The Geriatric Emergency Department Collaborative
Geriatric Emergency Care Applied Research Network (GEAR)

GEAR 2.0 Consensus Conference

Advancing Dementia Care

September 9-10, 2021

Virtual Meeting

Revised November 1

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Acronym Definitions

AD	Alzheimer's disease
ADRD	Alzheimer's disease and related dementias (ADRD)
AMT4	Abbreviated Mental Test 4
ED	Emergency Department
ER	Emergency Room
GEAR	Geriatric Emergency Care Applied Research Network
IQCODE	Informant Questionnaire on Cognitive Decline in the Elderly
LGBTQ	lesbian, gay, bisexual, transgender and queer
MCI	mild cognitive impairment
MMSE	Mini-Mental State Exam
MoCA	Montreal Cognitive Assessment
O3DY	Ottawa 3DY
PICO	Patient Intervention Comparison Outcomes
PLWD	Persons living with dementia
RFA	Request for Applications
SHARE	Support Health Activities Resources Education
SIS	Six-Item Screener
TICS	Telephone Interview for Cognitive Status
We DECide	We Discussing End-of-Life Choices
WG	working group

Executive Summary

The Geriatric Emergency Care Applied Research Network (GEAR) aims to establish infrastructure to support collaborative, interdisciplinary research to improve care for people living with dementia (PLWD) in the emergency department (ED) setting. On September 9-10, 2021, GEAR convened a virtual consensus conference on Advancing Dementia Care (GEAR-ADC) to prioritize research opportunities in each of four areas: detection and identification, communication and decision-making, care transitions, and ED care practices. Participants heard overviews of literature reviews performed by GEAR working groups (WGs) dedicated to these areas, explored priority questions proposed by each WG, and discussed specific research gaps and priorities related to these questions. The questions selected during this meeting will inform upcoming funding opportunities to be released in October 2021 that will help advance the science supporting emergency medical care for people living with dementia (PLWD).

Cross-Cutting Themes Across the Four Domains

Throughout the meeting, participants emphasized the importance of the following themes across all four domains.

- The ED's detection role is to screen for dementia, not diagnose dementia.
- Care for PLWD must incorporate feedback from PLWD themselves, care partners, clinicians, and community partners, as well as cross-talk between each of these groups. In addition to the importance of communicating with PLWD and their care partners, communication among physicians is essential to optimal care for PLWD.
- The barriers to and facilitators of emergency care for PLWD, as well as the unintended consequences of current care practices, must be understood in order to improve those practices. Further study is needed to evaluate care transition strategies, in particular, for all PLWD. Best practices from clinical care settings outside of the ED may be relevant to the ED and GEAR's efforts and actionable solutions.
- ED care must involve developing trust with PLWD, care partners, clinicians, and the overall health care system. ED staff must facilitate shared decision-making with PLWD and their care partners, regardless of dementia severity.
- Assessing identity-based factors—including cognitive impairment—and social determinants of health must be part of emergency care delivery for PLWD. Research relating to ED care practices must address how care can be tailored to disadvantaged and vulnerable populations.
- Identifying how public policies can incentivize better ED care for PLWD is critical.
- Researchers need to continue to interrogate innovative solutions (i.e., "think outside the box"), rather than be constrained to what currently seems feasible, in order to provide the best care to PLWD in the ED.

Five Ranked Priority Questions

Detection & Identification

1. What is the best approach in the ED to screen for cognitive impairment? (The approach includes population definitions, using data sources, screening tests effectiveness, efficacy, referral, etc.)
2. What are the most accurate and feasible tools and data to identify cognitive impairment in the absence of delirium or known dementia?
3. What is the value and potential unintended consequences of screening for cognitive impairment in the ED?
4. How can EDs feasibly take into account culture, language, ED environment, and communities of the population served when screening cognitive impairment in the ED? (e.g. does English as a second language impact screening of dementia?)
5. What information is needed to differentiate delirium vs. undiagnosed cognitive impairment vs. known dementia vs. mental health conditions?

Communication & Decision-Making

1. What are the barriers and facilitators of effective communication with persons living with dementia (or their care partners) during an episode of ED care, with attention to actionable elements/ideas?
2. What are valid and reliable measures or outcomes of "effective (short and long-term) communication" in patients with dementia?
3. What are the best practices (when/how) for engagement of care partners in care decision-making in the ED?
4. How do individual, provider, and system-level factors that influence communication for ED patients living with dementia (or their care partners)? (Examples include ethnic, gender, and socioeconomic factors or conscious or unconscious biases.)
5. How can each member of the ED care team (e.g., social workers, physicians, technicians, nurses, etc.) ensure high quality communication with PLWD, care partners, and other team members?

Care Transitions

1. What improves outcomes of ED-to-community care transitions among ED patients with impaired cognition and their care partners (e.g., system, program operations, individual/care-partner strengths/needs) and how can these be personalized for vulnerable pops?
2. What matters most to ED patients with impaired cognition and their care partners during the ED-to-community transition and how can these priorities best be measured?
3. What barriers, facilitators, and strategies, specifically leveraging implementation science methods, influence engagement, uptake, and success of care transition interventions, including national guidelines, policies, and best practices?
4. How can care partners and community organizations be best engaged and empowered to improve ED-to-community care transitions?

5. How can communication quality surrounding ED-to-community transitions be optimally measured?

ED Practices

1. How can we best evaluate in a patient-centric and care partner-centric manner the impact of ED interventions for PLWD?
2. Which environmental, operational, personnel, system, or policy changes best improve ED care for PLWD?
3. How can gaps in training and dementia care competencies among clinical and non-clinical staff be addressed in ways that achieve sustainable improvements in care delivery for PLWD?
4. How do various community and identity-based factors, including cognitive impairment, and social determinants of health impact delivery and receipt of ED care for PLWD?
5. What economic or other implementation science measures address viability of optimal ED Care practices for PLWD?

Note: All Workgroup members voted on the rankings either during the conference or after via online polling mechanisms.

Meeting Summary

Introduction and Overview of the Meeting

The GEAR 2.0 Consensus Conference opened with pre-recorded statements and testimonies from GEAR funders, including Dr. Susan Zieman from the National Institute on Aging, Ms. Adriane Lesser of West Health Institute, the American College of Emergency Physicians Emergency Medicine Foundation, and Ms. Rani Synder of The John A. Hartford Foundation, each of whom emphasized the importance of improving emergency care practices for people living with dementia (PLWD) and thanked all individuals working with GEAR for their efforts.

During the opening of the meeting, the history of GEAR was presented. GEAR was developed to establish infrastructure to support collaborative, interdisciplinary research to improve care for older adults. With funding from the National Institutes on Aging (NIA) and other partners, such as those highlighted in the pre-recorded video, GEAR is able to convene stakeholders from emergency medicine, geriatrics, nursing, and social work, as well as those representing health care systems, clinicians, researchers, medical specialty organizations, advocacy organizations, caregivers, and patients. GEAR 1.0 established a multifaceted approach to infrastructure development. The first phase of GEAR 1.0 established five key research priorities (cognitive impairment, medication safety, elder abuse, falls, and care transitions) for the care of older adults in the ED and ways to study them. The second phase of the project looks to test and validate a multi-center data bank of ED visits of older individuals with prospective data collected at Geriatric Emergency Department collaborative (GEDC) sites. Simultaneously, the project will support interdisciplinary multi-center 1-year pilot studies using GEAR infrastructure, and support researchers to improve emergency care for PLWD.

Building on the success of GEAR 1.0, Drs. Manish Shah and Ula Hwang described the purpose of GEAR's second round of infrastructure research prioritization (i.e., GEAR 2.0) and an expanded Consensus Conference. The mission of GEAR 2.0, which began in 2020, is to advance the science supporting emergency medical care for people living with dementia (PLWD) or Alzheimer's disease and related dementias (ADRD) by engaging with a wide variety of stakeholders, with an emphasis on PLWD and their care partners. To achieve this mission, GEAR 2.0 will have a phased approach with the first stage focused on the identification and prioritization of research gaps in critical areas of Care Transitions, Communication & Shared Decision Making, Detection, and ED Practices as related to emergency care for people with cognitive impairments or ADRD. The second stage will focus on supporting researchers to study these research priorities by awarding $1.1 million in partnered research funding support. Through these two stages, GEAR 2.0 aims to facilitate transdisciplinary and interorganizational partnership growth, disseminate and communicate across networks, fund nine research grants, and publish on the prioritized research projects and research gaps identified in the first stage.

The GEAR 2.0 Consensus Conference convened GEAR researchers, physicians, partners, patient advocates and other stakeholders to (1) determine the breadth of evidence for care of PLWD in ED care, (2) identify research and care practice gaps in emergency care for PLWD, and (3) prioritize research and practice gaps to be addressed in GEAR 2.0's pilot funding opportunities (which will be released in the fall of 2021 and posted here). The meeting revolved around four sessions (Detection and Identification, Communication and Decision-Making, Care Transitions, and ED Practices), each of which included an overview presentation of a GEAR Working Group's (WG's) preliminary work and review of priority questions, as well as four concurrent breakout sessions during which participants could discuss topics in greater depth. Following these discussions, each breakout group presented their recommendations and key discussion points related to the session topic and then all WG members voted on the updated priority questions.

Detection Overview and Priority Questions

Ula Hwang, MD, MPH, Yale University

Emergency care for older adults is suboptimal, and care is especially poor for older adults with dementia, despite the fact that these adults seek ED-based care more regularly than matched controls. ED identification of PLWD is particularly poor. Better detection of dementia may improve the ED staff's ability to implement interventions that can improve care coordination and patient safety and potentially reduce the rate of cognitive decline.

The GEAR Detection Working Group (WG) thus examined the potential role of the ED in dementia detection. The WG held many discussions regarding considerations that may lead to improvements in the detection of PLWD in the ED setting; based on these considerations, it focused its literature review by (1) replacing age cutoffs with exclusion of children in order to include all affected adult populations and (2) conceptualizing the ED's role as screening for rather than diagnosing dementia. The WG excluded papers on delirium from its literature searches.

The Detection WG then identified two Patient Intervention Comparison Outcomes (PICO) questions (summarized below) to guide their literature review of publications related to detection of dementia in ED settings.

- **PICO-1:** How can the ED best identify cognitive impairment? (Best in terms of sensitivity or reliability, etc.) Are there differences by race or ethnicity?
- **PICO-2:** Are there pragmatic cognitive impairment screening tools that can identify patients at risk of dementia? (Pragmatic in terms of ease of use, training, quickness to complete, etc.)

The literature review identified 2,160 articles pertaining to PICO-1 and excluded all but 44 of these publications; studies were excluded if (1) the primary measure of the study was not feasible or pragmatic, (2) the study was not conducted in the ED, (3) the study was not related to detecting dementia (e.g., the study focused on identifying traumatic brain injury or another condition), (4) full-text links to the publication were not available, (5) the article was a duplicate of another article, or (6) an English version of the publication was not available. For PICO-2, the literature review identified 3,259 publications, which were filtered to a total of 59 studies based on the review requirements.

Of the 44 publications identified in the PICO-1 review, approximately 33 percent reported demographic information. The 44 publications detailed 16 different instruments and tools. The most commonly used screening tools were the Six-Item Screener (SIS) and the Ottawa 3DY (O3DY), which were each used in 5 studies, and the most common outcome measures were the Mini-Mental State Exam (MMSE; included in 22 studies), the Telephone Interview for Cognitive Status (TICS; included in 4 studies), the Montreal Cognitive Assessment (MoCA; included in 3 studies), and the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE; included in 3 studies). Approximately 6 percent of the 59 PICO-2-identified publications reported demographic information and approximately 34 percent (20) of the publications assessed the feasibility of a given screening tool. Of those 20 publications, 13 focused on duration of the assessment and 3 focused on the assessment's acceptability to the patient. The majority of publications emphasized the need to select tools that were easy to learn and remember.

The Detection WG also found that 21 publications appeared in the filtered results for both the PICO-1 and -2 question reviews. In these 21 publications, the screening tool with the highest pooled sensitivity (90 percent) was the OD3Y, which was found to be easy to use, learn, and remember; the tool with the highest pooled specificity (79 percent) was the SIS, which requires less than 1 minute to complete. Two recent papers were mentioned by a conference participant that noted the Abbreviated Mental Test 4 (AMT4) also resulted in high pooled sensitivity and specificity (0.88 and 0.81, respectively).

Upon reviewing the results of the PICO question-guided literature reviews, the Detection WG identified key discussion points, summarized below:

PICO-1 Discussion Points

- Despite being the most common outcome measure in the literature review, the MMSE has become less commonly used because it has been copyrighted since 2007 and has a limited ability to evaluate executive functioning (some people with dementia can score high on this measure).
- Most studies identified took place during the 2000s and 2010s.
- More studies need to include demographics information.
- The studies displayed a wide variety of heterogeneous tools, instruments, and data sources.
- The WG debated whether the ED is the correct environment even for screening (without diagnosis). However, one study found no association between screening abilities/accuracy and a variety of factors, including time of day, crowding, private versus shared rooms, and number of hours spent in the ED.

PICO-2 Discussion Points

- Some current tools may be easy to use but have low diagnostic accuracy.
- It is important to consider how language affects pragmatic and diagnostic accuracy, particularly when English is not a patient's first language.
- Shorter-duration assessments may not accurately assess memory functioning.
- In addition to measuring how acceptable a given tool or outcome measure is for a physician, it may be possible to define a threshold of acceptability.

- A review of tools should consider who is actually administering them in the ED.
- Research should examine whether electronic medical records or other information (including informant history) can be used to identify risk factors and improve dementia screening.

Overlapping PICO-1/-2 Discussion Points

- The primary and most critical goal of ED-based care is to determine whether a patient is experiencing delirium.
- After assessing for delirium, the ED staff must differentiate between previously known versus unknown or new cognitive impairments in a given patient.
- ED screening must define who is the target population for screening (e.g., in terms of age, nursing home residency, etc.).
- The most foundational question is what strategy is the best approach for detecting dementia in the ED.

Using these discussion points, the Detection WG developed five questions (listed below) for meeting participants to discuss during the following breakout group session.

- **Question 1:** What is the best approach in the ED to evaluate cognitive impairment? What information is needed to differentiate delirium versus undiagnosed cognitive impairment versus known dementia?
- **Question 2:** What are the most accurate and feasible tools and data needed to identify cognitive impairment in the absence of delirium or known dementia? Should age be a determining factor if assessments are required?
- **Question 3:** How can EDs feasibly account for culture, language, clinical environment, and communities of the population served when detecting cognitive impairment in the ED? For example, does English as a second language impact screening of dementia?
- **Question 4:** Does the identification of cognitive impairment change ED decision making, clinical care, and patient outcomes?
- **Question 5:** With the national push for earlier detection, what is the role of the ED in facilitating earlier detection of dementia?

Detection Breakout Groups Debrief

Following the overview presentation, meeting participants transitioned into four breakout groups to discuss the five questions crafted and prioritized by the Detection WG and to identify any necessary edits or additions to the questions to ensure that they accurately exemplify the research priorities in this focus area. The following sections detail the answers and suggestions presented by each Breakout Group.

Breakout Group 1

Breakout Group 1 discussed concerns related to the lack of demographic data available within the identified studies, noting that without accounting for these data, a prioritized screening tool may result in further health disparities across racial/ethnic groups as well as socioeconomic groups. GEAR participants added that there is a difference between screening tools' *sensitivity* (i.e., ability to accurately designate a PLWD as positive for dementia) and *specificity* (i.e., enhanced ability to rule out *other* conditions) that is also relevant to the discussion of detection.

Breakout Group 1 emphasized their concern about ED staff recording specific medical codes related to dementia diagnoses that will follow a patient after receiving ED care and possibly impact their insurance plan or downstream care options. Thus, Breakout Group 1 urged ED staff to define a patient's cognitive impairment, but not to diagnose or assign a clinical label to the patient's condition; the ED should focus on screening, not diagnosing. Instead of trying to identify a patient's specific level or type of cognitive impairment in order to provide a diagnostic label, ED staff instead should focus on how to best engage patients in their own care and identify what resources are needed to accomplish that engagement. One patient advocate noted a preference for receiving false positive results, rather than false negative results, adding that the potential for receiving either false positive or negative results should not preclude the ED from providing screening.

Breakout Group 1 also posed the following discussion points that were not addressed by the literature review:

- The MMSE measure appears out of date and possibly more effective in screening for cognitive impairment, not dementia.
- Time is valuable in the ED and thus identifying priority care components may help improve overall ED care in real time.
- The literature review did not clearly identify how information is being shared in the ED and how information sharing alters care.
- Overall, screening for cognitive impairment is more important than identifying and excluding delirium.
- The ED must incorporate additional practices for obtaining appropriate consent for assessments from PLWD in order to prevent studies from biasing their patient population towards those PLWD that are more cognitively intact than others.
- Feasibility of screening tools in the ED is a paramount consideration for implementation.

Breakout Group 2

Breakout Group 2 emphasized that identifying patients with delirium in the ED may not be critical to emergency care practices, because the overall goal of the ED should be to provide appropriate care to patients with any type of cognitive impairment. However, if possible, ED staff should work to screen for both delirium and dementia in order to improve downstream care practices. Breakout Group 2 also discussed the purpose of screening in general, which they agreed should be to identify next steps for clinical care (not to facilitate population screening). Population screening is not well-supported in the current literature.

Participants then discussed how the outcome of screening and detection impacts those next steps in clinical care, noting that in many cases, the only viable steps are to refer patients to downstream care providers or educate them on practices to improve overall health. In many cases, the downstream outcomes, such as whether a patient received a specialist referral after ED screening, are not known. Breakout Group 2 agreed that the ED can be an appropriate setting for early detection of cognitive impairments, but that this detection may be difficult because of limited resources. They emphasized the importance of caregivers in helping ED staff detect cognitive impairments and communicate with patients; however, underserved populations are less likely to have care partners present in the ED and in these cases, the ED must build in additional culturally tailored capacities, such as interpreters or documents in different languages, to help facilitate communication.

Lastly, Breakout Group 2 discussed the importance of not underestimating the patient and tailoring care approaches to the needs of the patient in order to properly evaluate and document cognitive impairments and to ensure the ED staff does not provide incorrect evaluations—which, as mentioned by Breakout Group 1, may cause downstream care difficulties. Patient advocates emphasized that PLWD should not be underestimated and should be viewed as a valuable member of their own care plan. In addition, patient advocates noted that many PLWD live alone and do not have access to care partners and thus relying on care partners to provide additional information during screening is not feasible. One patient advocate recommended identifying training modules that could help ED staff provide documentation within a patient's records to indicate screening has occurred but not to label an individual with a specific diagnosis that can follow them, as well as stigmatize them, through downstream care.

Breakout Group 3

Breakout Group 3 identified many themes previously identified by Breakout Groups 1 and 2. Breakout Group 3 did not recommend omitting any of the prioritized questions, but did recommend editing some of the question language to expand on key concepts. Particularly for Question 5, Breakout Group 3 recommended incorporating a definition of dementia into the question in order to frame early detection within the biological framework of the disease. In addition, participants noted that the medical field and regulatory entities, such as FDA, have identified new screening methods, such as those using imaging technology, and discussed whether the ED plays a role in incorporating those methods into dementia screening procedures. For Question 4, participants recommended incorporating identification of cognitive impairment *severity*. One patient advocate noted that most PLWD do not obtain a diagnosis until later in life because they delayed receiving care in fear of being stigmatized.

For Question 3, participants discussed accounting for visual or physical disabilities, in addition to other care-related needs (e.g., culturally appropriate practices). In addition, they noted that more demographic data must be collected during studies of ED practices. For Question 2, participants discussed (1) whether age may be a factor to consider in selecting screening tools for the ED—noting that ages below 65 years old should not be omitted from screening because many early-stage PLWD may be missed—and (2) how the likelihood of a tool to result in false positives (as well as the unintended harm associated with those false positives) must be considered when selecting tools. For Question 1, Breakout Group 3 noted that the term 'approach' is vague and could be substituted with something more specific.

Breakout Group 4

Breakout Group 4 noted that the preliminary literature search highlighted the lack of studies generating evidence of the effect of early detection techniques on overall outcomes for PLWD and their downstream care plans, noting that GEAR might help the field by providing resources to generate such evidence. Breakout Group 4 agreed on the importance of Questions 4 and 5, adding that the role of the ED may also include following up with patients. Participants agreed that follow up communication with a patient is critical to maintaining care after discharge; however, the implementation strategies for such follow up practices have not yet been defined. The following discussion points were also highlighted by members of Breakout Group 4:

- Connecting patients with post-discharge resources (including those for diagnosis and other support) in an outpatient setting is critical for continuing care.
- Addressing possible overlap with mental health screening techniques and how to distinguish screening for dementia from screening for mental health conditions.
- Assessing the unintended consequences of screening, such as exacerbating health disparities, is important.
- PLWD should be actively communicated with during screening assessments and they should also receive the interpreted results of these assessments, so that they are well-informed on their own health and next steps for care.
- Dementia screening can be implemented during regular delirium screenings within the ED.

Patient advocates noted that sharing the results of screening assessments is more beneficial to the PLWD than harmful, noting that withholding any screening or diagnostic information further stigmatizes individuals and their condition.

Discussion

Discussion focused on how screening and detection can unintentionally lead to downstream stigma or complications experienced by the patient in other care settings. Participants emphasized the need for ED staff to focus on screening for cognitive impairments overall, not only detecting whether a person is affected by delirium or dementia, and to avoid 'labeling' the patient in a way that can impede downstream care, through false or stigmatized diagnoses. However, participants urged ED staff to always be honest with patients and to share all outcomes from screening assessments to ensure that patients are involved in their care plans and do not feel underestimated. In addition, discussion focused on the importance of documentation versus labelling (i.e., diagnosing a patient with a specific condition and incorporating that diagnosis into the patient's health record through healthcare or reimbursement codes), with the recommendations that ED care must identify other methods of documenting screening results, such as after-visit summaries, in order to prevent labelling patients with diagnoses that complicate their ability to obtain appropriate downstream care.

Session 1 Priority Question Voting Results

The initial priority questions were updated based on Breakout Group discussions. Meeting attendees who participated in GEAR WGs submitted votes online in order to prioritize the five updated detection-related questions. The resulting research priorities will be included in future Request for Applications (RFAs) in order to help applicants understand the target goals of GEAR-supported research projects. The final rank-order of the questions is shown below:

1. What is the best approach in the ED to screen for cognitive impairment? (The approach includes population definitions, using data sources, screening tests effectiveness, efficacy, referral, etc.)
2. What are the most accurate and feasible tools and data to identify cognitive impairment in the absence of delirium or known dementia?
3. What is the value and potential unintended consequences of screening for cognitive impairment in the ED?
4. How can EDs feasibly take into account culture, language, ED environment, and communities of the population served when screening cognitive impairment in the ED? (e.g. does English as a second language impact screening of dementia?)
5. What information is needed to differentiate delirium vs. undiagnosed cognitive impairment vs. known dementia vs. mental health conditions?

Patient Testimonies

Patient advocate Mr. Bob Savage shared that after he was diagnosed with dementia approximately 5 years ago, he and his wife visited a lawyer who quickly transferred all of his assets to his wife. At the same time, friends and acquaintances began to ignore him in conversations and speak directly to his wife because they perceived him to be unable to communicate. Mr. Savage confided that he at one point began to contemplate suicide and even ordered drugs from Mexico to do so. Instead, he began to participate in support groups and asked those close to him to be honest with him in relation to his dementia, while also allowing himself to honestly confide in others about his cognitive impairments.

Patient advocate Mrs. Deb Jobe shared that she was diagnosed with mild cognitive impairment (MCI) at a very young age. She encountered many individuals who believed that she appeared too young to be diagnosed with a cognitive impairment or that she did not look like someone who could have such a condition, which complicated the process of receiving an initial diagnosis and led many to disbelieve her diagnosis once it was obtained. Mrs. Jobe emphasized that cognitive impairments can take many different forms and stressed the need to be compassionate to all who share their cognitive impairment experience.

Patient advocate Mr. Mike Bellville shared his recent ER experience as a person diagnosed with Lewy body dementia. Mr. Belville went to the ER with chest pain, and the ED staff recommended that he remain under observation overnight; although they did not have any available beds in the cardiac unit, the staff stated that he was a perfect candidate for a new cardiac decision unit and asked additional questions about his medical history. Mr. Bellville shared that he had previously been diagnosed with dementia, hallucinations, and a sleep disorder. A staff member told him soon after that he was no longer a candidate for the new cardiac decision unit, despite being told only hours earlier that he was eligible; this quick change and the lack of explanation led Mr. Bellville to believe that his dementia was the cause. Approximately 8 hours later, however, the decision was reversed again and he was given a bed in the cardiac decision unit. Mr. Bellville emphasized the confusion he felt and overall left the ED feeling misunderstood and mistreated.

Communication & Decision Making Overview and Priority Questions

Chris Carpenter, MD, MS, Washington University of St. Louis School of Medicine

The key components of "ED communication" remain largely undefined, but existing research on ED communication in non-dementia populations demonstrates a suboptimal level of information exchange. Dementia may add layers of complexity to current ED communication strategies, but this complexity must be addressed in order to ensure the patient, as well as care partners, feel that they are part of the care process through shared decision-making strategies. Strategies employed by surgical medicine, particularly those that use patient values to drive patient-centered medicine practices, can be reapplied to ED care in order to improve communication for PLWD; these strategies involve engaging every vital participant in clinical care, including the patient, care partners, and the healthcare system overall, to enable appropriate information exchange, deliberation, and decisional control. The Communication & Decision-Making WG identified a list of 17 critical questions that were then narrowed to a set of five questions (shown below).

- **Question 1 (PICO-1):** How does communication and decision-making differ for PLWD compared to persons without dementia?
    - ***Population:*** ED patients ≥ 65 years old
    - ***Intervention:*** Efforts to evaluate communication or medical information exchange between ED healthcare teams and patients/care partners
    - ***Comparison:*** Standard processes and procedures for communication between patients, families, caregivers and the ED team
    - ***Outcomes:*** Differences between patients with and without dementia in communication effectiveness, admission rates, ED returns after 3 days and 30 days, and patient, caregiver, and provider experience
- **Question 2 (PICO-2):** Are there specific medical communication strategies (e.g., Teach Back or next day phone follow-up) that improve the process or outcomes of ED care in PLWD?
    - ***Population:*** ED patients ≥ 65 years old with known or suspected dementia or cognitive impairment discharged from the ED
    - ***Intervention:*** Augmented communication efforts
    - ***Comparison:*** Standard processes and procedures for communication between patients, families, caregivers and the ED team
    - ***Outcomes:*** Comprehension of discharge instructions and 24-hour recall of ED discharge instructions, ED returns at 24 hours and 30 days, hospital admissions at 1 week, and change in living situation at 3 months

- **Question 3:** How should presenting compliant, dementia severity, underlying frailty/vulnerability, or other patient-level factors influence the ED communication strategy?
- **Question 4:** How frequently (and to what extent) do sensory deficits confound patient-physician communication during episodes of emergency care in PLWD?
- **Question 5:** Are there members of the healthcare team (e.g., nurse, social worker, physician extenders, pharmacist, or physician) who receive specific training in how to communicate with and treat dementia patients and are able to communicate more effectively with PLWD and care partners?

The initial literature review of PICO-1 identified 5,451 abstracts, with 22 of these studies remaining eligible after excluding studies that were not ED-based, did not compare dementia outcomes to those without dementia, did not investigate a communication or decision-making intervention, were review articles, or were duplicate studies. Upon further review of these 22 studies, the Communication & Decision-Making WG noted that none compared communication strategies and outcomes directly between PLWD and those without dementia and thus the remaining literature review focused only on theories and studies of communication strategies with PLWD. Most studies did not include a component assessing dementia severity or diversity, equity, and inclusion parameters, and of those that did, most assessed a population that was at least 80 percent white. More than 75 percent of studies did not include information related to usual mental status during transfers to subsequent care, such as nursing homes; a lack of information during these transitions may prevent the home institution from fully understanding the patient’s needs. One study identified four negative consequences of poor communication with PLWD that magnify their vulnerability: (1) insufficient triaging for PLWD, (2) feelings of worry or waiting during the visit, (3) time pressure without attention to PLWD’s basic needs, and (4) negative relationships and interactions (including the PLWD feeling ignored).

For PICO-2, the Communication & Decision-Making WG identified 2,687 qualifying abstracts, which were filtered to 3 studies after applying the inclusion/exclusion criteria, which were identical to those used in PICO-1. These studies included one systematic review, one scoping review, and one United Kingdom National Health Service Foundation report. The Systematic review synthesized two healthcare team education efforts that did not occur within ED settings (the We Discussing End-of-Life Choices [We DECide] and the Support Health Activities Resources Education [SHARE] Program). The scoping review explored decision-making strategies for PLWD in acute care settings and identified that in many scenarios, care partners felt excluded, nurses tended to serve as primary communicators, and overall the communication between primary care and ED settings was discordant. The governmental report from the United Kingdom identified three communication themes for PLWD that contribute to a positive or negative overall hospital experience: (1) the importance of a patient feeling valued through staff interactions or person-centered care, (2) the integration of activities that promoted empowerment and disempowerment, and (3) the social and organizational environment of the clinic.

Based on its literature review, the Communication & Decision-Making WG prioritized five questions (listed below) for meeting participants to discuss during the following breakout group session.

- **Question 1:** What are the modifiable barriers to effective communication or facilitators of effective communication with PLWD (or care partners) during an episode of ED care?
- **Question 2:** Do ethnic, gender, and socioeconomic factors (i.e., patient characteristics) or unconscious biases (i.e., provider factors) influence communication for PLWD (or care partners) in the ED?
- **Question 3:** What are the most accurate and reliable measures or outcomes of effective communication in PLWD?
- **Question 4:** In an ED that includes social workers, nurses, physicians, technicians, case managers, and pharmacists, who is best suited to provide medical communication to PLWD (or care partners)?
- **Question 5:** What dementia severity threshold (if any) should trigger engagement of care partner decision-making in the ED?

Communication & Decision-Making Breakout Groups Debrief

Following the second patient testimony and the overview presentation, meeting participants transitioned into four breakout groups to discuss the five questions crafted and prioritized by the Communications & Decision-Making WG and to identify necessary edits or additions to the questions to ensure that they accurately exemplify the research priorities in this focus area. The following sections detail the answers and suggestions presented by each Breakout Group.

Breakout Group 1

Breakout Group 1 discussed the lack of research investigating optimal communication strategies in the ED. Research is needed to evaluate strategies for improving communication with PLWD, care partners, and other family members, as well as to assess dementia-specific communication training programs for ED staff. Breakout Group 1 identified several specific dimensions of communication that deserve research, including how structural and environmental elements of the ED, such as crowded clinics, can contribute to poor communication between staff and patients, and the importance of addressing patients' visual or hearing impairments to improve communication, such as by taking the patient to a quieter, private room to discuss their health or ensuring they have a hearing aid. Participants also noted that EDs must work to evaluate environmental factors that may ease fear or stress, including masks during the COVID-19 pandemic. They noted the need for studies that assess the broader impact of COVID-19 on the ED environment, including how the pandemic affects ED staff members' mental and physical wellbeing and thus indirectly their communication with patients.

Participants also identified dementia severity as a key factor in communication and emphasized the need to consider how a patient's specific stage of dementia—mild, moderate, or severe—should affect communication strategies. Participants also noted that efficient communication between the patient, care partner, and care provider is needed in order to obtain consent for

ED care. However, the path to obtaining consent when the patient cannot provide it and a care partner is not available is unclear. Participants discussed how and when to best involve care partners in the consenting and overall care process.

Breakout Group 1 noted that many of the publications did not state what training, if any, had been provided to help ED staff communicate—both verbally and non-verbally—with PLWD and did not indicate whether that training could be implemented in a cost-effective manner. The group emphasized the need for best practices for communicating with PLWD in different ED settings. They also noted, though, that communication in the ED is limited by the fact that EDs do not reliably screen for dementia diagnoses and thus do not necessarily know when they are communicating with PLWD. Breakout Group 1 also emphasized the need for more research on specific outcome measures, including those assessing medication adherence as a measure of communication.

Participants recommended that participants consider updating Question 3 to state "accurate, reliable, and feasible measures or outcomes"; however, the construct of feasibility can be biased by a viewer's assumptions and thus the feasibility of any measure or outcome must be interrogated objectively and quantitatively, if possible. Participants did not recommend omitting or adding to the WG's list of prioritized questions. However, Breakout Group 1 recommended that the Communication & Decision-Making WG consider lowering its age-related inclusion criterion because many individuals can present with dementia earlier than 65 years old.

Breakout Group 2

Breakout Group 2 echoed some of the recommendations offered by Breakout Group 1, noting that visual and hearing impairments should be viewed as modifiable barriers that merit study. For example, providing staff with clear facial coverings and other personal protective equipment might help PLWD better view the staff member's face and communicate. Environmental and structural factors of the ED can also be modified to fit a PLWD's needs, including finding methods to lower external noise or reduce crowding. Breakout Group 2 noted that best practices for communicating with PLWD can likely be shared across medical units and recommended that the WG expand its literature search to include studies performed in other clinics. Breakout Group 2 also emphasized the need for better measures of communication to be used in research studies in order to accurately assess the quality or gaps in communication between patients and ED staff.

Breakout Group 2 provided the following recommendations related to updating the priority questions:

- Question 1 can include nonverbal communication modalities, including hand-written notes or other documentation in order to easily share what was communicated in the ED and recommendations for post-ED care.

- Question 3 should be updated to include care partners and PLWD, and should also emphasize the need for investigation into the outcomes of efficacious communication strategies.
- For Question 4, participants recommended omitting the phrase “best suited” because that phrase is open to interpretation and many members of the ED staff are likely capable of proper communication, with the necessary training.
- Participants recommended omitting “severity thresholds” from Question 5, adding that any level of severity should trigger appropriate care and that a single threshold will not be applicable to all PLWD. They also noted that this question could be expanded to fully encompass how an ED *team* can best engage care partners and PLWD; members of these teams should not only communicate with each other, but also communicate consistent messages to PLWD and their care partners.

One patient advocate emphasized that significant focus has been placed on the care partner, but even more emphasis, particularly related to communication, must be placed on the patient themselves. Another patient advocate participant emphasized that every PLWD is different and experiences a range of “good days and bad days.” ED staff must find a communication strategy that is tailored to each PLWD at the particular moment of interaction.

Breakout Group 3

Breakout Group 3 focused on discussing Question 5 and agreed with Breakout Group 2 that the language related to a “severity threshold” should be removed from the question. Participants emphasized the importance of research on (1) engaging care partners in communication strategies and ensuring that all PLWD have care partners, and (2) using the “no care for us, without us” strategy of communicating with PLWD. Breakout Group 3 provided additional recommendations related to updating the questions, summarized below:

- Regarding Question 1, Breakout Group 3 recommended removing “modifiable” because the word can denote bias and some factors can be difficult to modify and updating the question to the following: “What are the barriers and facilitators of effective communication with PLWD (or their care partners) during an episode of ED care, with attention to actionable elements, factors and ideas?”.
- Question 2 should include examples of each type of factor included in the question (e.g., ethnic, gender, and socioeconomic factors and conscious or unconscious biases).
- Participants also recommended updating the language in Question 3 to state “what are the valid and reliable measures and outcomes of effective short- and long-term communication in PLWD?”
- Question 5 should be rewritten as “how best to ensure that all patients with dementia have care partners included in the conversation?”

Breakout Group 4

Breakout Group 4 emphasized that a main barrier to communication in the ED is a lack of staff training and experience. Communication must be viewed as bidirectional, such that the ED staff must understand the needs of PLWD and their care partners, but PLWD and care partners must also be able to understand ED staff. In addition, Breakout Group 4 emphasized that the focus on care partner communication must not displace research on communication with PLWD. Instead, Breakout Group 4 suggested that the focus of communication strategies should be to facilitate shared decision-making wherever possible, regardless of dementia severity. Participants also discussed the importance of identifying "what matters most" to PLWD and conveying those components to other physicians involved in a patient's care, adding that promoting communication among ED and non-ED providers is important. Breakout Group 4 also emphasized that ED physicians should note where the PLWD typically receives care, whether that be at home or a primary care physician's office, in order to identify physicians that provided proper communication and to further incorporate that physician into future care for the PLWD. ED staff can also incorporate specific skills that the care partners have into their communication strategies.

Participants also posed the following recommendations related to the priority questions:

- Question 2 should be rephrased to ask, "how can we appreciate the belief systems of care partners and how that influences care decisions, follow-up, etc.?"
- Participants recommended adding "feasible" into Question 3.
- Question 5 should be revised to the following: "What are the best practices for approaches to engagement of care partners in care decision-making in the ED?"

Discussion

Participants cautioned that the concept of feasibility can artificially limit communication strategies within the ED; methods and measures that may once have been considered technologically infeasible have now become commonplace as the field innovated. Participants also agreed that although dementia severity is an important factor in ED communication, PLWD can be highly heterogeneous, leading a low-severity patient to experience severe symptoms or a typically high-severity patient to have a 'good day' in terms of cognition or communication. Participants also encouraged the adoption of the "nothing about us, without us" strategy for implementing care for PLWD, which requires that no care decisions are made for a patient without communicating with the patient and including the patient in shared decision-making.

Session 2 Priority Question Voting Results

The initial priority questions were updated based on Breakout Group discussions. Meeting attendees who participate in GEAR WGs submitted votes online in order to prioritize the five updated detection-related questions. These scientific question priorities will be included in future RFAs in order to help applicants understand the target goals of GEAR-supported research projects. The final rank-order of the questions is shown below:

1. What are the barriers and facilitators of effective communication with persons living with dementia (or their care partners) during an episode of ED care, with attention to actionable elements/ideas?

2. What are valid and reliable measures or outcomes of "effective (short and long-term) communication" in patients with dementia?
3. What are the best practices (when/how) for engagement of care partners in care decision-making in the ED?
4. How do individual, provider, and system-level factors that influence communication for ED patients living with dementia (or their care partners)? (Examples include ethnic, gender, and socioeconomic factors or conscious or unconscious biases.)
5. How can each member of the ED care team (e.g., social workers, physicians, technicians, nurses, etc.) ensure high quality communication with PLWD, care partners, and other team members?

Session 3: Care Transitions

Patient Testimony

Patient advocate Mrs. Deb Jobe shared that she was diagnosed with posterior cortical atrophy and MCI at 53 years old. During a recent trip to visit her daughter, Mrs. Jobe began to feel ill and went to a local urgent care center, accompanied by her daughter. She expressed that even on a good day, she can experience trouble remembering specific details, but when she feels ill, remembering becomes even more difficult. Thankfully, Mrs. Jobe and her daughter received exemplary care from the ED staff, who communicated with both her and her daughter (i.e., her care partner) to determine the reason for the visit and initiate a care plan. Mrs. Jobe emphasized that the ED staff never discounted or undermined her feelings and symptoms, which made her feel valued as a patient and as a person. She noted that the presence of her care partner helped with her transition from the ED to care at home because her daughter could help her remember the care plan post-discharge (e.g., what medications to take). She recommended that all physicians and other ED staff communicate with both the patient and care partners to improve overall care transitions.

Care Transitions Overview and Priority Questions

Manish Shah, MD, MPH, University of Wisconsin-Madison

Approximately 50 percent of PLWD are discharged to their homes after receiving ED care but approximately 40 percent of PLWD will experience an adverse event (including ED revisits, other hospitalizations, or death) in the 30 days following discharge, which is a significantly higher rate than for those without dementia. With this context in mind, the Care Transitions WG decided that the scope of its PICO-driven literature review would (1) focus broadly on studies addressing cognitive impairment (not studies detecting only dementia, because in some studies dementia diagnoses are unknown) and (2) target studies that address the ED-to-home or ED-to-community transitions. The Care Transitions WG identified two key PICO questions (listed below) to help guide its subsequent literature review.

- **PICO-1:** What interventions delivered to ED patients with impaired cognition and their care partners improved ED discharge transition?

- **PICO-2:** What measures of quality ED discharge transitions are important to varying groups of ED patients with impaired cognition and their care partners?

The Care Transitions WG also identified several key search terms to consider during the literature review (including continuity of patient care, continuum of care, patient discharge, after care, home rehabilitation, nursing homes, skilled nursing facilities, home care services, follow-up visits, and activities of daily living), as well as key inclusion criteria (i.e., the study must occur in the ED, focus on dementia, AD, or cognitive impairment, and assess discharge outcomes) and exclusion criteria (studies that focus on hospital admissions, transfers, or non-dementia-related conditions).

The literature review identified 3,884 publications, which were filtered according to the key search terms and inclusion/exclusion criteria to identify seven articles for PICO-1 and three articles for PICO-2. None of the PICO-1 studies with mixed populations separately analyzed subjects with cognitive impairments, but two studies focused exclusively on cognitively impaired patients and one study found a 75 percent decrease in ED revisits within 30 days following intervention implementation. The three studies identified for PICO-2 highlighted the importance of many measures; however, only some of these studies may have analyzed ED revisits as an outcome.

Based on the PICO question-guided literature review, the Care Transition WG prioritized five questions (listed below) for meeting participants to discuss during the following breakout group session.

- **Question 1:** What are the key structural characteristics of ED-to-home care transitions intervention programs to improve outcomes for ED patients with cognitive impairment and their care partners?
- **Question 2:** Who are the key personnel needed to successfully implement ED-to-home care transitions intervention programs for ED patients with cognitive impairment and their care partners?
- **Question 3:** What strategies promote engagement, uptake, and success of care transition interventions for ED patients with cognitive impairment and their care partners?
- **Question 4:** What care transition outcomes are important to ED patients with cognitive impairment and their care partners?
- **Question 5:** What are the historical and research barriers preventing the ED patient and care partner voice from guiding ED-to-home care transitions outcome measures?

In addition to the main five questions, the Care Transitions WG identified several additional questions for breakout groups to consider during their discussions, summarized below:

- What should the program be compromised of (e.g., home visits, phone calls, telemedicine visits, in-person follow-up, or referral for services)?
- Where should the program operationally reside (e.g., ED, health systems, community organizations, or national organizations)?

- What population should be the target of the program (e.g., ED clinicians, nurses, primary care providers, ED patients, care partners, or ED systems)?
- What goal should the program target (e.g., communications, skills, knowledge, or care activities)?
- Who should deliver the program (e.g., ED clinicians, nurses, community paramedics, community health workers, social workers, or lay persons)?
- Who should train intervention personnel (e.g., ED clinicians, PLWD, care partners, or social workers)?
- How does potential reluctance to accept assistance or denial regarding cognitive impairment limit the success of care transition interventions?
- How can we engage care partners in the care transition process if they have not yet been designated as the legally authorized representative?
- How do we modulate the intensity of the intervention based on individual ED patient need?

Care Transitions Breakout Groups Debrief

Following the overview presentation, meeting participants transitioned into four breakout groups to discuss the five questions crafted and prioritized by the Care Transitions WG and to identify necessary edits or additions to the questions to ensure that they accurately exemplify the research priorities in this focus area. The following sections detail the answers and suggestions presented by each Breakout Group.

Breakout Group 1

Breakout Group 1 highlighted the lack of publications identified in the literature review that found specific effective care transition strategies and emphasized that research in this area is a prime opportunity for GEAR-ADC. They noted that studies also did not address how care transitions are ultimately integrated within healthcare policy, including how transitions fit within payment reimbursement systems. The field appeared to lack standardized tools to evaluate care transitions, as well as measures to evaluate those tools; Breakout Group 1 emphasized the importance of developing patient-centric measures, in particular, because any enhancement of ED practices should take into account what a patient perceives to be a successful ED visit. Group 1 also emphasized the need to incorporate communication components into *all* outcome measures. Participants identified the importance of understanding the reason why the patient is visiting the ED and emphasized the need to collect more information related to this reason.

Breakout Group 1 noted the role of hospitalists in improving care transitions. Drawing expertise from other hospital departments with standardized care transition pathways; this expertise might suggest the need for a care transitions toolkit—which could help ED staff quickly and accurately assess PLWD—that could be broadly disseminated to EDs. However, participants noted that having too many individuals involved in the care transition plan may also be detrimental. The group also emphasized the importance of considering effective care transitions for PLWD without care partners.

Related to Question 5, participants discussed how care partners can be better incorporated into care transition policies and how to identify an individual to engage if a patient does not have a care partner; these issues could be incorporated into a care transitions toolkit. Breakout Group 1 noted that Questions 3 and 4 appeared appropriate in their proposed form. Patient advocates recommended using in the ED a kind of worksheet produced by many assisted living facilities to identify personal information important to a PLWD, such as hobbies, favorite foods, and other information; this document could help improve a PLWD's ED care and visit. One patient advocate emphasized that they find ED settings overwhelming because of an inability to fully communicate their situation and noted that a worksheet detailing such issues would be helpful.

Participants noted that the Alzheimer's Association has developed evidence-based practices regarding care transitions; however, these practices are not focused on specific dementia stages.

Breakout Group 2

The scope of care transitions for PLWD can be broad and thus Breakout Group 2 elected to focus on the ED-to-home care transition, with "home" defined as where the patient resides (which could be either their own home or a nursing facility). Understanding the patient's living situation may help improve the transition to the ED. In addition, most patients come to the ED for a medical reason unrelated to their cognitive impairment and understanding both the clinical symptoms and cognitive impairment must be equally prioritized to help the patient and to identify what tools or resources the patient may need after leaving the ED.

Breakout Group 2 also discussed the legal liabilities and financial incentives related to why healthcare systems seek to treat patients within the ED. Particularly, Breakout Group 2 identified that the fee-for-service system incentivizes ED trips. Identifying new locations to send patients and PLWD during a healthcare emergency, particularly locations that have improved environmental capabilities for PLWD, would help to improve care.

Breakout Group 2 highlighted the importance of the community's role in care transitions and how to better equip communities with the resources and capacities to receive patients from the ED and provide them with sufficient care to prevent, or lessen the need, for further ED visits. The group discussed historical barriers to care transitions and noted that community organizations are not well-equipped to help with ED-to-home transitions. Although Breakout Group 2 determined that the ED-to-community transition is likely outside of the scope of the PICO questions, participants did identify that one method to improve community transitions is to improve fund utilization. Many studies of community transitions are not well designed, leading to eventual requests for additional funding to consider transition parameters and community capacities that could have been studied within the original investigation.

Participants also discussed outcomes related to care transitions, particularly which outcomes would help determine whether a care transition is effective and successful for the patient and the ED. Breakout Group 2 considered combining Questions 1 and 2, which may allow the GEAR 2.0 research priorities to be more focused on how to identify the outcomes and parameters that result in a successful care transition. Participants emphasized outcome measures that indicate “what matters most” to patients and their families should be the highest priority for care transition-related studies. The group also suggested studying the processes by which care partners and family resources can be leveraged for successful transitions. Although participants did not focus on Question 3, they did indicate that PLWD and their care partners must be included in discussions related to the care transition plan.

In addition, many studies may not include patients with cognitive impairments in their studies because of the potential associated difficulty; however, GEAR 2.0 must encourage researchers to include the cognitively impaired population in studies, or at least to state why this population was not included.

Breakout Group 2 did not recommend edits to Questions 3 or 5.

Breakout Group 3

Breakout Group 3 recommended highlighting the importance of reaching underserved populations and including minoritized groups or socioeconomically disadvantaged individuals, either by incorporating language within each of the Care Transitions questions or by establishing it as an overarching question (within this area or across all four areas). Breakout Group 3 identified several aspects of ED care transitions that should be a focus of future research, including the dramatic variation in resources at a patient’s home, whether it be a private house or nursing home, which should be considered by ED staff when discharging a patient; the opportunities for ED staff to connect PLWD with social workers at discharge to create a continuum of care; the possibility of linking different care resources within communities; and the importance of activating caregivers at transitional moments. They noted that research should balance all of these desirable steps with a consideration of pragmatism (i.e., what can be done feasibly). For example, Breakout Group 3 emphasized the importance of recognizing stress and burnout within care partners may improve the overall transition. Participants noted that one particularly resource, call lines, may need to be updated to improve quality and outcomes. One patient advocate recommended enhancing training resources for hotlines.

They also recommended incorporating “implementation science” into Question 3 and considering what stakeholders, standards, and policies should be part of that expansion; members of other GEAR 2.0 WGs should likely be involved because this topic applies to the needs of other focus areas. Participants added that research in the care transitions area should not be constrained to what measures and strategies are available and feasible within 2021 technology and that researchers much continue to look forward to create innovative solutions.

Breakout Group 4

Breakout Group 4 echoed Breakout Group 3’s recommendation to focus on the incorporation of underserved populations into each of the prioritized questions, adding that nursing home and long-term care facilities should also be included in a separate, additional priority question.

Participants also recommended broadening Question 1 by removing the term “structural” in order to allow the question to also address community or family support factors. Regardless of the breadth of support considered, Breakout Group 4 discussed the *safety* of care transitions and recommended incorporating safety as a care transition outcome of high importance for which researchers should develop measures; in addition, participants recommended incorporating a priority question focused on developing measures to evaluate the safety of care transitions. Studies of relative safety must consider social determinants of health, the level of a patient’s cognitive impairment, and the patient’s functional abilities during care transitions. Patients and care partners may not evaluate or view safety in the same terms as a physician, and thus capturing the viewpoints of each of these parties is critical to evaluating optimal outcomes. New tools may be available to help further incorporate measures of safety into care transitions-focused studies.

Different care transitions (e.g., to different facilities or for individuals with differing levels of resources) and the distinct needs of different individuals within those types of transitions must also be considered. Breakout Group 4 emphasized the importance of facilitating research studies on the care transitions of newly diagnosed PLWD, in particular. Participants recommended the addition of patient- and care partner-centric language into the priority questions, particularly Questions 1 and 4.

Discussion

Participants overall emphasized the importance of training ED staff on care transitions, including training related to hotlines to provide brief advice to PLWD. Participants also noted that care transitions must take advantage of all resources available, including hospitalists, digital tools, and support documentation for family caregivers. Participants recommended that one resource could be a quick documentation guide for each patient that lists their preferences—including hobbies, foods, and other information—to help ED staff provide specific care to that patient during their care transition. Participants also emphasized that care transitions can be affected by the detection and screening capabilities of the ED and that labelling of patients with specific codes or diagnoses can cause issues during later care, particularly related to reimbursements or processes associated with the Centers for Medicare and Medicaid Services (CMS).

Session 3 Priority Questions Voting Results

The initial priority questions were updated based on Breakout Group discussions. Meeting attendees who participate in GEAR WGs submitted votes online in order to prioritize the five detection-related questions. These scientific question priorities will be included in future RFAs in order to help applicants understand the target goals of GEAR-supported research projects. The final rank-order of the questions is shown below:

1. What improves outcomes of ED-to-community care transitions among ED patients with impaired cognition and their care partners (e.g., system, program operations, individual/care-partner strengths/needs) and how can these be personalized for vulnerable pops?

2. What matters most to ED patients with impaired cognition and their care partners during the ED-to-community transition and how can these priorities best be measured?
3. What barriers, facilitators, and strategies, specifically leveraging implementation science methods, influence engagement, uptake, and success of care transition interventions, including national guidelines, policies, and best practices?
4. How can care partners and community organizations be best engaged and empowered to improve ED-to-community care transitions?
5. How can communication quality surrounding ED-to-community transitions be optimally measured?

Participants recommended that Question 4 be updated to include PLWD.

Session 4: ED Care Practices

Care Partner Testimony

Patient advocate and former AD care partner Dr. Allan Vann shared his experiences during ER visits with his wife. Most experiences were quite negative due to a lack of staff training or a refusal by ED staff to view his wife as a priority for triage. His wife would have received better ER care if she had been treated by well-trained staff who knew how to use non-verbal techniques to help communicate with her, particularly when assessing pain, and knew to communicate with him (i.e., her care partner) to obtain additional information that might be critical in providing care. However, these positive experiences were not the majority, and unfortunately, many visits led to increased discomfort and pain to his wife. Dr. Vann noted that in addition to causing discomfort, inattention to proper care practices may mask or exacerbate the issues that led to the ED visit or even cause new health issues. All of these negative effects may be avoided if ED staff viewed AD patients with higher priority.

ED Care Practices Overview and Priority Questions

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The goal of the ED Practices WG is to develop key questions and identify research gaps in optimal care for PLWD who are seeking acute, unscheduled care in the ED or through alternative means, such as telehealth or community paramedicine. The ED Practices WG's literature review identified 6,348 publications, which were filtered to 23 articles for PICO-1 and 26 articles for PICO-2 according to inclusion/exclusion criteria, relevance to the WG's goals, and the two prioritized PICO questions (shown below).

- **PICO-1:** What components of ED care improve patient-centered outcomes for PLWD?
- **PICO-2:** How do emergency care needs for PLWD differ from other patients in the ED?

The inclusion criteria for PICO-1 included studies focusing on adults 19 years old or older with dementia who were seeking care in the ED and studies involving a quantitative evaluation of one or more ED care components, whereas the inclusion criteria for PICO-2 included studies that focused on adults who were 19 years old or older and described emergency care needs for PLWD or compared these needs to a person without dementia. Exclusion criteria for both PICO questions included articles that focused on interventions more relevant to the Detection, Communication, or Care Transition WG's scope. The main findings related to PICO-1 and PICO-2 are summarized below:

PICO-1 Literature Review Main Findings

- Comprehensive geriatric assessments in a dedicated ED unit were able to decrease the likelihood of 30-day readmission and increase odds of admission on index ED visit.
- Certain physical environment changes were described as favorable to caregivers and staff. These environmental resources may include a screen or dome/cover to decrease stimulation, dedicated bays for PLWD, and remote monitoring methods.
- The Family Confusion Assessment Method improved the detection of delirium in PLWD by 20 percent and abnormal Richmond Agitation Sedation Scale scores were found to have a sensitivity of 95 percent and specificity of 85 percent for detecting delirium.
- Studies detailed potential strategies to assess delirium responses and provided recommendations related to management of behavioral complications and staff education; however, these strategies and recommendations were not tested or evaluated.
- Several studies mentioned pain assessment tools, including the Pain Assessment in Advanced Dementia Scale tool (which nurses find acceptable) and the Abbey Pain Scale (which is found to be burdensome); however, pain assessment tools are less likely to be validated in PLWD than in other older adults and do not seem to impact on time to analgesia
- Nurses felt the presence of families and dementia companions improved ED care for PLWD.
- Implementation of a dementia care companion program helped to decrease falls and behavioral disturbances in PLWD, although only one out of five sites participating in this program was an ED; the other four were inpatient settings.
- Incorporating a low-stimulation bed shade into care improved patient mood, alertness, and general wellbeing in a subjective, per family manner.
- Palliative care consultations were rare in the ED, but, when available, made patients more likely to select treatment plans with comfort measures and less likely to select life-prolonging measures.
- Fall prevention programs did not provide any improvement in ED practices for PLWD.
- Transitions of PLWD from ED to a hospital-at-home setting led to decreased instances of sleeping disorders, agitation, feeding disorders, and use of antipsychotics.

PICO-2 Literature Review Main Findings

- Key domains include pain, falls/injury, activities of daily living, behavioral disturbance, altered mental status, fluid/electrolyte balance, infection (e.g., pneumonia, urinary tract infections, or other infections), changes in dementia severity or new delirium in addition to dementia, and cardiovascular, respiratory, digestive, stroke, and non-specific clinical characteristics. Patients experienced difficulties communicating their levels of pain and 45 percent of PLWD in the ED identified pain as part of the reason for their visit. Difficulties with activities of daily living often continued or worsened after ED visits.

- Points of ED vulnerability for PLWD patients include futile or advanced treatment that may not be congruent with a patient's wishes, advanced care planning, triage practices, waiting in the ED for longer than expected, feeling ignored, families keeping vigil, and basic needs.
- Studies highlighted the importance of addressing environmental aspects of the ED, including noise, lighting, and privacy, as well as basic needs of PLWD, including nutrition, hydration, and mobility.

Through the literature review, the ED Practices WG prioritized five questions (listed below) for meeting participants to discuss during the following breakout group session.

- **Question 1:** What patient-centered metrics best measure the impact of ED interventions for PLWD?
- **Question 2:** How do social determinants of health, such as race, ethnicity, wealth, and access to medical care, impact delivery of optimal ED care for PLWD?
- **Question 3:** What is the impact of length of stay in waiting rooms and the total length of stay in the ED on PLWD? How is this effect best mitigated?
- **Question 4:** Which environmental or operational changes to the ED best improve optimal ED care for PLWD?
- **Question 5:** What are the knowledge and training gaps for emergency clinicians and nonclinical staff regarding optimal care for PLWD?

ED Practices Breakout Groups Debrief

Following the overview presentation, meeting participants transitioned into four breakout groups to discuss the five questions crafted and prioritized by the ED Practices WG and to identify any necessary edits or additions to the questions to ensure that they accurately exemplify the research priorities in this focus area. The following sections detail the answers and suggestions presented by each Breakout Group.

Breakout Group 1

Breakout Group recommended including financial measures in Question 1, such as the costs and benefits of ED interventions. They suggested that a better understanding of the financial benefits of ED care improvements may increase availability of funding for related research. They also discussed incorporating language into Question 1 related to considering physical and chemical restraints as potential outcomes for PLWD in the ED. Participants also discussed whether patient navigator services may be useful to evaluate outcomes of Question 2, noting that the evaluation of these services could be better standardized; however, some rural healthcare systems may not have access to these services. Breakout Group 1 suggested assessing policy and regulatory changes as part of the operational changes mentioned in Question 4, including how to better triage PLWD and include other ED staff to improve practices. They also recommended incorporating a new question with the following language: What are the return on investment items that can also improve patient-centered outcomes?

Breakout Group 2

Breakout Group 2 offered the following recommended edits to the priority questions:

- Incorporate "care partner-centered metrics" (e.g., trust) into Question 1.
- Update Question 2 to state "impact the *receipt* and delivery of care" and transform the question to focus more on the patient rather than population level; the latter level is currently suggested by the phrase "social determinants of health."
- Include language related to upstream factors, as well as environmental and operational changes, in Question 4.
- Combine Questions 3 and 4.
- Expand the ED Practices' scope to include alternative destinations to receive care beyond the ED

Participants discussed whether the issues that led the PLWD to visit the ED should also be included in the "environmental or operational changes" mentioned in Question 4. They also endorsed the current language of Question 5, stating that the language is appropriately broad.

One patient advocate noted that resources detailing communication strategies for PLWD exist.

Breakout Group 3

Breakout Group 3 focused on Question 4 and identified the need for better scientific support for environmental changes that may improve PLWD experiences in the ED, such as non-slick surfaces, clocks, and special lighting, which are often found in nursing homes. Operational changes that may deserve further study include technologically supported care, such as headphones to limit noise overstimulation, a card programmed with information about the PLWD to inform the physician of a care plan (including "what matters most" to that PLWD) and facilitate communication, or the development of dementia-specific templates in EHRs. Participants noted that the language in Question 5 should be more focused on empathy, which may not be susceptible to training, rather than on training needs. Finally, the group observed that all questions could apply to many populations beyond PLWD and thus recommended more fully focusing follow-up work on PLWD specifically.

One patient advocate noted that noise-cancelling headphones may be helpful to PLWD in ED settings; however, this approach may not be appropriate for all PLWD, as some may find the use of headphones difficult or uncomfortable.

Breakout Group 4

Breakout Group 4 noted that the priority questions appeared very broad, but agreed that this breadth was likely intentional and useful for casting a wide research net. Breakout Group 4 thus recommended updating Question 3 include language relating to triage practices and their impact on length of waiting room stay. Breakout Group 4 also recommended updating some of the priority questions and incorporating new questions (summarized below).

- Updated Question 1: How can we best evaluate, in a patient-centric manner, the impact of ED interventions for PLWD? This change would remove the overly technical term “metric,” which does not seem like a patient-oriented approaches.
- Updated Question 2: How do various identity-based factors, including cognitive impairment and social determinants of health, impact the delivery of ED care of PLWD? This change would avoid conflating identity with social determinants of health and would prevent the question from excluding lesbian, gay, bisexual, transgender and queer (LGBTQ) individuals and those with cognitive impairments.
- Updated Question 4: Which environmental or operational changes to the ED best improve ED care for PLWD? Consider addressing the inherent chaos of the ED, system-level changes and workflow practices, and timing of arrival/admission (including time of day and time of week).
- Updated Question 5: How can gaps in training and dementia care competencies among clinical and nonclinical staff be addressed in ways that facilitate sustainable improvements in care delivery for PLWD? Training should focus on behavior change among staff; merely increasing knowledge is inadequate to initiate and sustain changes in care delivery.
- New Question: How can we adapt best care practices from other care settings for the ED setting? What does the literature convey and how can those findings improve best practices?)
- New Question: Medications are an important aspect of optimal care. How can medications be addressed in the ED?

Breakout Group 4 recommended that optimal care in the ED should be a research focus of the ED Practices WG.

Discussion

Participants reemphasized a theme brought up during previous discussions, which was the importance of not limiting innovation to current technology and of assessing the feasibility and efficacy of new technology, particularly given its potentially different impacts across individuals or across people at different stages of disease. Participants noted that headphones for PLWD could be worth studying to help minimize ED noise or other environmental factors that may be overwhelming or distressing. In addition, instruments that improve hearing, such as hearing aids or amplifiers, may also be useful for PLWD with hearing issues. Participants observed that such technological changes may require focusing on systemic change in order to achieve better individual-level outcomes. In some cases, that systemic change might need to happen outside the ED (e.g., in CMS reimbursement or other public policy) in order to shape what is possible within the ED. Engaging other stakeholders may be essential to secure buy-in to such changes.

Session 4 Priority Question Voting Results

The initial priority questions were updated based on Breakout Group discussions. Meeting attendees who participate in the ED Practices WG, as well as other GEAR WGs, submitted votes online in order to prioritize the five updated detection-related questions. These scientific question priorities will be included in future RFAs in order to help applicants understand the target goals of GEAR-supported research projects. The final rank-order of the questions is shown below:

ED Practices

1. How can we best evaluate in a patient-centric and care partner-centric manner the impact of ED interventions for PLWD?
2. Which environmental, operational, personnel, system, or policy changes best improve ED care for PLWD?
3. How can gaps in training and dementia care competencies among clinical and non-clinical staff be addressed in ways that achieve sustainable improvements in care delivery for PLWD?
4. How do various community and identity-based factors, including cognitive impairment, and social determinants of health impact delivery and receipt of ED care for PLWD?
5. What economic or other implementation science measures address viability of optimal ED Care practices for PLWD?

Closing Remarks

Dr. Manish Shah thanked participants for attending and actively participating in the meeting's breakout groups. Dr. Ula Hwang notified participants that over the upcoming week, WG members absent from this meeting will vote on each of the priority questions posed during today's meeting. Monthly WG meetings will continue to finalize manuscripts for each of the WG's research areas' priorities and gaps. GEAR leadership will release GEAR 2.0 RFAs to address each of these prioritized research areas during October.

The following themes emerged across all four sessions.

- The ED's detection role is to screen for dementia, not diagnose dementia.
- Care for PLWD must incorporate feedback from PLWD themselves, care partners, clinicians, and community partners, as well as cross-talk between each of these groups. In addition to the importance of communicating with PLWD and their care partners, communication among physicians is essential to optimal care for PLWD.
- The barriers to and facilitators of emergency care for PLWD, as well as the unintended consequences of current care practices, must be understood in order to improve those practices. Further study is needed to evaluate care transition strategies, in particular, for all PLWD. Best practices from clinical care settings outside of the ED may be relevant to the ED and GEAR's efforts and actionable solutions.
- ED care must involve developing trust with PLWD, care partners, clinicians, and the overall health care system. ED staff must facilitate shared decision-making with PLWD and their care partners, regardless of dementia severity.
- Assessing identity-based factors—including cognitive impairment—and social determinants of health must be part of emergency care delivery for PLWD. Research relating to ED care practices must address how care can be tailored to disadvantaged and vulnerable populations.
- Identifying how public policies can incentivize better ED care for PLWD is critical.

- Researchers need to continue to interrogate innovative solutions (i.e., “think outside the box”), rather than be constrained to what currently seems feasible, in order to provide the best care to PLWD in the ED.

Based on the importance of the relationship between clinicians, PLWD, and “care partners,” participants concluded by reflecting on the multiple terms used throughout the meeting to refer to family members or friends without dementia who help PLWD during ED care visits. They emphasized that the term care partner is often preferred because it conveys collaboration rather than oversight and can encompass more roles than other similar terms, such as carer, care provider, or care advocate.

Post-Conference Reflections by Persons Living With Dementia and Care Partner Participants

Following the adjournment of the meeting, GEAR leadership and coordinators held a session to hear conference-specific feedback from attending patient advocates and care partners. During this session, patient advocates and care partners provided the following feedback:

- The breakout sessions during which meeting participants were able to discuss major issues related to PLWD care in EDs was highly informative and effective; however, the post-debrief sessions during which WG members updated the priority questions with feedback from meeting participants was rushed and could have been given more time in the agenda.
- A countdown timer could be incorporated into the slide deck to inform meeting participants of the time remaining in a break.
- Patient advocates expressed gratitude for including them in the shaping of research priorities and allowing them to share their stories.
- Patient advocates recommended including additional stakeholders from the reimbursement field of the healthcare system.
- Patient advocates requested that materials generated from the meeting, including summaries and links provided in the chat transcript, be provided via email or mail.
- Patient advocates noted that accessing the voting polls and reading the text on the poll website were both difficult at times and that process could be improved.
- One patient advocate recommended continuing to consider aggregate populations in future research priorities.
- One patient advocate noted that each Breakout Group used different terminologies to refer to the same components of ED care and recommended developing consistent terminologies.
- Patient advocates noted that the overall meeting was rushed during certain portions, which caused PLWD to feel that they were continuously trying to keep up with the speed of the meeting.
- One patient advocate noted that the National Alzheimer’s Project Act will soon release recommendations on dementia-related terminologies, such as those for

caregivers/carers/care partners, and recommended that GEAR follow those recommendations.

- Overall, patient advocates praised the efforts of GEAR and recommended that future dementia-related conferences follow a similar model to that used by GEAR.

Appendix 1: Participants and Attendees

Neelum Aggarwal, MD, Rush University
Heather Allore, PhD, Yale University
Amy Aloysi, MD, MPH, Icahn School of Medicine at Mount Sinai
Fernanda Bellolio, MD, MS, Mayo Clinic
Mike Bellville, Patient Advocate, Dementia Action Alliance, Dementia Alliance International, Alzheimer Association
Emmy Betz, MD, MPH, University of Colorado
Kevin Biese, MD, MAT, University of North Carolina, Chapel Hill
Cynthia Brandt, MD, MPH, Yale University
Ryan Carnahan, PharmD, MS, University of Iowa
Chris Carpenter, MD, MS, Washington University of St. Louis School of Medicine
David Carr, MD, Washington University of St. Louis School of Medicine
Jennie Chin Hansen, MSN, Milken Institute, California Department of Health and Human Services, and CommonSpirit Health
Jeff Dussetschleger, DDS, MPH, Yale University
Dwayne Dobschuetz, APN, MSN, RN, Northwestern University Feinberg School of Medicine
Scott Dresden, MD, MS, Northwestern University Feinberg School of Medicine
Michael Ellenbogen, Patient Advocate, Us Against Alzheimer's, Milken Institute
Marcus Escobedo, MPA, The John A. Hartford Foundation
Jason Falvey, DPT, PhD, University of Maryland
Beverley Foster, Patient Advocate
Cameron Gettel, MD, Yale University
Angela Gifford, MA, University of Wisconsin-Madison
Heidi Gil, LiveWell
Andrea Gilmore-Bykovskyi, PhD, RN, University of Wisconsin-Madison
Elizabeth Goldberg, MS, ScM, Brown University
Jin Han, MD, MSc, Vanderbilt University School of Medicine
James Hardy, MD, University of California, San Francisco
Nicki Hastings, MD, Duke University
Jon Mark Hirshon, MD, PhD, MH, University of Maryland School of Medicine
Ly Hoang, University of Wisconsin-Madison
Tess Hogan, MD, University of Chicago Medical Center
Will Hung, MD, MPH, Icahn School of Medicine at Mount Sinai
Ula Hwang, MD, MPH, Yale University
Eric Isaacs, MD, Zuckerberg San Francisco General Hospital and Trauma Center
Navenna Jaspal, University of Wisconsin-Madison
Deb Jobe, Patient Advocate, National Alzheimer's Association Early Stage Advisory Group
Jerry Johnson, MD, University of Pennsylvania
Kathleen Kelly, MPA, Family Caregiver Alliance
Maura Kennedy, MD, Massachusetts General Hospital
Amy Kind, MD, PhD, University of Wisconsin-Madison

Laura Lacritz, PhD, UT Southwestern Medical Center
Jesseca Leggett, MBA, Washington University in St. Louis
Adriane Lesser, MS, West Health
Nancy Lundebjerg, MPA, American Geriatrics Society
Michael Malone, MD, Aurora Health Care and University of Wisconsin-Madison
Aaron Malsch, RN, MSN, GSNCS-BC, Advocate Aurora Health
Michelle Moccia, DNP, St. Mary Mercy Hospital
Monica Moreno, PhD, MSW, University at Albany, State University of New York System
Nancy Morrow-Howell, PhD, MSW, Washington in St. Louis Brown School
Armin Nowroozpoor, MD, Yale University
Brenda Oiyemhonlan, MD, MHSA, MPH, The Permanente Medical Group, Inc
William Perry, PhD, University of California, San Diego
Beth Prusaczyk, PhD, MSW, Washington University in St. Louis
Kristin Rising, MD, MS, Thomas Jefferson University Hospitals
Bob Savage, Patient Advocate, LiveWell
Manish Shah, MD, MPH, University of Wisconsin-Madison
Nina Silverberg, PhD, Alzheimer's Disease Research Centers
Rani Synder, PhD, MPA, The John A. Hartford Foundation
Tresa Spencer, PhD, Jefferson Neurobehavioral Group and National Academy of Neuropsychology
Laura Stabler, MPH, Geriatric Emergency Department Collaborative
Conor Sullivan, MD, Geriatric Emergency Department Collaborative
Joe Suyama, MD, University of Pittsburgh Medical Center
Jeremy Swartzberg, MD, Kaiser Permanente
Zachary Taylor, Northwestern University
Vaishal Tolia, MD, MPH, University of California, San Diego
Allan Vann, MS, EdD, Patient Advocate
Teresa Webb, Patient Advocate, Association for Frontotemporal Dementia
Susan Zieman, MD, PhD, National Institute on Aging