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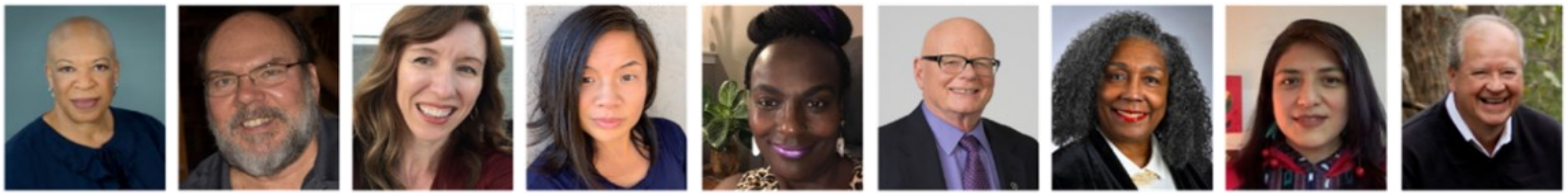

The IMPACT Collaboratory Lived Experience Panel: Reflections on Accomplishments and Recommendations for Continued Work

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Executive Summary

This report describes feedback from four prior panel series summary reports and summarizes the overarching themes that emerged during discussions about panel member roles and panel processes between the NIA IMPACT Collaboratory's Lived Experience Panel, the Engaging Partners Team, and the Alzheimer's Association. These conversations also took place with IMPACT's Community Review Panel and will be reflected in a separate report.

This report includes highlights and themes identified from prior panel reports and recommendations for future work. The goal of these discussions was to learn about the Lived Experience Panel members' insights on how to improve the content and process of the meeting sessions, their experience as panel members, and to continue developing the Lived Experience Panel as a model for the research consortium to engage people living with cognitive symptoms and care partners in the design of their research on dementia-related care and support. Panel members shared their experiences during the meeting sessions, including any benefits and challenges to their participation, changes in perspectives after their participation, how research and the Lived Experience Panel can have a better impact on dementia-related care and support, and how they can be better supported by the Lived Experience Panel organizers. Direct quotes enhance the reader's experience of this process as a dialogue. See below for an outline of key takeaways from each report section.

Key Takeaways from Reflections on Work with Prior Reports

Report 1: *"Priorities for Person and Caregiver Relevant Outcomes in Dementia Intervention Research"*

- **Research priorities** - Research should focus more on healthcare, social, and emotional needs and less on reducing hospitalizations. Although hospitalizations are sometimes needed, panelists highlighted the complex relationship between addressing healthcare, social, and emotional needs to reduce hospitalizations in the long term.

- **Inclusivity** - Incorporating lived experiences into the research process, including those from historically excluded communities, is valuable for community education and engagement.

Report 2: *"Ethical Challenges in Conducting Research Using a Waiver of Informed Consent with People Living with Dementia"*

- **Trustworthiness** - To ensure trustworthiness, research projects using a waiver of informed consent must prioritize dementia-friendly approaches, timely notifications for participation, community research engagement, the involvement of trustworthy researchers, and a mutual exchange of benefits between researchers and participants. To facilitate the notification process, panel members recommended employing advisory boards, research navigators, and media advertisements as effective tools.

Report 3: *"Voices of the Lived Experience Panel: Health Equity in Dementia Care and Research"*

- **Partnerships -** To increase research opportunities, researchers should develop partnerships with community-based organizations that serve as influential advocates in the community. These organizations could potentially receive state or federal funding for research as long as they comply with the same standards expected from traditional research entities.

Report 4: *"Perspectives on the Evaluation and Measurement of Goal-Concordant Care for Persons Living with Dementia"*

- **Decision-making -** To better capture the complexity and multilayered nature of the decision-making process, researchers should consider using terms beyond *goal-concordant care*. In addition, panel members emphasized the need for increasing education about disease progression, raising awareness of the goal identification process, understanding advocacy journeys, and addressing the challenges of managing care partner responsibilities.

Key Takeaways from Discussion of Roles and Processes

Topic 1: *Most Significant Aspects of the Lived Experience Panel*

- **Social Support -** The Lived Experience Panel serves as a social support group where panelists share their experiences which may involve complex emotions.

Topic 2: *Benefits of Participating in the Lived Experience Panel*

- **Learning process -** Panel participants reported feeling challenged to learn about complex research concepts and processes. Additionally, members valued "hearing the other side of the story", which included learning about the challenges and narratives of other subgroups within the panel.

Topic 3: *Challenges of Participating in the Lived Experience Panel*

- **Cultivating Relationships -** Building confidence and trust between the panelists, researchers, and facilitators takes time. Being in a room or video conference with people across different stages of dementia-related care and support provides an opportunity for participants to reflect on decisions that have been made in the past or need to be made in the future.

Topic 4: *Value of Role on the Lived Experience Panel*

- **Expert Panelists -** Panel members are the experts of their own experiences and journeys in dementia-related care and support. However, during the sessions, they had to overcome self-doubts of knowledge and expectations in order to fully participate.

Topic 5: *Panel Member Perspectives about Research and its Impact on Dementia-related Care and Support*

- **Representation -** There is a need for more diverse community representation in all stages of research planning and implementation. Diversity should be considered in terms of age, race, ethnicity, gender identity, sexual orientation, education, socioeconomic status, geographic location (e.g., urban, non-urban, rural), stages of dementia-related diagnosis and care, and relevant care environment.

- **Accessibility -** Research opportunities and findings must be accessible and usable by the communities they are designed to help. This may involve research engagement with community members, grassroots organizations, and primary care providers.

Topic 6: *Increasing Access to Panel Reports to Increase Impact on Future Research and Dementia-related Care*

- **Sharing Reports -** increasing dissemination efforts to reach audiences outside the research community might help to increase accessibility, understanding, and impact of these efforts.

- **Dissemination** - efforts should be documented and shared with panel members.

Topic 7: *Improving the Lived Experience Panel Participation Experience for Current and Future Panelists*

- **Meeting Format -** More time should be given to panel members to process discussions and emotions. Meetings should be smaller to foster a welcoming space and use of jargon and technical terms should be avoided.

Our results and recommendations highlight the importance of continuing the work of the Lived Experience Panel to serve as a model for engaging people living with cognitive symptoms and care partners in research efforts as collaborators. The recommendations provided may serve as a guideline for the creation of other lived experience panels and as a building block for the future work of the IMPACT Collaboratory as this phase of the panel comes to a close.

About the NIA IMPACT Collaboratory

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-pharmacological 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 Administration 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 the leading voluntary health organization in care, support, and research. Its mission is to lead the way to end Alzheimer's and all other dementias by accelerating global research, driving risk reduction, 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 (7 members), Vascular dementia (1), and Mild cognitive impairment (2). Some panelists represented more than one type of dementia. The panel included people with the following characteristics and identities: Female (7), Male (3), Asian-American (1), Black or African American (3), White (4), and Latina (2).

About the Engaging Partners Team

The Engaging Partners Team 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.[1]

About the Design and Statistics Core

The Design and Statistics Core focuses on biostatistical methods for the design, conduct, and analysis of health system-embedded pragmatic clinical trials (ePCTs) among people living with dementia (PLWD) and care partners. Core members develop and disseminate novel biostatistical approaches for the design and conduct of ePCTs; provide guidance to investigators on design, power and sample size, analytic methods and reproducibility. They train the next generation of biostatisticians and collaborate with other Cores on the development of methods and tools supporting ePCT design.[1]

About the Ethics and Regulations Core

The Ethics and Regulation Core focuses on how to design and conduct embedded pragmatic clinical trials (ePCTs) among people living with dementia (PLWD) and their care partners while protecting the rights and welfare of participants and assuring that regulatory issues are

addressed. Core members develop and disseminate guidelines and best practices to address particular ethical issues and regulatory structures encountered in conducting ePCTs among PLWD and their care partners. Members provide guidance and training to investigators in areas of ethical uncertainty, and help investigators navigate the regulatory complexities that arise when conducting ePCTs among PLWD and care partners.

About the Health Equity Team

The Health Equity Team 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]

About the Patient and Caregiver Relevant Outcomes Core

The Patient and Caregiver Relevant Outcomes (PCRO) Core focuses on developing and supporting use of PCROs pertaining to people living with dementia (PLWD) and their care partners in the design and conduct of embedded pragmatic clinical trials (ePCTs).

Reports, Roles, and Processes from a Lived Experience Panel in Dementia Care and Research

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 insights and perspectives from the IMPACT Collaboratory Lived Experience Panel as a model for researchers to engage people living with cognitive symptoms and care partners in the design of research agendas and clinical trials on dementia care. Reflections were collected through a survey and a series of conversations between the Lived Experience Panel, the Engaging Partners Team, and the Alzheimer's Association during Winter 2024.

Overview

Members of the Lived Experience Panel have participated in more than four series of topic-specific meetings to discuss issues relevant to developing and conducting research studies for people living with cognitive symptoms and their care partners. Panelists have listened to presentations and contributed their thoughts, experiences, and perspectives about living with cognitive symptoms and how to improve the accessibility and relevance of research efforts.

To complete the current report, panelists were asked for a final round of feedback on past report conclusions and asked to share their ideas on how to improve the content and processes of the

meeting sessions. Members were asked to provide feedback on best practices to improve preparation for and support of panel members to improve engagement in meetings, participation in scholarly products, community engagement in research, and enhance communication strategies for the inclusion of different perspectives. In this series of panel meetings, panelists were asked to share thoughts about the value of their role, benefits, and challenges to participation, changes in perspectives after collaborating with researchers and people with other lived experiences. They were also asked for thoughts about ways organizers can improve member support in future efforts and how to increase the impact of past and future reports on dementia care and research efforts.

Information was collected from panel members via feedback form. Details about the process and key themes that emerged from the feedback form and facilitated discussions are described below. These findings were presented to panel members during two additional meetings, during which they were asked to provide feedback and comments about our interpretation of the results. Their input was integrated into the final report presented here, ensuring a collaborative approach between the panel members, facilitators, and report writers.

Reflections on Work with Prior Reports

A structured feedback form was sent to panel members inviting their comments related to the previous four reports. This feedback form included a series of broad discussion prompts with specific questions related to each topic-specific report.

There were two reasons for inviting the panel members to comment on past published work. First, it was an opportunity to “continue a conversation” with the panelists, inviting them to further engage in previous dialogues. Second, we were curious if any opinions may have changed or if panelists had new thoughts to contribute to the discussion since the writing of the earlier reports.

The first section of the feedback form, **Meeting Logistics & Engagement Reflection**, had five questions aimed at gathering panel members’ perceptions on the logistics and engagement processes before, during, and after the meetings. Three open-ended questions were included:

1. How did you learn about the NIA IMPACT Collaboratory and what did you like and/or dislike about the process of recruitment to work with the Lived Experience Panel?
2. Do you have any comments about the meeting logistics?
3. Do you have any comments about the engagement process?

The second section of the feedback form, **Content Reflection**, was split into four subsections based on each of the four topic-specific Lived Experience Panel reports. Each subsection had the report’s title, a summary of the report, and a set of 2 to 4 prompts based on that specific report. These prompts were developed by the panel organizers and reviewed by the original report writers from the three IMPACT Cores and Teams that facilitated panel discussions including: the Patient and Caregiver Relevant Outcomes Core, the Ethics and Regulations Core, and the IMPACT Health Equity Team.

The feedback form was distributed through Google Forms, allowing participants approximately two weeks to submit their responses. The panel organizers received, reviewed, and summarized the collected feedback. A synopsis of the questions and responses is presented below, accompanied by example quotes. See Appendix A for a full list of questions and report summary originally included in the feedback form.

Report 1: "Priorities for Person and Caregiver Relevant Outcomes in Dementia Intervention Research"[2]

Q1 & Q2: Explores issues related to research priorities focused on needs related to health and social care, emotional needs, reducing hospitalizations, and living according to personal preferences.

In general, panel members agreed that research should focus more on healthcare, social and emotional needs. There seemed to be a small distinction between healthcare needs and social and emotional needs among some panelists. One panelist mentioned that needs related to healthcare should be prioritized due to the complex and expensive healthcare system. On the other hand, another member mentioned that social and emotional needs are a foundation for other aspects of healthcare and emphasis should be put on that. Most members agreed that research should focus less on reducing hospitalizations. However, two members expressed a neutral position given that hospitalizations are sometimes needed. Finally, two members highlighted the intertwined relationship between healthcare, social, and emotional needs to reduce hospitalizations in the long-term.

"People don't want to go to the hospital, there is already a negative consequence for both caregivers and persons living with a diagnosis."

"I believe it depends on the case by case, how much or how little of a priority this would have for any given family."

Q3: What suggestions do you have for researchers to help them focus on your priorities and put your priorities into their research?

To better focus on priorities relevant to people living with cognitive symptoms and their care partners, panel members emphasized the need for researchers to integrate people with lived experiences into their projects. This involves engaging with individuals who can share their stories and recommendations. One panelist suggested that questions be short and that sufficient time be provided for those with lived experience to express themselves and for researchers to actively listen. Panelists acknowledged the importance of health equity and encouraged the inclusion of vulnerable populations in these discussions, such as people from rural America and undocumented individuals. One member noted that the abundance of resources on Alzheimer and other dementias can make it challenging to find specific information needed. As a potential

solution, another member suggested allocating resources for the lived experience or advisory panels, using the Lived Experience Panel as a model.

"Keep questions short and concise, let "us" respond… and just LISTEN."

"I'd like to commend the Collaborative for the diversity of the panel, but I am certain I do not speak for the large number of persons/caregivers who look like me."

Q4: What suggestions do you have to ensure that people living with cognitive symptoms and their care partners have active involvement in all stages of research?

Panel members proposed various strategies to enhance the involvement of people living with cognitive symptoms and their care partners in research at all stages. Some of their suggestions included direct outreach to potential participants, providing remote opportunities and, providing information without research jargon, monetary compensation, expressions of appreciation, and a commitment from researchers to change. Panel members stressed the importance of engaging people with lived experience across all stages of research but identified a few stages during which feedback in most critical, including topic selection, research design, and findings dissemination. A panelist suggested that research teams should include at least 30% of individuals with lived experience, particularly from historically underrepresented communities. Two members mentioned that while incorporating lived experiences into research is valuable for community education and engagement, the role of clinicians and researchers should not be underestimated. While some panel members emphasized the importance of active involvement throughout the research process, other members acknowledged that it might not be the primary expectation or goal for every participant.

"Ask the person living with cognitive symptoms and their care partner in designing the research or ask what they think of this research project."

"I would like to see the focus on continued inclusion of panelists from a broad range of backgrounds. The role of clinicians in the health care delivery system for people living with dementia and their care partners should not be underestimated."

Report 2: "Ethical Challenges in Conducting Research Using a Waiver of Informed Consent with People Living with Dementia"[3]

Q1: Inquires about whether panelists agree or disagree with the following report outcomes: researchers must be trustworthy, research participation notification should be timely, research should be designed in dementia-friendly ways, there should be increased emphasis on engaging partners in all stages if the research is operating under a waiver of informed consent.

Lived Experience Panel Members agreed on several key principles for conducting research:

- Trustworthiness: Researchers must demonstrate integrity and reliability
- Timely notification: Participants should be promptly informed about their involvement.
- Dementia-Friendly Approach: Research should be accessible and considerate to those with dementia and their care partners.
- Continuous Engagement: Active engagement of participants is crucial throughout all stages of research, especially when utilizing waivers of informed consent.

One member highlighted the importance of defining what "trustworthy" means to the panel. Panelists also emphasized the importance of a mutual exchange of information or benefits between researchers and participants. Research should not only gather data or insights from participants but should also provide some sort of value in return (e.g., teaching early-career researchers, improving education, accommodating participants' needs, or offering tangible compensation). One member emphasized the value of preexisting relationships, for example, between nursing home residents and their administrators, employees, or paid caregivers when conducting research in their facilities.

Q2: What suggestions do you have to ensure that people living with cognitive symptoms and their care partners are able to contribute to the notification of research being done with a waiver of informed consent in their facilities?

Several strategies were recommended by panel members to improve engagement of people with lived experiences in the research notification process under a waiver of informed consent. Some suggestions from the panel included:

- establishing advisory boards,
- hiring research navigators,
- leveraging varied advertising channels (*e.g.*, television, radio, and social media), and
- partnering with patient advocacy organizations.

To ensure accessibility, panelists emphasized that participant-facing information should use plain language with minimal use of jargon and technical terms. They also stressed that time restraints should be respected, and timely notification of research projects and results should be provided.

"Ensure that language/terminology does not create a barrier and hinder effective communication."

"The use of ads in television, radio, and social media might be a way to ensure that families are aware of research being done with a waiver of informed consent."

Report 3: "Voices of the Lived Experience Panel: Health Equity in Dementia Care and Research"[4]

Q1: What suggestions do you have to effectively disseminate research opportunities and results to people living with cognitive symptoms and their care partners?

To effectively disseminate research opportunities and results, Lived Experience Panel members suggested using advertising through television, social media, radio stations, and public transportation. Additionally, they recommended establishing partnerships with community-based or religious organizations known for advocating for people living with cognitive symptoms and their care partners. Members emphasized the need for collaboration between primary care providers, who are the primary point of contact for family support and information dissemination through various life stages. One member emphasized the importance of providing informational materials that describe the different types of dementia and cognitive impairments. Additionally, panelists stressed the importance of considering racial, ethnic, and socioeconomic factors in research. There was a strong emphasis that researchers, participants, locations, and organizations should reflect the diversity of the communities they serve. This includes adopting a culturally sensitive approach and focus on health equity in their work.

"It not only matters how the opportunity is presented but who is presenting it."

"Make them [research opportunities] easily accessible to people living with dementia, through Alz Assoc. and my doctor and clinician."

"I am hopeful about all of the AD/ADRD info sheets I see out there that address that dementias can look very different and have behavioral symptoms."

Q2: What suggestions do you have for IMPACT Collaboratory investigators to engage with community-based organizations to improve access to research efforts?

Panel members suggested researchers enhance their engagement with community-based organizations by developing and nurturing partnerships with both local and national organizations. This includes forming relationships with community health workers, parent-teacher associations, and elected officials. Depending on the targeted geographic location and population, researchers were advised to organize community-based events within their established network to reach community members and collaborate with leadership teams of other organizations.

Q3: What are your thoughts about community-based organizations being funded to conduct research? Would you support research occurring in their work?

Panel members stressed that community-based organizations receiving funding to conduct research should be held to the same standards and expectations as research institutions. This

includes ensuring informed consent, providing timely notification of research participation, striving for diversity in participant recruitment, and ensuring a full understanding among their members. A collaborative approach to research would yield several benefits including. It would bring research opportunities to the community, promote patient-centered research practices, improve recruitment and retention rates, engage key partners, and enhancing overall awareness and knowledge within the community.

"I think that would be a good idea and I would support research occurring in those organizations."

Q4: If federal or state funders offered research infrastructure support to help community-based organizations conduct research, what would be your thoughts about such funding?

Most Lived Experience Panel members agreed that state or federal funding should be allocated toward supporting research infrastructure for community-based organizations as long as it does not overwhelm their current work. To increase the likelihood of success, a member suggested that research entities offer assistance throughout the research process. Two other members mentioned that government funding for community-based organizations may be currently happening, underscoring the importance of ongoing collaboration. However, one member mentioned participants may not typically pay attention to program funders, they do pay attention to the organization or person reaching out to them.

"Grassroots organizations can bring in the voices of some of the most hard-to-reach members of their communities."

Report 4: "Perspectives on the Evaluation and Measurement of Goal-Concordant Care for Persons Living with Dementia"[5]

Q1: Comments on whether you agree or disagree with the report's outcome that "goal-concordant care" may not accurately reflect the decision-making process and issues faced by people living with cognitive symptoms in the current healthcare environment.

The majority of Lived Experience Panel members questioned the degree to which the phrase "goal-concordant care" adequately reflects the complexity of decision-making in healthcare for individuals living with cognitive symptoms and their care partners. Panel members expressed concern that the phrase can be overwhelming and fail to fully align with the actual decision-making processes by families in this journey. One panelist noted that the concern may stem from the need to ensure inclusivity, encompassing the multi-layered experiences involved in healthcare decision-making. Another panelist underscored the importance of covering basic needs before exploring choices for people living with cognitive symptoms and their care partners.

"I agree with the panel members, but I also think the concern has to do with the use of that particular phrasing and not necessarily its intended meaning, or the desire to ensure the term is inclusive of a multi-layered experience. Simple language is important in what may be emotionally charged exchanges."

Q2: What should researchers consider when they are studying the best ways to guide people to advocate for their personal goals and values during healthcare decisions?

To support people living with cognitive symptoms and their care partners in their advocacy journey, panel members suggested researchers consider:

- Increasing awareness and knowledge on the goal identification process and why it matters.
- Management of distress for care partners and people living with cognitive symptoms.
- Educating families about disease progression (e.g., timeline and what it might look like).
- Advocacy journeys among care partners of people with other health conditions (e.g., people with intellectual and developmental disabilities).
- Using a socio-cultural lens in advocacy (e.g., social, economic, and family distinctions).
- Acknowledging the person (e.g., patient-centered approach, asking about their journey and who accompanies them).

Q3: What subtopics related to goal-concordant care do you think should be studied in research?

Panel members recommended exploring several subtopics related to goal-concordant care:

- Advocacy and Participation in your Own Healthcare Decisions
- Understanding and Supporting Collective Decisions through Difficult Times
- How to Set Concordant-Goals that Reflect Personal Needs and Values.

Logistics and Engagement

Lived Experience Panel members were asked to share their perceptions on meeting logistics and engagement. A summary of their responses is provided below, although more information is provided in the following sections and Appendix B of this document.

How did LEP members learn about the NIA IMPACT Collaboratory?

All three people living with cognitive symptoms and two care partners mentioned having been recruited through the Alzheimer's Association. Among proxies, recruitment was completed through online nomination (1), IMPACT Collaboratory (1), and peer networking (2), along with one more care partner also being recruited by peer networking.

Meeting Logistics

Among people living with cognitive symptoms, two members said that meetings were scheduled too far apart, which made it difficult to recall what was discussed from one meeting to the next.

One care partner mentioned that time management over Zoom seemed unrealistic given the meeting agendas and the number of people participating in them. Another care partner mentioned feeling overwhelmed by the number of different IMPACT teams and faces in the meetings. One proxy member mentioned being impressed by the pace and frequency of meetings, along with the inclusion of neurodiverse members. Overall, participants expressed comfort with the Zoom platform for meetings. (Appendix B, Figure 1)

The majority of participants indicated that meeting length (90%), meeting structure (88%), amount of pre-reading (60%), and time given to prepare for meetings (90%) was about the right length.

Meeting Engagement

Panel members said it was sometimes difficult to engage during meetings because of the amount of information and number of people involved, saying it was sometimes overwhelming and challenging to understand their role in the discussion. Panel members expressed different feelings about their role in the meetings. One proxy member stated that the Lived Experience Panel organizers made them feel heard while another proxy member mentioned not always knowing what was being asked of them.

"The process was mostly seamless though I wasn't always sure of what was being asked."

The majority of participants indicated that they felt comfortable speaking in the group (80%), felt their feedback was incorporated into reports (80%), felt recognition for participating (70%), there was enough time for them to contribute during and after the meetings (80%), felt facilitators valued their contributions (90%), facilitators appeared trustworthy (80%), facilitators were properly introduced (70%), completing surveys was worth their time and valuable (80%), communication within the LEP members was clear during meetings (80%), and felt received sufficient communication and updates from LEP organizers (90%). Nonetheless, 50% of participants disagreed when asked if their concerns were addressed throughout their participation and 44% disagreed when asked if they had any input in selecting meeting topics. (Appendix B, Figure 2)

Lived Experience Panel Discussions of Roles and Processes

Our goal was to understand opportunities and challenges for the Lived Experience Panel member experience and impact on the scientific community and beyond. Panel organizers, the IMPACT Engaging Partners Team, and the Alzheimer's Association, created a series of broad discussion questions based on each report to elicit panel member's experiences and recommendations for future sessions and reports.

In Winter 2024, a series of four virtual meetings were conducted, consisting of three 90-minute sessions tailored to each of the three Lived Experience Panel subgroups (e.g., people living with cognitive symptoms, care partners, and proxies), and one 120-minute session for the entire

Lived Experience Panel. Participants included members of the Lived Experience Panel, the IMPACT Engaging Partners Team, the Alzheimer's Association, and the Design and Statistics Core. Each meeting was facilitated by a representative from one of the mentioned entities, with introductions and closing facilitated by the Engaging Partners Team. Before each session, panel members received agendas, pre-reading materials, and discussion prompts. The discussion for each group was centered around the following prompts:

1. Can you talk about the value of your role in your experience in the LEP?
2. What were some benefits of being part of this LEP team (e.g., investigators, people living with cognitive symptoms, care partners, and proxies)?
3. Can you share some of the challenges involved with your responsibility in the LEP?
4. If you think back over all the things that you have discussed during LEP meetings and the survey you have just completed, what stands out to you as most significant?
5. What are your ideas on how the LEP reports can have a greater impact on future research and dementia-related care?
6. Has your experience in LEP changed the way you think about research and its impact on care and support for people living with cognitive symptoms and their caregivers?
7. What are your ideas on how IMPACT Collaboratory can support you or someone looking to be part of the LEP team? What advice do you have for panelists in the future?

Each session started with an overview of the meeting's objectives and panel member expectations. Panelists were invited to ask questions about the survey or goals of the meeting series. Throughout the discussions, the facilitators took notes and asked clarifying questions to ensure accurate interpretation and recording of the panelists' insights. Several members of the panel used the Zoom chat feature to contribute shorter comments. At the end of each subgroup meeting panel members were thanked for their participation and reminded of the follow-up meeting with the full Lived Experience Panel on February 14, 2024.

The subgroup meeting with People Living with Cognitive Symptoms was convened on January 31, 2024. Facilitators included two team members from the Alzheimer's Association and one Faculty Scholar from the IMPACT Engaging Partners Team.

The subgroup meeting with Proxies for People Living with Cognitive Impairment was convened on February 5, 2024. Facilitators included two team members from the IMPACT Design and Statistics Core and one Faculty Scholar from the IMPACT Engaging Partners Team. In addition to discussing the survey questions sent to all groups, during this meeting, the proxies were asked *What does it mean to be a proxy for you?*

The **Care Partner Subgroup Meeting** was convened on February 7, 2024. Facilitators included two team members from the IMPACT Engaging Partners Team, with one being a Faculty Scholar.

The **Full Group Meeting** gathered the entire LEP on February 14, 2024. Facilitators from both the Alzheimer's Association and the IMPACT Engaging Partners Team led the session, and facilitators from the subgroup sessions were invited to participate. Similar to previous meetings, the session started with an overview of the meeting objectives and expectations from the panel participants. Then, facilitators presented an overview of the survey findings and facilitated subgroup discussions, providing an opportunity for panel members to listen to the meeting's content and share feedback and insights. The meeting concluded by thanking the panel for their participation and indicating that a follow-up meeting would be scheduled to review the summary report prepared by the IMPACT Engaging Partners Team and the Alzheimer's Association.

Two **Report Review Meetings** were held on May 1, and May 15, 2024. Facilitators from both the Alzheimer's Association and the IMPACT Engaging Partners Team led the session. Before this session, participants received a drafted version of this report and were asked to come prepared with comments and suggestions to add to the final report. Facilitators presented an overview of the report's key takeaways, topics, theme results, and report recommendations, and asked panel members to share their feedback and comments which were incorporated into the final report.

Review and Synthesis of Meeting Content

All meetings were recorded and transcribed using Zoom Video Communications software. The IMPACT Engaging Partners Team and the Alzheimer's Association members reviewed all recordings, transcripts, and notes after each subgroup session and again after the final session with the entire Lived Experience Panel. Themes are based on each main discussion prompt and subthemes are based on themes that emerged from all four discussions. Results were reviewed and refined by the IMPACT Engaging Partners Team and the Alzheimer's Association members. Themes are listed below.

Topics/Results

Topic 1: Most Significant Aspects for Lived Experience Panel Members

Reflecting on past Lived Experience Panel meetings and the feedback form that panel members received, panelists were asked to share what were the most significant aspects of their experience. One of the themes that emerged was the relevance of past meeting topics (theme 1.1) and how they related to the panelists' lived experiences. For example, discussions about a waiver of informed consent and access to information resonated for participants who have been part of previous research projects but have not received information on the study results and how their participation impacted the research. In addition, it was emphasized that members felt empowered (theme 1.2) by being heard during Lived Experience Panel meetings and finding their voice in the community. Panelists also mentioned the importance of listening to other people's stories (theme 1.3), especially in recognizing that the journey does not have to be isolated. For example, several panel members brought up that there is a sense of community, as members find understanding among those who share similar circumstances and experiences. During the discussion, panelists discussed how participating in public settings may come with

complex emotions. They highlighted the challenge of reclaiming their own identity across various life stages and caring for themselves or someone else (theme 1.4). Other panelists provided insight into the cultural dynamic of being a caregiver and how that impacts healthcare decisions (theme 1.5).

Topic 1. Most Significant Aspects for LEP Members	
Theme 1.1: Past Topics Relating to Prior Reports	*"[...] I felt like the most important parts of things we shared about our own stories were the ways in which we felt we experienced discrimination and ways our loved ones experienced discrimination."* *"I liked the goal-concordant care topic, I had never heard of that term before and really liked the idea of the concept."* *"[...] it's okay not to focus on reducing hospitalizations. In my response I was thinking yeah, nobody wants to go to the hospital but sometimes you have to go. Looking at it more than a number and the reasons behind it are important for researchers to develop programs or have therapeutics that impact disease progression."* *"I agree, to me it was like if we are participating, why can't we have the information when we are done. Other projects that I have been involved in, I would like to know the outcome. What did you find that was beneficial to the field? That discussion was good, it could have been longer."*
Theme 1.2: Impact of Empowered Voices	*"What was most significant to me was that no matter what the topic was, someone was listening to me. My voice was important. They said that our voices were being heard and they mattered."* *"[...] I heard myself becoming more of an advocate out in the community. When I would have conversations with other people, I would talk more and suggest things that I heard in this group. I would be more informed. I became an advocate in my personal interactions, that was significant for me as well."*
Theme 1.3: Feeling Connected to Others	*"I really liked being in the room with people who have a diagnosis and proxies. I really enjoyed hearing everybody's stories and hearing what was most important for people, or what proxies and care partners thought was most important to the person they were representing and caring for."* *"[...] Something that stands out is hearing these elements of uniqueness but somehow still so intertwined. There is a language within us that we understand when someone says something."*

Theme 1.4: Reclaiming your Identity and Purpose	*"[...] so much of caregiving is about somebody else [...]. I had been trying to sort out what happened for years, I just felt I had to reclaim my own life and try to move on." "[...] I felt that my world came down and I had no more purpose. There is a lot that has happened post that I feel like no one is talking about that or at least I have not been in these spaces."* *"There is a lot that's sacrificed and there is even a lot after the person has transitioned."*
Theme 1.5: Role of the Culture of Caregiving in Dementia Care	*"No one wants to be in a nursing home, I guess everybody knows that. I heard repeatedly that it was a value of people's culture but I gotta tell you, my culture does not want to be in a nursing home either but that's where we ended up. That was a little bit hard."* *"I have learned that the cultural aspect that we pin on it, is not a ethnic/racial culture, is an Alzheimer's or dementia caregiving culture. Is not about being a woman, Latina, Mexican, vs about anyone else. It's "this is what we got going on" and we make difficult decisions."*

Topic 2: Benefits of Participating in the Lived Experience Panel

When asked about the benefits of their participation, panel members highlighted a sense of belonging and social support as an important motivational force for their participation (theme 2.1). Several panelists mentioned that being heard, being valued as part of a team, and being appreciated by others was a fundamental part of their experience. In addition, the opportunity to connect with others who share similar experiences encouraged them to continue the journey. Another benefit of Lived Experience Panel participation was an education or learning process (theme 2.2). Panelists mentioned being challenged to learn complex research concepts and processes, as well as gaining insight into the type of research that is being conducted in the field. Also, members valued hearing "the other side of the story", even though it was sometimes challenging to process. For instance, people with cognitive symptoms were able to listen to care partners, who are or were caring for people with cognitive symptoms at later stages or who are deceased.

Topic 2. Benefits of Participating in the Lived Experience Panel	
Theme 2.1: Sense of Belonging & Social Support	*"It gave me a voice, made me feel part of it and feel valued. Individually it probably would've been impossible for me to accomplish it, but as a team it could be done."* *"Caregiving is so invisible, we are all emotional that you are listening to us, because a lot of time people are tired of listening to caregivers."* *"I am a big fan of the "other related dementias". I learned that her case belongs. Belonging in the room was big, I wish I had known that from the beginning."* *"[...] as everyone has touched on, is being a part of a community."* *"I have not met everyone in person but there is a warmth when I see these faces, whether they are smiling or crying because we were able to connect."*
Theme 2.2: Learnings from Other Member's Stories and Researchers	*"Listening to what the care partners and proxies had to say, gave me more information and opened my eyes to some things that I was feeling and had experienced but could not verbalize."* *"The horrors down the road, I am not sure I want to face or know that. How can I help or what can I do for my care partner? It is difficult to understand that okay that's where i am going [...]"* *"I noted that they are interested in what we have to say. Bottom line is without us they couldn't do this project. Just as we need them to give us direction. It was a good learning experience for everyone involved."*

Topic 3: Challenges of Participating in the Lived Experience Panel

Panel members were asked to reflect on challenges of participating in the Lived Experience Panel. First, panelists mentioned that technical terms and working through multiple projects and facilitators made it challenging to feel in a welcoming space and fully participate during the sessions (theme 3.1). Some members admitted that sometimes they were not sure what was being asked of them, making them wonder if it was accurate to speak up or if their perspective was relevant to the discussion. Nonetheless, some panelists emphasized that it was important to remind themselves that this panel is about them, the people with lived experience. Participants also thought that the limit in time was a challenge for them to fully participate (theme 3.2). For example, participants said that some sessions were too long and there was a short time to reflect and share their perspectives, which made it hard for them to be engaged. As a suggestion, one panel member mentioned that providing space for comments or questions before each meeting would make a difference. Finally, panelists again highlighted the challenges that may come with sharing personal experiences in public settings when other life situations are

simultaneously happening (theme 3.3). For instance, a panelist mentioned that they had to rethink who they were and what their purpose on the Lived Experience Panel was after their loved one passed away.

Topic 3. Challenges of Participating in the Lived Experience Panel	
Theme 3.1: The Impact of Research Language	*"One of my biggest challenges was just really understanding what was going on all the time. [...] names and faces were always changing. There were lots of acronyms and research jargon to pick up on. [...] Sometimes I wonder if what I was saying was relevant to what was going on or if I was just blowing smoke and everybody could tell, which made me not want to speak out at times."* *"I grounded myself in the title of the group, "this is the lived experience panel". So, we are the masters of our lives and the experts. I had to remind myself."* *"Also, some of the words that were used… I had to go and look them up and that took time. For example, the decision-making that we went through, it was a little hard to wrap my mind around it."*
Theme 3.2: Time Constraints	*"The challenge for me was the time element. Some sessions were too long, and I would be brain dead, which makes it overwhelming at times."* *"[...] to really maximize what you get from the members of the Lived Experience Panel, maybe slow things down, try a little harder to explain things. Make sure everyone is coming along, don't leave anyone behind. That happened to me a lot of times, I really was left behind."* *"[...] Sometimes I would have something to contribute but there was a lot of other stuff going on, I didn't get to say it and it slipped my mind."*
Theme 3.3: Challenges of Sharing Personal Experiences in Public Settings	*"I am generally a positive and hopeful person but around this experience I have so much anger. You don't want to speak or act in anger."* *"That whole notion of questioning my identity or trying to rethink or re engage in my own identity. I debated about continuing in the group. That transition was difficult."* *"'Pause and try to filter it through what my person would want to say at that moment.' I would really try to start saying that to remind myself what my voice is for in this space."*

Topic 4: Value of Role on the Lived Experience Panel

Panel members were asked to reflect on the value of their role as a person living with cognitive symptoms, care partner, or proxy representative. Overall, they expressed varying levels of fulfillment, including a sense of meaningful contribution and appreciation for their valued perspective (theme 4.1). Their perceived contribution depended on a few factors relating to their time on the panel, their level of comfort with researchers and facilitators, and the stage of their journey on dementia-related care and support. Although some panel members initially felt hesitant to engage and contribute to the panel discussions, all panelists reported eventually appreciating the opportunity to share their experiences and perspectives, regardless of expertise or background (theme 4.2). Panelists suggested continued fostering of an open space where all can feel comfortable being honest and open without fear of repercussions for first-time panelists. Some also noted that the recency of dementia-related care and support issues can influence an individuals' readiness to actively participate. For instance, if a new concern recently occurred, there might be hesitancy to discuss it with the panel or because they were still processing their personal responses.

Themes specifically related to the proxy role emphasized the importance of advocating for their loved ones, despite the challenges that it may come with. Panelists highlighted the complexity of maneuvering multiple roles, whether it was directly or indirectly (theme 4.3). Often, these roles - such as being a caregiver, advocate, individual, mother, or spouse- conflicted with one another, making it hard to balance emotions during decision-making processes. Participating in these meetings provided panelists an opportunity to reflect on many aspects of their journey, with many expressing a desire to have had this opportunity in the past but finding satisfaction with the present moment (theme 4.4). During these reflections, panelists noted feelings of resentment towards the disease, rather than toward their loved ones, and recognized how this may influence their voice during the panel. Some felt very comfortable expressing their loved ones' voices and some had to consciously remind themselves to speak as their loved ones as opposed to from their caregiving experience. Finally, proxy members recognized this opportunity as a chance to honor their loved ones by sharing their stories in hopes of helping those who are currently undergoing similar experiences and who will go through this journey in the future (theme 4.5).

Topic 4. Value of Role on the Lived Experience Panel	
Theme 4.1: The Platform as a Way to Feel Appreciated and Valued	*"[...] I certainly felt that my input was valued initially, though I have to say it was intimidating."* *"[...] The fact that there's 3 of us that are the ones essentially kind of with the spotlight. it just feels like. You know, we're probing at a subject, and it's just feeling a little scientific in nature versus with such a topic like care, giving something that is very much very personal, very tied to emotions, and essentially just challenging first for many people to to discuss. So that level of trust comes with time."*

	"[...] So the first time that we got together. I kind of felt like I was brought. [...] I didn't come with a lot of input so I didn't feel like I was really valuable. I wouldn't. I don't think I realized what the expectation was. So the next time we got together I know I realized what the expectation was. So I went over the project. I took detailed notes. I was able to give more feedback, and at that point I really did feel like my input was valuable, valuable at that point." *"[...] people living with the disease can still contribute even though it's sometimes our clinical staff or even maybe our care partners are maybe trying to hold us back."*
Theme 4.2: Evolution of Engagement	*"[...] a year ago. I don't know if I could have said anything about this to anybody in public. So because it was just too raw."* *"[...] I can speak to different stages of the experience, you know, as a proxy for my mom, but also as a care partner. And so I'm just. I'm just sitting with and thinking about how it changes. You know the information that I end up sharing and I think it also speaks to where you are in your process."* *"[...] I think back to the time in my life where I was in crisis mode. It was very hard for me to show up in a space and not talk about myself like I think that now I'm able to you know pull back, reflect, think about how my experience could have been other people's experience, and how we could make suggestions or recommendations that could be valuable for lots of people."*
Theme 4.3: Acknowledgement that the proxy role is one of many hats	*"[...] I'm my mom's person. I'm her advocate. I'm the one to make sure that she is clean, safe and cared for, right like that's my job. And that's my, that's one of my jobs, right? Because I have kids. I'm all these things, but I distinctly remember, almost like assuming and putting on a whole different hat because I recognized in that moment I didn't have the bandwidth to grieve or to like. Just be in that place. So that resonates greatly with me. That idea of kind of having to set aside, you know, the relationship or the role to sustain or to like, almost protects my ability and my energy to even care for her."* *"[...] I felt very comfortable speaking in my mother's voice because I had been doing it for so long."* *"[...] I also found that I had to set aside my role sometimes my familiar role as her daughter as opposed to being her advocate. And sometimes those 2 roles clashed. "*
Theme 4.4: Proxy Positive Self Reflection and	*"[...] being a proxy in this kind of official capacity is at the heart of what it means to be an advocate."*

Advocacy Embodiment	*"[...] by naming it you're reminding us that we're doing something important. And you're reminding us that it is a job, a role, even if it's a job that you consider a privilege and honor that you want to have. It is still a job. It takes time and emotional and physical energy. It takes financial resources often. But at the end of the day it feels very much like a great expression of advocacy."* *"[...] We were moving so fast through the illness that I did what I had to do when I had to do it without consciously thinking about exactly what I was, what role I was playing. I just sort of responded to what was going on. That's one of my regrets, so far as my mother's illness is concerned. I wish I had thought about it more. I wish I had analyzed it more while we were going through it. But it just wasn't that time for me. Circumstances demanded that. I just keep rolling."*
Theme 4.5: Final Chance for Sharing	*"[...] a final chance for my mother's journey through this disease to maybe help someone else that will go through it."*

Topic 5: Lived Experience Panel Member Perspectives about Research and its Impact on Dementia-related Care and Support

To assess changes in Lived Experience Panel members' perspectives, panelists were asked to reflect on research and the impact it can have on individuals living with cognitive symptoms and their care partners. For some panelists, their involvement in the panel did not significantly change the way they think about research (theme 5.1). Nonetheless, several panelists mentioned that their experience on the panel validated their existing understanding of research and expanded their knowledge about it (theme 5.2). Panel members highlighted the need for diverse community representation throughout the research process, particularly after learning current research practices. Some considerations for community inclusion include urban and rural geographic locations, diverse stages of dementia-related diagnosis and care, and in-home care, and senior and/or memory care facilities. Moreover, they emphasized that for research to have a positive impact on care and support, research findings must find their way back to the communities that contributed and made it possible.

Topic 5. Lived Experience Panel Member Perspectives about Research and its Impact on Dementia-related Care and Support	
Theme 5.1: Reinforced perspective	*"[...] I don't think it's changed my way of thinking about research a lot, because I've always been a very strong proponent of, you know, I need to get involved in research."* *"[...] No, I learned more about it, but I don't think it's changed my thought pattern."*

Theme 5.2: Learning Process and Considerations for Community Inclusion	*"[...] I would say that it just continues to confirm the need for a lot more representation from communities that we don't necessarily see in the data."* *"[...] So it's definitely that I already had a deep appreciation for research. Because I do believe that that's the only way that we can get better at serving our communities. And when we have more different voices and lived experiences."* *"[...] The importance of it really making a difference in the lives of the people that it is supposed to help. So, therefore there must be a way for it to come down the pipeline and be usable by them."* *"[...] I had a narrow vision of who was researching and what they were doing and what they were looking for. But I think it's a lot larger than I ever realized."*

Topic 6: Increasing Access to Lived Experience Panel Reports to Have a Greater Impact on Future Research and Dementia-related Care and Support

Thinking about the short-term and long-term impact of Lived Experience Panel reports on dementia-related care and support, panelists were encouraged to share their ideas on increasing access to the reports. Initially, panel members requested clarifications on past report's distribution strategies and the short-term impact within the research community (theme 6.1). For example, panelists proposed monitoring and sharing information on: 1) who is reading these reports? and 2) how are researchers implementing its results? Secondly, to increase access, panel members suggested sharing the reports with a broader audience, including community members, grassroots organizations, and primary care providers (theme 6.2). Some strategies could include community events, executive summaries without technical terms and research jargon, creating pamphlets, offering multiple versions of the report, and adding graphics to enhance understanding of the results.

Topic 6. Increasing Access to Lived Experience Panel Reports to Have a Greater Impact on Future Research and Dementia-related Care and Support	
Theme 6.1: Clarifying Current Strategies on Report Distribution	*"[...] if we're going through all this effort to do these reports, one would hope that they would be utilized, and maybe they're being more utilized than we even know about and on. Can anybody even answer that question? Or are the reports being used."* *"[...] Can you keep track of how many you've sent out. or who's requesting the information or collecting so much data. It seems like we could collect that, too."* *"[...] And I know there are others like them around the country that are in the business of providing care for Alzheimer's patients. So the question*

	is. Are they getting these reports, and are they learning about your research?"
Theme 6.2: New Strategies for Increasing access to report results	*"[...] It really needs to come back to communities right? And so things like town halls on these topics are just dissemination that really comes to the ground level."* *"Even though you may feel, you know that what you're doing is informing other researchers on how to carry out this research. I think what you can do with these results is inform communities on why it's important to participate in research right?"* *"[...] versions that can be read by a cross section of people. I had a lot of trouble with some of these reports understanding them. And I would like to see someone who might pick up a pamphlet."* *"[...] We all are different learners and consume information in different ways. Right? So even if there was a graphic like if there was like a one-page graphic like literally a comic or even, you know, a video clip."*

Topic 7: Improving the Lived Experience Panel Experience for Current and Future Panelists

Lived Experience Panel members shared ideas on how to enhance member experience and support and offered advice for future panelists. They emphasized the importance of a good onboarding experience and how it may need to be different for the three distinct subgroups (theme 7.1). For example, they suggested having subgroup meetings to facilitate introductions and build trust before larger group sessions. In addition, several panelists recommended pairing up new panelists with experienced members to form a mentorship role. In terms of meeting logistics, panelists proposed shorter and more frequent meetings to allow more time for people to share their thoughts and feedback while reducing their cognitive strain (e.g., attention span, information overload) (theme 7.2). They also advocated for smaller group settings to foster a welcoming space where participants and facilitators are more familiar with each other and facilitate the process of discussions and emotions. Furthermore, panel members highlighted the importance of avoiding jargon and technical terms during meetings to ensure comprehension among participants. Among proxy members, they appreciated reminders from panel organizers about them "speaking on behalf of" their loved ones but noted the emotional challenges that come from this experience (theme 7.3). For example, one panelist expressed difficulty adapting to the difference between their decisions versus the preferences of the person they were caring for.

Topic 7. Improving the Lived Experience Panel Experience for Current and Future Panelists	
Theme 7.1: The Importance of Onboarding as an LEP Member	*"The interview to be part of the Lived Experience Panel was a great experience. That experience was extremely helpful to understand what was asked of me. The materials were fine but it's not the same as having a human explain it. After her leaving, I felt a little disconnected with my onboarding. I didn't quite know what was expected of me. Onboarding is an important part of being in the Lived Experience Panel."* *"[Lived Experience Panel organizer] interviewed me, and I agree, you know, that was, it was a great process, and it was really, you know, good to be able to hear what everything was about and to, you know, tell my mom 's story and my experience."* *"Maybe if some new panelists come on board, maybe to have them kind of connected up with somebody who has been on [the Lived Experience Panel] for a while and maybe could help mentor them a little bit."* *"If, like just the caregivers, there was an onboarding session, there'd be, I don't know, 3 or 4 people on the screen to introduce ourselves to each other before we got to the larger group."*
Theme 7.2: Meeting Logistics Recommendations	*"[...] We need longer [time] to process. We need longer [time] to talk. We need to find the vocabulary and make sure people understand where we're coming from .... Shorten it up, because you lose people after 40 [minutes] unless they're doing something to stay in touch. They're going to drift off and think about something else. So I think a 60 min timeframe and also more meetings and more feedback, more response."* *"[...] I wish it had been smaller the whole way through. But yes, I think you know, any way that you can create intimacy for you know, for what is a personal topic, I think is a good thing."* *"In a lot of cases, we get into the habit of using all these shortcuts to make it move along faster but if you don't follow along, you kind of lose track of it. The research language can be pretty dry, it is not like reading a novel. It's just hard to follow along when you don't understand and try to look up a word and continue to be lost."*
Theme 7.3: "Speaking on Behalf of"	*"Appreciated when it was verbalized. I would think about how to make it visual and put it on the slide."* *"It was just a different way to think about it. It made me think that sometimes I didn't know what my mother wanted and I couldn't solve*

	it. It was gut wrenching to know that I wasn't doing what my mother would have wanted but it is honest." *"[...] Not frustration but realization and recognition for the emotions that come up and in my world who do I talk to about that?"*

Discussion

Overall, our discussions on prior reports, roles, and processes of the Lived Experience Panel highlighted the need to continue developing lived experience panels as a reciprocal partnership between community members and researchers.

Similar to previous report conclusions, researchers must include people with lived experiences during the research process to ensure that relevant priorities are being addressed. Using the Lived Experience Panel as a model, researchers could allocate resources to create other lived experiences or advisory panels. Ideally, these collaborations should include active recruitment, remote opportunities, information in simple language, monetary compensation, and the team's commitment to addressing population health disparities. To achieve active involvement and engagement, members of the panel, researchers, clinicians, and other engaging partners should have a pre-established role and expectations which are effectively communicated to panel members.

To address issues of equity and inclusion in practice and research dissemination, panel members suggested partnerships between researchers and local, and state-wide community-based organizations. These partnerships provide unique opportunities to address population health disparities by providing social and peer support, community engagement activities, and connecting individuals with research opportunities. To increase collaborative efforts, community-based organizations could receive state or federal funding allocated for research infrastructure support. For instance, they could support the development of research questions, improve the ability to obtain informed consent, increase cultural sensitivity, and increase community trust and ownership within research. Members also emphasized partnerships with clinical providers and advertisement entities such as television and social media across different geographic regions to increase awareness and understanding of dementia care and support and research opportunities.

The construct of goal-concordant care aims to describe clinical care based on previously identified goals and values by people living with cognitive symptoms and their care team. Nonetheless, panel members have repeatedly emphasized that this term does not accurately reflect the multilayered healthcare decision-making experience. An overarching theme in this discussion was that research should aim to understand how collective decisions are made through difficult times, how to incorporate other advocacy journeys in dementia-related care and support, and how to increase awareness and understanding of concordant goals based on personal and team-based needs and values.

Recommendations - Best Practices for a Lived Experience Panel

Based on the findings of the Lived Experience Panel discussions and feedback forms, the following are best practice recommendations for creating and implementing lived experience panels.

Processes and Roles in a Lived Experience Panel

- **Sense of belonging -** Provide a space for social support, learning motivation, and self-reflection for people at different stages of dementia-related care and support. Do this to support panel members who may experience the work as an important contribution to their journey.

- **Value and appreciation -** Build trustworthy relationships between the team members to increase feelings of value, engagement, and appreciation. For instance, communication and contributions increase when the participants know and understand what is expected of them as experts.

- **Reflection -** Encourage use of additional resources to reflect on painful or unsettled experiences related to the meeting content (e.g., suggestions for individualized support, additional time for silence and reflection, open floor discussions, or online whiteboards).

- **Voice and identity -** Acknowledge the multiple roles of care partners and proxies outside a lived experience panel, which involves making decisions that could conflict with their emotions and values. These experiences, whether positive or negative, influence their voice and identity on the panel and in their lives.

- **Representation -** Increase the representation of people living with cognitive symptoms in different stages of the disease (e.g., people who were just diagnosed versus people living with moderate to severe symptoms).

Research and its Impact on Dementia-related Care and Support

- **Diversity -** Increase the diversity of dementia-related care and support research (i.e., age, race, ethnicity, gender identity, sexual orientation, education, socioeconomic status, geographic location (e.g., urban, non-urban, rural), stages of dementia-related diagnosis and care, and individuals within in-home care, senior and/or memory care facilities, etc.).

- **Transparency -** Document and share the *Lived Experience Panel* report dissemination strategies and results (*e.g.*, the number and names of outreached organizations) with the panel members in a meaningful way.

- **Community accessibility -** Enhance the accessibility of *Lived Experience Panel* reports within community settings by providing other versions, such as executive summaries in non-technical language, pamphlets, or graphics, to engage community members, grassroots organizations, and primary care providers.

- **Direct interactions -** Provide more and varying opportunities for researchers to interact with and learn from people with lived experiences.

Enhancing the Experience of Lived Experience Panel Members

- **Peer mentorship -** Consider a peer mentorship program for new *Lived Experience Panel* members to facilitate introductions and build trust within the group. Some benefits include fostering relationships before full group meetings, pre- and post-meeting debriefs, and cultivating confidence among panelists to succeed in their respective roles.
- **Consistency -** Be consistent in who is attending/leading the meetings, the pace and frequency, and communication pre- and post-meetings.
- **Lay the groundwork -** Share background information on the facilitators and meeting topics before each meeting to set panel members up for success during meetings.
- **Multiple media -** Provide diverse media of information (e.g., electronic, print, oral) to account for multiple learning styles. Incorporate infographics or similar at-a-glance visually appealing alternatives for dense content.
- **Clear individualized communication -** Use plain language. Avoid using acronyms or research jargon and provide reminders for term definitions. People with lived experiences do not necessarily have a research background. Offer additional individualized time to panelists who request it and use this time to enhance their understanding and build bi-directional learning patterns.
- **Increase engagement -** Provide more time for panel members to process, think, ask questions, and share feedback. Limiting the number of people in meetings makes panel members more likely to be comfortable being vulnerable and sharing. Provide an after-meeting option to share any final thoughts.

References

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. Bennett AV, Hanson LC, Epstein-Lubow G, Zimmerman SI. The 2021-2022 Lived Experience Panel Report: Priorities for Person and Caregiver Relevant Outcomes in Dementia Intervention Research. NIA IMPACT Collaboratory; 2022. doi: 10.58234/82222234

3. Largent E, Karlawish J, Joffe S, Epstein-Lubow G. The 2021-2022 Lived Experience Panel Report: Ethical Challenges in Conducting Research Using a Waiver of Informed Consent with People Living with Dementia. NIA IMPACT Collaboratory; 2022. doi: 10.58234/92591162

4. Aranda MP, Ali T, Barnette W, Brammer B, Brandt K, Cruz R, Downer M, Fashaw-Walters S, Foss D, Gutierrez-Parker L, Hinton L, James FG, Epstein-Lubow G, Malone C, Michael C, Moss K, Peak KD, Rocha JS. 2022-2023 Lived Experience Panel Report: Voices of the Lived Experience Panel: Health Equity in Dementia Care and Research. NIA IMPACT Collaboratory; 2023. doi: 10.58234/23680579

5. Niznik J, Bennett A, Ernecoff NC, Zimmerman S, Wessell K, Hanson L, Epstein-Lubow G, Malone C, Barnette W, Brammer B, Brandt K, Cruz R, Downer M, Foss D, Gutierrez-Parker L, James FG, Rocha JS, Wagner A. 2023-2024 Lived Experience Panel Report: Perspectives on Evaluating and Measuring Goal-Concordant Care for People Living with Dementia. NIA IMPACT Collaboratory; 2024. doi: 10.58234/35429703

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Appendix A. Feedback Form - Questions by Report

Report 1: *"Priorities for Person and Caregiver Relevant Outcomes in Dementia Intervention Research"*

Core: IMPACT Patient and Caregiver Relevant Outcomes Core

Summary: In April 2021, two meetings were held to 1) identify study outcomes that are important to people living with cognitive symptoms and their care partners and 2) discuss their thoughts on two outcomes often studied by IMPACT researchers: reducing hospitalizations and living life according to personal preferences. An outcome is the result of a research study that researchers want to improve. LEP members identified two types of study outcomes as their priority for topics that should be studied in order to make the issues better for people living with cognitive symptoms and their caregivers.

Conclusion: The two types of study outcomes the LEP prioritized were: 1) needs related to health care (e.g., informational support, specialized clinicians, cultural responsiveness, access to respite care and companionship) and 2) social and emotional needs (e.g., loneliness, social inclusion, care partners burden). Regarding the commonly studied outcome, *reducing hospitalizations*, most LEP members reported this outcome to be very important and responses varied by a range of concerns (e.g., confusion, financial burden, family burden, racism) and benefits (e.g., medical care and symptom management) about hospitalizations. The other commonly studied outcome, *living life according to personal preferences*, was mostly rated as very important but rated as somewhat or not important by others. LEP members stated that the importance of autonomy and preference-driven care has to be seen in the context of the tension that can sometimes occur between people living with cognitive symptoms and their care partners related to complex decision-making processes.

Questions:

1. Please provide comments on whether you agree or disagree with the following report outcomes that research (ePCTs) should focus MORE on:
   - needs related to health care (e.g., informational support, specialized clinicians, cultural responsiveness, access to respite care and companionship)
   - social and emotional needs (e.g., loneliness, social inclusion, care partners burden)
2. Please provide comments on whether you agree or disagree with the following report outcomes that research (ePCTs) should focus LESS on:
   - reducing hospitalizations
   - living life according to personal preferences
3. What suggestions do you have for researchers to help them focus on your priorities and put your priorities into their research?
4. What suggestions do you have to ensure that people living with cognitive symptoms and their care partners have active involvement in all stages of research (designing the research,

completing the ePCT, reporting of the results, and planning future studies or changes in clinical care)?

Report 2: *"Ethical Challenges in Conducting Research Using a Waiver of Informed Consent with People Living with Dementia"*

Core: IMPACT Ethics and Regulations Core

Summary: Between December 2021 and January 2022, two meetings were held to discuss ethical challenges in using waivers of informed consent. A waiver of informed consent can be allowed in a study that carries less than minimal risk for research participants, and when obtaining written informed consent would jeopardize the ability to research at all. When there is a waiver of informed consent, the research team is not under the same requirements to share information about the study or ask the participants if they agree to be part of the study. In the LEP meetings, the facilitators presented an example in which researchers used a waiver of informed consent in a study about changing the length of nursing assistant shifts within participating long-term care residences. Then, LEP members were asked five questions related to 1) personal participation in this study, 2) the use of a waiver of informed consent, 3) minimal risk, 4) rights, and welfare protection, and 5) research participation notification.

Conclusion: After the discussion, LEP members stated that studies should be designed in dementia-friendly ways, researchers must be trustworthy, and there should be an increased emphasis on engaging partners (e.g., people living with dementia and others involved in their care) in all stages when a study is designed with a waiver of informed consent. In addition, accurate timeliness and research participation notification were emphasized as key to keeping trust between participants and researchers.

Questions:

1. Aligning with the report conclusion, provide (optional) comments on whether you agree or disagree with the following report outcomes that
    - researchers must be trustworthy
    - research participation notification should be timely
    - research should be designed in dementia-friendly ways
    - there should be increased emphasis on engaging partners in all stages if the research is operating under a waiver of informed consent
2. What suggestions do you have for IMPACT Collaboratory investigators to ensure that people living with cognitive symptoms and their care partners are able to contribute to the notification of research being done with a waiver of informed consent in their facilities (for example, integration of Community/Patient Advisory Boards, as consultants or collaborators)?

Report 3: *"Voices of the Lived Experience Panel: Health Equity in Dementia Care and Research"*

Core: IMPACT Health Equity Team

Summary: Three meetings were held between October and November 2022 to learn about LEP members' experiences and insights related to health equity in dementia care and research practices. One key takeaway from these meetings is the diversity of human experience associated with Alzheimer's Disease and Alzheimer's disease-related dementia (AD/ADRD) and the need for a broad plan to understand and address vulnerabilities within the systems of care.

Conclusion: LEP members emphasized the heterogeneity of diseases within AD/ADRD and their changing needs across time. Panel members suggested the development of flexible and accountable systems of care to ensure that programs and services are implemented equitably. Also, they pointed out that broad outreach is needed to learn about community values and preferences for providing timely and easily understandable information about research opportunities and findings.

Questions:

1. What suggestions do you have for IMPACT Collaboratory investigators to effectively disseminate research opportunities and results of these studies to people living with cognitive symptoms and their care partners?

2. What suggestions do you have for IMPACT Collaboratory investigators to engage with community-based organizations to improve access to research efforts?

3. What are your thoughts about community-based organizations being funded to conduct research? Thinking about the community-based organizations you have worked with, would you support research occurring among their work?

4. If federal or state funders (as opposed to private or other entities) offered research infrastructure support to help community-based organizations conduct research, what would be your thoughts about such funding? (for example, offering community-based organizations assistance with grant writing, more availability of research opportunities, etc.)

Report 4: *"Perspectives on the Evaluation and Measurement of Goal-Concordant Care for Persons Living with Dementia"*

Core: IMPACT Patient and Caregiver Relevant Outcomes Core

Summary: Three meetings took place in September 2023 to discuss opportunities and limitations of evaluating goal-concordant care for people living with cognitive symptoms and their care partners. Note: Goal-concordant care means to provide medical care that honors the patient's goals and values.

Conclusion: LEP members stated that the term "goal-concordant care" does not reflect the experience and priorities of people living with cognitive symptoms and their care partners. Panel members stated this term may oversimplify the complex process of healthcare decision making for individuals and families. Some important considerations for decision-making include financial concerns, the accessibility of care, family perspectives, and “hidden decision makers”. Besides these considerations, LEP members discussed the potential role of personal factors, such as self-advocacy and system-level factors, such as economic and social obstacles, in their ability to make goal-concordant healthcare decisions.

Questions:

1. Please provide (optional) comments on whether you agree or disagree with the report's outcome that "goal-concordant care” may not accurately reflect the decision-making process and issues faced by people living with cognitive symptoms in the current healthcare environment.

2. What suggestions do you have for researchers who want to study these issues, including, specifically:

    - What should researchers consider when they are studying best ways to guide people to advocate for their personal goals and values during healthcare decisions?
    - What subtopics related to goal-concordant care do you think should be studied in research (for example, the process of deciding when multiple people are involved, the possibility that someone’s wishes could change as their cognitive symptoms change)?

Appendix B. LEP Member Perceptions on Meeting Logistics and Engagement

Figure 1. Lived Experience Panel Perceptions on Meeting Logistics

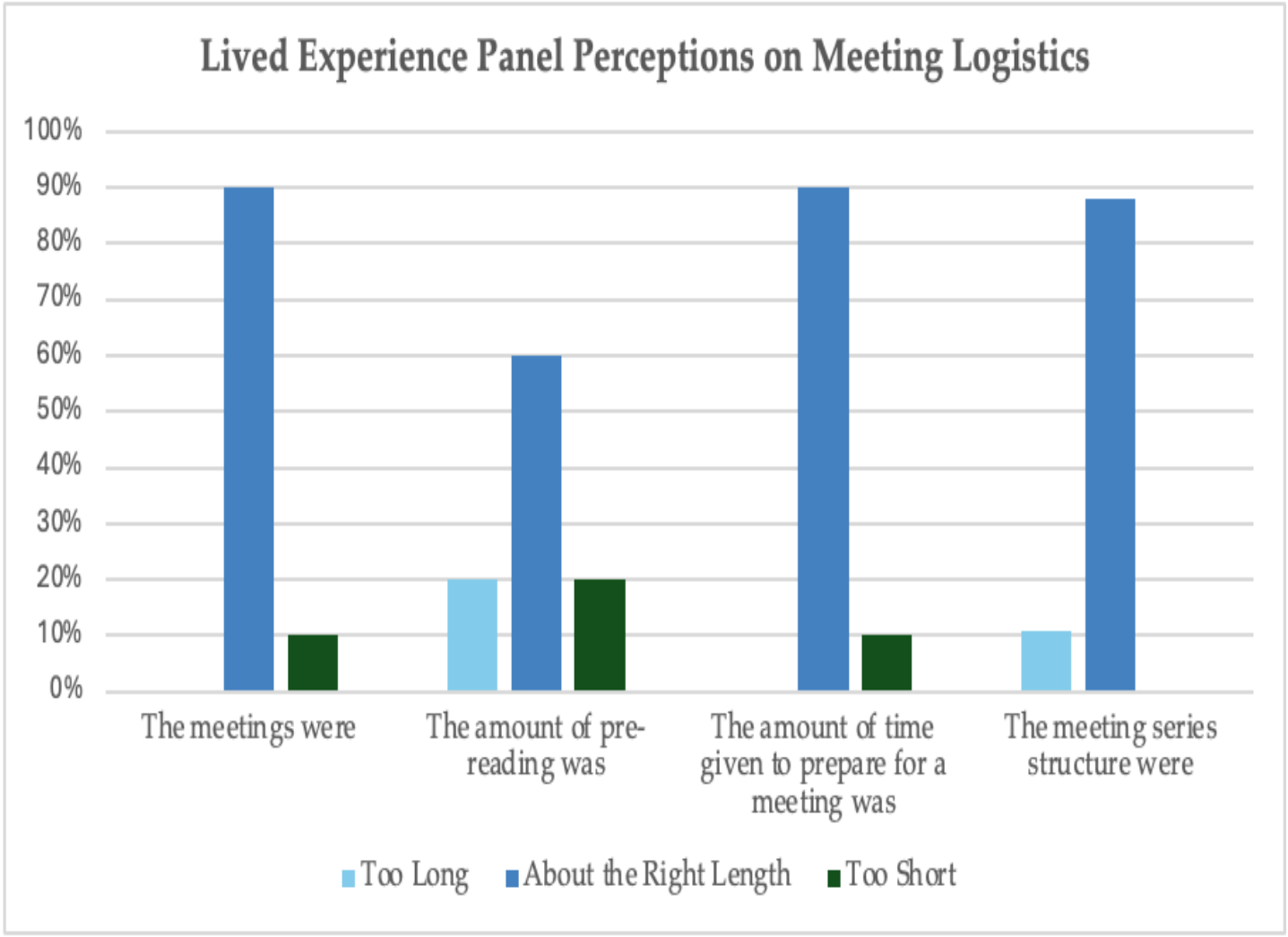

Figure 2. Lived Experience Panel Perceptions on Engagement During Meeting