providers who do not show humility and respect in their care of underserved populations, further undermining trust in healthcare systems.

Members emphasized that research needs to be broadly inclusive of people with dementia and care partners. They shared personal frustrations based on their own experiences of having been excluded from research studies due to restrictive inclusion criteria or because of a lack of timely information about opportunities to participate.

Conclusion

To address issues of equity in practice and research, panel members suggested the development of flexible and accountable systems of care. Healthcare systems need better processes to hold themselves accountable for high-quality of care and to ensure that programs and services are implemented equitably. Accountability might, for example, include the development of shared “tools” such as customized “checklists” for navigation of dementia care and community resources post-diagnosis that can be tracked over time by people living with dementia, their family, and their interdisciplinary care team.

A tailored and flexible approach is essential for dementia care and research to adapt to the changing care needs across the illness trajectory, and the values and preferences of people with dementia and care partners. This flexible approach must be coupled with an attitude of urgency and responsiveness to the needs presented by people living with dementia and their care partners by competent and efficient practitioners who foster trust in the clinical encounter. Researchers must also hold themselves accountable in terms of engaging and including populations most vulnerable to inequities in access and quality of care. To achieve more equity in research, panel members emphasized the importance of researchers reaching out broadly to community networks and organizations to learn about community values and preferences and to provide timely and easily understood information about research opportunities. More **accountable** and **flexible** approaches in care and research will be best suited to reducing inequities and improving access and quality for all.



Reflections from Panel Members

Overall, members' feedback was positive as reflected by statements that they felt heard, that their experiences were represented in the body of the report, and they no longer felt invisible. As stated by a member,

I think the title for this (report) is powerful ... I enjoyed reading the entire report because for me, it helped to put my experience in perspective. When you're siloed, (it) is often difficult to even imagine what other people are experiencing. In fact, you feel invisible. (Proxy)

Another member chimed in about her hope for this report:

I'm hoping that this document will open up some doors for the medical community, and the mental health folks that they see that we are human beings. We're not just the disease. We're not just Alzheimer's people. We're not just dementia people, you know, we have opinions, and we have things that we have to say. (PLWD)

All panelists appreciated seeing such a robust representation of their thoughts, quotes, and their understanding of concepts and definitions in the report. As one person stated, *"It is obvious to me from reading this entire thing that you really listened to what we had to say. It feels really good to be heard"* (Proxy). Another member shared that she was able to recall the sessions vividly, could hear all their voices, and was honored to be a part of this work. Panel members agreed that *"[the report] helped to put [their] experience(s) in perspective"* (Proxy) and that reading this report assured them that they were heard. As one member put it: This report gave her late mother *"a voice."*

Extremely meaningful ... I will always feel like my mother, and I were standing at the bus stop, but the transportation was leaving from the pier. We should have been catching the ship, but we went to the wrong place. It brings out a lot of emotion in me, even two years later, that I sort of missed the boat ... So, this is a very emotional part of the report for me. And I'm very glad that you included this. (Proxy)

Feedback from the Lived Experience Panel on this Report

Members of the Lived Experience Panel were invited to review a draft of this report and provide written and verbal feedback on each of its elements. The report has been iteratively edited to reflect feedback related to previous themes and new insights. Members emphasized their desire that this work be disseminated widely and used to improve equity in dementia care and research.



References Cited

1. Quiñones AR, Mitchell SL, Jackson JD, Aranda MP, Dilworth-Anderson P, McCarthy EP, Hinton L. Achieving Health Equity in Embedded Pragmatic Trials for People Living with Dementia and Their Family Caregivers. *J Am Geriatr Soc.* 2020 Jul;68 Suppl 2(Suppl 2): S8-S13. doi: 10.1111/jgs.16614. PMID: 32589281; PMCID: PMC7422698.
2. Aranda MP, Kremer IN, Hinton L, Zissimopoulos J, Whitmer RA, Hummel CH, Trejo L, Fabius C. Impact of dementia: Health disparities, population trends, care interventions, and economic costs. *J Am Geriatr Soc.* 2021 Jul;69(7):1774-1783. doi: 10.1111/jgs.17345. PMID: 34245588; PMCID: PMC8608182.
3. Braveman P. What are health disparities and health equity? We need to be clear. *Public Health Rep.* 2014 Jan-Feb;129 Suppl 2(Suppl 2):5-8. doi: 10.1177/00333549141291S203. PMID: 24385658; PMCID: PMC3863701.
4. Best Practices for Integrating Health Equity into Embedded Pragmatic Clinical Trials for Dementia Care. NIA IMPACT Collaboratory; 2022. doi: <https://doi.org/10.58234/74152992>.

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