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The Geriatric Emergency care Applied Research (GEAR) Network Approach: A Protocol To Advance Stakeholder Consensus and Research Priorities in Geriatrics and Dementia Care in the Emergency Department

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The Geriatric Emergency care Applied Research (GEAR) Network Approach: A Protocol To Advance Stakeholder Consensus and Research Priorities in Geriatrics and Dementia Care in the Emergency Department

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58 On behalf of The GEAR* and GEAR 2.0** Networks
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For peer review only

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ABSTRACT

Introduction

Increasingly, older adults are turning to emergency departments (EDs) to address health care needs. To achieve these research demands, infrastructure is needed to both generate evidence of intervention impact and advance development of implementation science, pragmatic trials evaluation, and dissemination of findings from studies addressing the emergency care needs of older adults. The Geriatric Emergency Care Applied Research Network (<https://gearnetwork.org>) has been created in response to these scientific needs – to build a transdisciplinary infrastructure to support the research that will optimize emergency care for older adults and persons living with dementia (PLWD).

Methods and Analysis

In this paper we describe the GEAR Network infrastructure and its approach with scoping reviews to identify research and clinical gaps and then come to consensus-driven research priorities by a transdisciplinary taskforce of stakeholders that includes patients and care partners. We describe how priority topic areas are ascertained, the process of conducting scoping reviews with integrated academic librarians performing standardized searches and providing quality control on reviews, input and support from the taskforce, and conducting a large-scale consensus workshop to prioritize future research topics. The GEAR Network approach provides a framework and systematic approach to develop a research agenda and support research in geriatric emergency care.

Ethics and dissemination

This is a systematic review of previously conducted research; accordingly, it does not constitute human subjects research needing ethics review. This review will be prepared as a manuscript and submitted for publication to a peer-reviewed journal, and the results will be presented at conferences.

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Strengths and limitations of the study:

- The inclusion of transdisciplinary stakeholder participants as part of the scoping review and consensus process to identify research gaps and priorities.
- Cross coordination with medical librarians of scoping review searches.
- Creation of a Health Equity Advisory Board to ensure meaningful inclusion of diverse populations in studies focused on the emergency care of people living with dementia.
- A well-defined search strategy created by a team of academic research librarians to search a broad group of databases.
- Small body of published literature in topic areas.

INTRODUCTION

Increasingly, older adults are turning to emergency departments (EDs) to address health care needs.^{1,2} Older adults (aged 65 and older) in the United States visit the ED at a rate of 51.1 per 100 persons per year.³ Recommendations to transform EDs to better care for older adults have included redesigning services and processes.⁴⁻⁶ Geriatric emergency care and Geriatric EDs (GEDs) have emerged over the past decade as innovative solutions to better provide emergency care for older adults.^{4,6-8} However, many of the processes, protocols, and care models targeting older patients with emergency care remain untested in the unique ED setting. Consequently, *the impact of geriatric emergency care for older adults is unknown.*^{9,10} Further, novel interventions and best practices tailored to the ED setting need to be developed for both older adults and persons living with dementia (PLWD). To achieve these research demands, infrastructure is needed for GEDs to both generate evidence of intervention impact and advance development of implementation science, pragmatic trials evaluation, and dissemination of findings from these studies.¹¹

The Geriatric Emergency Care Applied Research (GEAR) Network was created in response to these scientific needs – to build a transdisciplinary infrastructure to support the research that will optimize emergency care for older adults and PLWD.¹² The GEAR Network (<https://gearnetwork.org>) is supported by the National Institute on Aging (NIA) and partner organizations, The Gary and Mary West Health Institute and The John A. Hartford Foundation (jointly on the The Geriatric Emergency Department Collaborative grant) with two phased awards: GEAR (R33 AG058926) and GEAR 2.0 - Advancing Dementia Care (GEAR 2.0 ADC) (R61 AG069822). In the first phase of both awards, key stakeholders from emergency medicine,

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2
3 geriatrics, nursing, psychiatry, pharmacy, social work, individuals representing health care
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5 systems, clinicians, researchers, medical specialty organizations, advocacy organizations,
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7 caregivers, older adults, and people living with dementia to identify consensus-driven research
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9 priorities that will improve the care of older adults (GEAR). GEAR 2.0 ADC added PLWD and
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11 care partners to the team. The second phase consists of pilot grant funding to support
12
13 investigators that advance research priorities identified by stakeholder consensus.
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18 The original GEAR project (hereafter referred to simply as GEAR) is dedicated to
19
20 improving ED care of the older adult and focused on the priority topics of: care transitions,
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22 cognitive impairment – delirium, medication safety, elder abuse, and falls. Four of the five GEAR
23
24 research priorities have already been published using this approach.¹³⁻¹⁶ GEAR 2.0 ADC is
25
26 focused on optimizing emergency care for persons living with dementia and their care partners
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28 in the priority areas of: ED practices, ED care transitions, detection, and communication and
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30 shared decision making.
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35 In this paper we describe the Phase 1 methods used by GEAR 2.0 ADC to identify
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37 consensus-driven research priorities, which were based on methods used for GEAR. We
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39 describe how we identified the priority topic areas, conducted scoping reviews in each topic
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41 area while integrating input from a transdisciplinary stakeholder taskforce, integrated academic
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43 librarians in the review process to perform standardized searches and provide quality control,
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45 and conducted a large-scale consensus conference to prioritize future research. The GEAR
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47 Network approach may be valuable for other specialties, disciplines, and organizations
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49 attempting to identify research and practice gaps, generate evidence, build collaborations, and
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51 target high-yield research questions to optimize the care of older adults.
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METHODS / DESIGN

GEAR 2.0 ADC Design and Structure

Like GEAR, GEAR 2.0 ADC is a phased program that provides infrastructure to the support mission of increasing transdisciplinary research to improve emergency care for persons living with dementia and their care partners. The organizational structure of GEAR 2.0 ADC (Figure 1) consists of committees that guide operations, a taskforce of stakeholder members that join workgroups and participate in the consensus conference during the first phase (2 years), and Cores that support training and expert consultation for pilot studies that will be conducted during the second phase (3 years).

The Executive Committee

GEAR 2.0 ADC is operationally coordinated by the Executive Committee that oversees and guides the program and activities in both phases. The Executive Committee is led by geriatric emergency medicine investigators who also lead one of the 4 priority topic workgroups. Each of these leads were selected based on geriatric emergency medicine expertise and the concurrent engagement of local Alzheimer's Disease Research Center faculty at their sites. These investigators supervise the GEAR 2.0 ADC efforts and meet virtually on a biweekly basis.

The Oversight Committee

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3 The Oversight Committee consists of content experts in geriatrics, emergency medicine,
4 and Alzheimer's Disease and Related Disorders (ADRD) that provides high-level guidance to the
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6 Executive Committee during quarterly meetings. Representatives from the NIA also participate
7
8 in these meetings to hear updates and progress of GEAR 2.0 ADC activities. The Oversight
9
10 Committee provides interdisciplinary guidance on the project direction, content and research
11
12 approaches, and future directions to address cross-disciplinary gaps highlighted by the
13
14 American Geriatrics Society conference series.¹⁷
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23 Health Equity Advisory Board

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25 To address the need for greater equity in emergency care research in geriatrics and
26
27 dementia care both with regards to PLWD, care partners, and researchers, a Health Equity
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29 Advisory Board (HEAB) was created. The HEAB provides guidance and feedback on GEAR 2.0
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31 ADC activities, to ensure meaningful inclusion of diverse populations in studies focused on the
32
33 emergency care of people living with dementia. HEAB members include PLWD, their caregiver
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35 and care partners, advocates, and stakeholders all from underrepresented populations or
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37 groups. Current board members include individuals that are African American, Hispanic, Asian,
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39 and lesbian. The HEAB will follow the NIA Health Disparities Research Framework¹⁸ approach
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41 and will work with partner organizations like the IMPACT (Imbedded Pragmatic Alzheimer's
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43 disease and AD-Related Dementias Clinical Trials) Collaboratory, an organization that is
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45 developing strategies to address diversity and inclusion in studies focused on PLWD.¹⁹
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54 Project Team Staff

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3 GEAR 2.0 ADC activities are supported by smaller project teams where each of the
4 Executive Committee leads are located. Local project team members include a research
5 coordinator and academic medical school librarian to facilitate GEAR 2.0 ADC activities, the bulk
6 of which includes including conducting the scoping reviews. Additional activities of the
7 research coordinators include coordinating communication with all members, and organizing
8 meetings (including presentations, recordings, minute preparation).
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20 *Patient and Public Involvement Statements:*

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23 Throughout the Methods, the involvement, inclusion, and representation of patients,
24 and public partners are described. The GEAR 2.0 ADC Taskforce and Workgroups are
25 transdisciplinary groups of stakeholders committed to improve the emergency care of PLWD.
26 Members were identified to participate based on content expertise, their positions in partner
27 organizations, and referrals from other invited members. The Executive Committee invited
28 participants to ensure diversity of background and expertise while ensuring a manageable
29 group size. They include emergency physicians, geriatricians, neurologists, psychiatrists,
30 neuropsychologists, nurses, social workers, pharmacists, physical therapists, patient advocates,
31 and most importantly PLWD and their care partners.
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47 GEAR 2.0 ADC Taskforce and Workgroups

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50 The GEAR 2.0 ADC Taskforce is a transdisciplinary group of stakeholders committed to
51 improve the emergency care of PLWD. Members were identified to participate based on
52 content expertise, their positions in partner organizations, and referrals from other invited
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3 members. The Executive Committee invited participants to ensure diversity of background and
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5 expertise while ensuring a manageable group size. They include emergency physicians,
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7 geriatricians, neurologists, psychiatrists, neuropsychologists, nurses, social workers,
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9 pharmacists, physical therapists, patient advocates, and most importantly PLWD and their care
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11 partners. (Figure 2)
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15 Taskforce members participate on one or more workgroups that represented research
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17 and clinical practice priorities in four topics (see below for how these topics were chosen):
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- 20 1. Optimal ED care practices for PLWD and their caregivers (ED Practices)
- 21 2. Optimal ED care transitions for PLWD and their caregivers (ED Care Transitions)
- 22 3. Approaches to identify ED PLWD (diagnosed and undiagnosed ADRD) (Detection)
- 23 4. Approaches to communication and shared decision making in ED treatment and
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25 disposition for PLWD and their caregivers (Communication and decision making).
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38 Approach

39 GEAR 2.0 ADC operational overview

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42 During the first phase, GEAR 2.0 ADC identified and prioritized research by completing
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44 scoping reviews in each of the priority topics and then held a two-day consensus conference of
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46 key stakeholders who discussed and voted on research priorities to optimize emergency care
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48 for PLWD. The GEAR Network Consensus Conference approach is modeled after the Cornell
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50 Institute for Translational Research on Aging (CITRA) process for developing stakeholder-based
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3 translational research agendas in aging.²⁰ Unlike CITRA, the GEAR Network approach has more
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5 extensive preparatory work prior to the consensus conference that includes completion of
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7 scoping reviews in pre-selected priority areas prior to the Consensus Conference. Completion
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9 of the scoping review required: 1. Proposing initial research priorities in each of the domains. 2.
10
11 Using a Population, Intervention, Comparison, Outcome (PICO) framework for the research
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13 questions to conduct structured literature searches with academic librarians to identify
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15 publications related to the domains (Round 1 priority research questions), 3. Summarizing the
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17 most recent scientific reviews of ED-based trials, observational, and/or retrospective studies (if
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19 any) that address the priority area, 4. Extracting major conclusions from relevant literature
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21 identified or other systematic reviews related to the PICO question. The results of the scoping
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23 reviews were then used as the basis for discussion and considerations of research priorities at
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25 the consensus conference.
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32 During the second phase, GEAR 2.0 ADC will fund pilot studies that encourage
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34 transdisciplinary collaboration to address the research priorities ranked by the stakeholders
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36 from the first phase.
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42 Priority Domain Determination

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44 GEAR 2.0 ADC Taskforce members ranked priority topics in December 2019 during the
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46 grant proposal preparation process. The Executive Committee proposed the multiple priority
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48 topics which the Taskforce ranked. These were then emailed as a survey to Taskforce members
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50 to rank the importance of each topic and the top ones were selected to be the focus of GEAR
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3 2.0 ADC activities. Based on past experience in GEAR, the decision was made to limit efforts to
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5 four workgroups based on capacity and workload.
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10 Workgroup Pre-Conference Activities

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13 Each workgroup was led by an Executive Committee member lead and supported by the
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15 Project Team Staff. At the study kickoff meeting, Taskforce members were invited to participate
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17 in any of the four workgroups representing research and practice priority domains. Taskforce
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19 members joined workgroups based on their interests and expertise, noting their preferences
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21 through an online survey. Though most requests were honored, some respondents were
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23 assigned to non-primary choices to ensure diversity of background and maintain workable
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25 group sizes of 12-14 participants. While participants were encouraged to only engage with one
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27 group, a number engaged in multiple groups.
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33 Each workgroup's leader developed a charter document that consisted of a description
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35 of the workgroup's topic, goals, meeting dates, membership list, as well as expectations of both
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37 group leadership and participants. All workgroups met monthly for one hour, while work
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39 continued asynchronously through emails moderated by the group leadership. Files are
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41 accessible through cloud-based file sharing tools and servers to provide a single source of
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43 information for all members. These workgroup meetings served to review the progress of the
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45 project, to discuss and reflect on project findings, and to frame project directions. Workgroups
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47 particularly had extensive discussions to develop key questions and identify research gaps using
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49 the PICO approach.²¹
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Phase 1: Scoping Review Process

In preparation for the GEAR 2.0 ADC Consensus Conference, scoping reviews were conducted in the four domains. We followed the PRISMA ScR – Scoping review checklist process to explore both the breadth of literature in this area and identify the knowledge and practice gaps.²² Scoping reviews are preferred for this type of work as they incorporate a wider range of literature than systematic reviews and can provide more synthesized ideas for future systematic reviews.^{22, 23}

Development of PICO Research Questions

Each workgroup brainstormed potential PICO questions within their domains. The workgroups iteratively refined and reviewed the questions and then submitted them to the Executive Committee for review. Each workgroup had approximately 20 questions. The Executive Committee, through joint discussion among the workgroup leads, ensured that questions were distinct. The full Taskforce ranked questions for each workgroup via an online survey (Qualtrics). A respondent weighting system was used to identify the top research questions with workgroup members' ranking weighted double that of other taskforce members. The top two questions were then formatted using the PICO approach.²¹ (Tables 1-4)

Table 1. Communication and Decision-Making PICO Research Questions

Preliminary PICO Questions	Final Two PICO Questions
1. As a decision-making strategy, does accelerated triage for patients with severe dementia improve the process or outcomes of ED care? 2. How does “communication and decision-making” differ for persons with dementia compared to persons without dementia (examples: obtaining information, ascertaining pain severity)?	Question 1: How does communication and decision-making differ for persons with dementia compared to persons without dementia?

3. How should presenting complaint, dementia severity, underlying frailty/vulnerability or other patient-level factors influence the ED communication strategy?
4. Are there specific medical communication strategies (such as “Teach Back” or next day telephone follow-up) that improve the process or outcomes of ED care in persons with dementia?
5. Is safe, effective, and efficient Shared Decision Making possible in persons with dementia or other cognitive impairment?
6. How frequently (and to what extent) do overlying sensory deficits (hearing impairment, vision problems) confound patient-physician communication during episodes of emergency care in persons with dementia?
7. Are members of the healthcare team (nurse, social worker, physician extenders, pharmacist, and/or physicians) who receive specific training in how to communicate with and treat dementia patients able to communicate more effectively with dementia patients and their caregivers?
8. Do patients and care partners who are unaware of or seemingly in denial of a dementia diagnosis benefit from rapid referral for a 2nd opinion to a dementia clinic (MDC or GAC)?
9. What approaches are effective and accessible (considering health literacy needs, etc.) for providing education to patients and caregivers in the ED about the diagnosis of dementia and accessible local resources in the community?
10. How can emergency medicine providers ascertain when the caregiver does or does not understand the patient’s baseline condition or vulnerability to stresses of illness or injury (or pharmacological interventions)?
11. When (and how) do emergency medicine providers seek additional details from caregiver?
12. What cognitive impairment diagnosis or findings should be communicated by emergency department providers to inpatient providers and primary care physicians regarding concerns about dementia?
13. What specific resources (home safety assessment, fall prevention, geropsych follow up, social work abuse assessment, Alzheimer’s Association, etc.) should be communicated (and how) to the patient and caregiver to improve quality of care and prevent future ED visits/hospitalizations?
14. What is the potential role(s) of Observation units (short stay visits) in assisting communication and medical decision making in dementia care? Could they reduce the number of ED visits and/or the time patients stay in the ED?
15. How can lack of cultural understanding by ED healthcare providers limit alignment of communication of options and ascertaining comprehension of options?
16. How do patients’ cultural differences influence how dementia resources may be accepted, available and/or followed and how should communication strategies differ among various populations that come to the ED to acknowledge these differences?
17. How does the presence of dementia interact with inequities in emergency medicine healthcare delivery?

Question 2: Are there specific medical communication strategies (such as “teach-back” or next day telephone follow-up) that improve the process or outcomes of ED care in persons with dementia?

Table 2. Detection/ Identification of Dementia/Cognitive Impairment PICO Research Questions

Preliminary PICO Questions	Final Two PICO Questions
<ol style="list-style-type: none"> 1. Which ED patients (diagnosed vs. undiagnosed, by age group) should be screened for cognitive impairment? (mild cognitive impairment (MCI), dementia)? Are there differences by race and ethnicity? 2. How can the ED best identify cognitive impairment? (Best in terms of sensitivity, reliability, practicality, ease and speed of completion, etc.) Are there differences by race or ethnicity? 3. 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.) 4. Can educational programs improve detection of dementia in ED patients? 5. Who in the ED should complete cognitive impairment screenings or assessments? (ED clinicians (physicians, nurses, etc.), non-clinicians (technicians, research assistants, etc.), patients completing self-assessments on interactive tables, etc.) 6. Is there an objective bedside diagnostic test in the ED (i.e., plasma test, bedside EEG, etc.) to improve dementia screening accuracy? (e.g., plasma test) 7. When in the ED care continuum should cognitive screening be done? (before, during, after the ED visit) 8. Can the ED screen for undiagnosed dementia and refer patients for further assessment? Are there differences by race and ethnicity? 9. How to account for language and cultural differences with diverse ED population in existing screening tools for cognitive impairment? 10. Is the electronic health record optimized to alert healthcare providers of patients already diagnosed with dementia? 11. Does identification of patients with dementia change ED outcomes for these patients? 12. What outcomes are associated with undiagnosed dementia in the ED? 13. What outcomes are associated with undetected dementia in the ED? 14. What is the impact (positive / negative) of ED dementia screening? 15. In cases of known dementia, does detection include assessment for patient and caregiver support? 16. What are the ethical responsibilities of the ED clinicians to convey information about screening results versus diagnoses? 17. What are the repercussions about reporting dementia detected in the ED and their impact on subsequent care, patient stigma or anxiety? 18. How do symptoms of cognitive impairment without a diagnosis affect persons with dementia, particularly since diagnostic uncertainty frequently occurs in emergency medicine? 	<p>Question 1: How can the ED best identify cognitive impairment? (Best in terms of sensitivity, specificity, reliability, practicality, easy and speed of completion, etc.) Are there differences by race or ethnicity?</p> <p>Question 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.)</p>

Table 3. Care Transitions PICO Research Questions

Preliminary PICO Questions	Final Two PICO Questions
<ol style="list-style-type: none"> 1. What interventions (e.g., Electronic Medical Record, coaching, follow up; to be defined in the PICO) delivered to ED patients with impaired cognition improve ED to home transitions? (or to other settings like Skilled Nursing Facility/Nursing Home/hospice) 2. What components of interventions delivered to ED patients with impaired cognition improve ED to home transitions? 3. What interventions delivered to caregivers of ED patients with impaired cognition improve ED to home transitions? (or to other settings like Skilled Nursing Facility/Nursing Home/hospice) 4. What components of interventions delivered to caregivers of ED patients with impaired cognition improve ED to home transitions. 5. What elements of care transitions have the greatest negative impact when it comes to the care of PLWD transitioning from ED to a new place (home, facility, unit) 6. What are patient-centered metrics of quality transitions for ED patients with impaired cognition? 7. What predicts an ED patient with impaired cognition for needing support with care transitions / having poor outcomes from care transitions? 8. Would prioritizing ED care for patients with impaired cognition (similar to trauma/stroke) lead to a more positive transition to home (or to other settings)? 9. What are characteristics of the care partner that enable or impede effective care transitions? 10. What are interventions that can be applied across multiple transitions longitudinally that improve the care of PLWD? 11. How do PLWD, care partners, and other stakeholders define care needs and goals specific to ED transitions? 12. Who are the essential personnel required to optimize ED care transitions for PLWD (social work, nursing, ED physician, primary care/inpatient team, care partner, others)? 13. What decisions around care transitions should cognitively impaired patients make? 14. How can ED providers determine if the patient has a safe living environment and, if needed, improve the living situation? 15. What is the most effective form of follow-up for persons with dementia and at what time interval? 16. What interventions optimize ED physician communication to inpatient and primary care providers regarding concerns related to cognition of ED patients? 	<p>Question 1: What interventions delivered to ED patients with impaired cognition and their care partners improve ED discharge transitions?</p> <p>Question 2: What measures of quality ED discharge transitions are important to varying groups of ED patients with impaired cognition and their care partners?</p>

Table 4. Optimal ED Practices PICO Research Questions

Preliminary PICO Questions	Final Two PICO Questions
<ol style="list-style-type: none"> 1. How do emergency care needs differ for PLWD differ from other patients in the ED? 2. What components of ED care improve patient-centered outcomes for PLWD? 3. Possible components may include: ED environment, patient length of stay in the ED, evaluation and identification of delirium, assessment and treatment of pain, management of agitation, scheduling outpatient follow-up, etc. 4. What patient-centered metrics best measure the impact of ED interventions for persons with dementia? 5. Does optimal ED care prevent incident delirium for PLWD in the ED? 6. How does severity of dementia and presence of other health issues impact the optimal delivery of ED care for PLWD? 7. How do social determinants of health such as race, ethnicity, wealth, and access to medical care impact delivery of optimal ED care for PLWD? 8. How frequently are PLWD evaluated for delirium in the ED? 9. How accurately do ED clinicians identify delirium in PLWD in usual practice? 10. What is the accuracy of delirium identification tools for PLWD in the ED? 11. How can rapidly progressive dementia be identified in the ED? Should patients with rapidly progressive dementia be admitted for expedited workup? 12. What are the best pharmacological and non-pharmacological strategies to manage agitation and other behavioral concerns for PLWD in the ED? 13. How adequately is pain controlled in the ED for PLWD? 14. How frequently are alternative measures for pain assessment such as the Behavioral Pain Scale, or Critical Care Pain Observation Tool used in the ED for PLWD? 15. How frequently are alternative measures for pain assessment such as the Behavioral Pain Scale or Critical Care Pain Observation Tool taught to emergency clinicians? 16. How accurate are screening techniques which are commonly used ED for PLWD? Commonly used screening techniques may include techniques to identify delirium, pain, depression, and abuse. 17. What are the knowledge and training gaps for emergency clinicians and nonclinical staff regarding optimal care of PLWD? Non-clinical staff may include personnel such as security, and registration. 18. How can emergency clinicians best interact with care partners to provide optimal ED care for PLWD? 19. How does care partner involvement impact ED care for PLWD? Are these impacts different when care partners are present compared to paid caregivers? 20. What are the impacts of pragmatic approaches to providing acute unscheduled care such as home care, community paramedicine, telemedicine, or 3D telemedicine on patient-centered outcomes for PLWD? 21. How do emergency clinicians best connect PLWD with community resources? 22. When concern for dementia or cognitive impairment is identified in the ED, how do clinicians address concerns with patient autonomy and capacity? Should these concerns be reported to anyone? For example, the patient's family, primary care clinician, or adult protective services. 	<p>Question 1: <i>What components of emergency department care improve patient-centered outcomes for persons with dementia?</i></p> <p>Question 2: <i>How do emergency care needs for persons with dementia differ from other patients in the emergency department?</i></p>

Medical Librarian Collaboration

Medical librarians from each workgroup leads institution working together developed a standardized core search strategy for the workgroups, as well as topic specific modifications for the scoping reviews. Prior studies have demonstrated this collaboration style creates higher quality search strategies and minimizes review bias.²⁴⁻²⁶ To confirm the search strategies developed would capture the articles sought after, exemplar articles were identified. The searches were reviewed to ensure inclusion of these articles.

The librarians worked together to identify relevant bibliographic databases to maximize capture of relevant articles while limiting duplication. Databases searched included Medline (Ovid), Embase, Cochrane Central Register of Controlled Trials, CINAHL, PsychINFO, PubMed Central, Web of Science, and ProQuest Theses and Dissertations. For a list of databases used by the Workgroups, see Table 5. Databases searched by Workgroups. Each site librarian conducted the literature search, identified article duplication, and uploaded the results to Covidence, a systematic review software (Veritas Health Innovation, Melbourne, Australia. Available at www.covidence.org). The scoping reviews for each group are registered on Open Science Framework.²⁷⁻³⁰

Table 5. Databases searched by Workgroups

Database searched	Workgroup			
	Detection	Communication	Practices	Transitions
MEDLINE (Ovid)	X	X	X	X
Embase	X	X	X	X

Cochrane Central Register of Controlled Trials	X	X	X	X
CINAHL (Ebsco)	X	X	X	X
PsycINFO (Ebsco)	X	X	X	
PubMed Central	X	X	X	X
Web of Science	X	X	X	X
ProQuest Theses & Dissertations		X		

The workgroup lead and a trained research associate independently screened the titles and abstracts of all articles uploaded into Covidence for relevance. Articles that were obviously irrelevant to the study questions were excluded. The reviewers adjudicated any disagreements. If they did not agree, a third-party reviewer made the final decision. The full text of articles identified as potentially relevant were then reviewed in the same manner. Data were abstracted from the articles deemed relevant. To ensure consistency in the conduct of the scoping reviews, workgroup leads and project team members discussed progress at the biweekly meetings and communicated frequently through email correspondence.

Phase 1: GEAR 2.0 ADC Consensus Conference

The culmination of the scoping review process resulted in presentations of these synthesized results from each domain at a two-day consensus conference of the full GEAR 2.0 ADC Taskforce in September 2021. At the conference, Taskforce members were mixed and distributed across smaller groups to discuss the findings of the scoping reviews. The goal of

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2
3 these small groups was to provide stakeholder insight and recommendations on the current
4
5 knowledge base and to provide suggestions for future research and pilot grants. After small
6
7 group discussion, there was an opportunity for shared debrief of these breakout sessions. Each
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9 workgroup then incorporated the feedback and themes heard from the small group discussion
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11 to prepare five research priorities, based on the scoping review results and transdisciplinary
12
13 stakeholder recommendations. The full taskforce then ranked these research priorities using an
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15 online survey (Pollevywhere.com). Taskforce members unable to attend the conference were
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17 asked to vote asynchronously, for 100% participation by all Taskforce and Health Equity
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19 Advisory Board members. Results of each scoping reviews, their search methodology, and
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21 ranked research priorities will be published separately.
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30 Copies of the GEAR and GEAR 2.0 ADC Consensus Conference Summaries are available on the
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32 GEAR website: <https://gearnetwork.org/manuscripts-publications/>
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37 Phase 2: GEAR 2.0 ADC Pilot funding

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39 During the second phase, pilot funding opportunities will be made available to
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41 investigators. Proposals for pilot studies must address the research priorities recommended by
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43 the GEAR 2.0 ADC Taskforce and HEAB members from the GEAR 2.0 ADC Consensus
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45 Conference. During this phase, the GEAR 2.0 ADC Cores will become active and support early
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47 research addressing research gaps and priorities recommended by the GEAR 2.0 ADC Taskforce.
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49 In addition to pilot funding, the Research Core, Data and Informatics Core, and Dissemination
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51 and Implementation Core will provide guidance to pilot awardees as they conduct their studies,
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3 including training sessions to enhance and increase transdisciplinary collaboration within and
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5 across the GEAR 2.0 ADC Network. These will be held as virtual training webinars, conferences
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7 and office hours, and bi-monthly research progress meetings where awardees will have the
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9 opportunity to share their study progress with each other.
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15 GEAR 2.0 ADC pilot funding opportunities can be found on the GEAR website:

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17 <https://gearnetwork.org/grants-and-funding-opportunities/>
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23 **DISCUSSION**

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25 In this paper we present a framework establishing an infrastructure to advance geriatric
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27 emergency medicine research. The value of this framework, and more importantly the
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29 representation of key stakeholders, is unique and critical to guide optimally future research
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31 addressing practice gaps that matter to all those engaged in all facets of emergency care for
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33 PLWD and their care partners. It differs from other previous agenda setting processes directed
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35 at geriatric emergency care³¹⁻³⁴ in the following ways: 1. The inclusion of stakeholder
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37 participation as part of the scoping review and consensus process to identify research gaps and
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39 priorities, 2. Cross coordination with medical librarians of scoping review searches, 3. Creation
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41 of a Health Equity Advisory Board to ensure meaningful inclusion of diverse populations in
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43 studies focused on the emergency care of people living with dementia, and 4. Provision of pilot
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45 funding to initiate research in the recommended consensus research priorities.
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52 A significant strength of the GEAR Network approach is the inclusion of patients,
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54 individuals that use the healthcare system, and care partners as part of the process. It is a
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3 priority of the GEAR Network to include their experiences and perspectives and to learn what
4 matters to them about the emergency care they receive. Further, GEAR Network strives to
5 share with these stakeholders' reasons why health and medical care occurs the way it does, to
6 enable them to engage meaningfully, and to integrate their critical feedback and
7 recommendations on the topics throughout the entire GEAR Network approach. For GEAR 2.0
8 ADC, this has even greater relevance coupled with challenges faced by PLWD, all of whom have
9 cognitive impairment with varying degrees of severity. While the PLWD who participate in
10 GEAR 2.0 ADC are in the early stages of dementia and remain high functioning, they, along with
11 care partners and many other stakeholders who are not researchers nor clinicians, are not as
12 familiar with taskforce or agenda setting research processes.

13
14 Preparatory background steps by the GEAR 2.0 ADC Project Team with these non-
15 research and non-clinical stakeholders are necessary to support their full engagement.
16 Following the Empowering Partnership principals of and working with the Livewell Dementia
17 Specialists organization,³⁵ GEAR 2.0 ADC set up several working sessions with the non-
18 researchers and non-clinicians Taskforce members, including separate preparatory video
19 conferences, providing printed folders of all conference materials in advance of the meeting,
20 and providing opportunities for feedback about conference format and to address any
21 questions they might have prior to the conference. There was also an additional debrief
22 session after the GEAR 2.0 ADC Consensus Conference to gather additional suggestions and
23 feedback about the conference from these individuals. When working with PLWD with early to
24 middle stage dementia, it is important to recognize there may be varying degrees of cognitive
25 function that may impact tasks and activities. For example, the survey ranking many potential

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3 questions initially proposed by workgroups required significant mental focus to complete for
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5 individuals of all levels of cognitive function. This was even more challenging for some PLWD
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7 members who found the survey format difficult to comprehend fully. To incorporate their
8
9 input, once the top four choices were identified, their thoughts on each were discussed
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11 separately with them. Concurrently, other PLWD members did not express any difficulty with
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13 the survey. It is important that researchers consider the potential limitations of PLWD in
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15 research engagement and find ways to enable their full participation.
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21 Another innovative feature of the scoping review process in GEAR 2.0 ADC was the
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23 collaboration of research librarians from four different institution sites and their inclusion early
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25 in PICO question development. Each workgroup's assigned librarian participated in meetings
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27 when PICO question development was occurring. This provided unique insight and
28
29 understanding as to the group's thought process that allowed the librarian to craft the
30
31 appropriate search strategy. It was decided that the four librarians would develop a
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33 standardized search for the elements consistent between the groups and then tailor the
34
35 remaining elements for their specific groups. By cooperating on core search development, the
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37 librarians were quickly able to develop a highly effective search strategy, minimizing bias.²⁶ The
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39 standardization of the common elements helped ensure consistency in articles identified
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41 between groups.²⁵
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48 As part of its mission, GEAR 2.0 ADC has also prioritized addressing equity through
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50 diversity and inclusion in its research agenda. The concern is multifactorial as it includes the
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52 diversity and composition of the workgroups, the defining of the questions, and
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54 implementation in the future pilot grants to be offered by GEAR 2.0 ADC. Despite continuous
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3 efforts to increase diversity of the taskforce and while equally split in member gender, the
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5 workgroups and PLWD representatives are overwhelmingly Caucasian. This is a challenge for
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7 many organizations attempting to increase diversity in representation and health equity with
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9 research, especially for PLWD. Within the workgroups, Diversity Equity and Inclusion was
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11 discussed in terms of the patients seen in the ED. The discussions included race, gender,
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13 ethnic/religious affiliation, sex identification, along with the impact of social determinants of
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15 health. Identifying additional workgroup members whose participation would broaden the
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17 groups' diversity would have taken more time than the groups had, thus the decision was made
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19 to create a "Health Equity Advisory Board"(HEAB) of members from underrepresented and
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21 disenfranchised groups to review and provide input on the output of the workgroups and GEAR
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23 2.0 ADC processes. The GEAR 2.0 ADC PIs along with the workgroup leads have developed a
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25 framework for the board that includes quarterly meetings that preview consensus conference
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27 materials to incorporate feedback before the conference and sharing materials and will involve
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29 the HEAB when selecting GEAR 2.0 ADC pilot studies to fund.
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37 Finally, perhaps the most significant and unique feature of the GEAR Network research
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39 infrastructure is its provision of pilot funding for the research priorities generated by its
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41 consensus stakeholder process. Support is directed to build preliminary research and evidence
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43 in clinical and research gaps identified by scoping review processes that were voted by
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45 transdisciplinary members of the field and by patients and their care partners. This novel
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47 approach targets funding for stated and ranked priorities by "putting money where our mouth
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49 is." It is hoped that the funding from these pilot studies will foster interest and research in
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51 needed areas of geriatric- and dementia-related emergency care, increase and diversify the
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3 pool and foci of researchers, and generate preliminary evidence and data for larger scale study
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5 proposals that are critically needed to advance the science of geriatric emergency care.
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8 In summary, the GEAR Network approach provides a framework and systematic
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10 approach to review the literature for research and practice gaps. Further, the GEAR Network
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12 approach gives insight as to how to engage key stakeholders from all facets of caring for older
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14 adults and persons living with dementia to define and state what research priorities matter.
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16 This approach may be used by other disciplines, professions, and specialties to advance
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18 research priorities in aging.
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3 Statements/Declarations
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5
6 *Authors' contributions:*
7

8 All authors read and approved the final manuscript.
9

10 CRC conceived the approach, provided methodological guidance, oversaw the implementation
11 and operations of the approach, and provided review and edits in the writing____
12
13

14 SD organized the implementation and operations of the approach and was a major contributor
15 in writing
16

17 JD organized the implementation and operations of the research approach and was a major
18 contributor in writing the manuscript.
19
20

21 AG organized the implementation and operations of the research approach and was a major
22 contributor in writing the manuscript.
23
24

25 LH organized the implementation and operations of the research approach and was a major
26 contributor in writing the manuscript.
27
28

29 UH secured funding, conceived the approach, organized the infrastructure and partnerships,
30 organized the implementation and operations of the approach, was a major contributor in
31 writing and overseeing the manuscript.
32
33

34 JL organized the implementation and operations of the research approach and was a major
35 contributor in writing the manuscript.
36
37

38 AN organized the implementation and operations of the research approach and was a major
39 contributor in writing the manuscript.
40
41

42 MNS secured funding, conceived the approach, organized the infrastructure and partnerships,
43 organized the implementation and operations of the approach, was a major contributor in
44 writing and overseeing the manuscript.
45
46

47 ZT organized the implementation and operations of the research approach and was a major
48 contributor in writing the manuscript.
49

50
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53 each of which fosters and supports the development of research infrastructures to promote
54 studies that address the research and clinical gaps in the aging process and related health fields
55 through: (1) research performed and proposed through contracts; (2) a program of research
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3 grants and individual and institutional pilot awards; (3) cooperation and collaboration with
4 other Departmental agencies, voluntary organizations, and other institutions; and (4) collection
5 and dissemination of the findings of aging and dementia related studies.
6
7

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9

10 National Institute on Aging [R61 AG069822 (Hwang, Shah)]
11

12
13 Emergency Medicine Foundation [N/A]
14

15 The Gary and Mary West Health Institute [The Geriatric Emergency Department Collaborative]
16

17
18 The John A. Hartford Foundation [The Geriatric Emergency Department Collaborative]
19
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23
24 *Competing interest statements:*

25 CRC – none

26 SD – none

27 JD – none

28 AG – none

29 LH – none

30 UH – none

31 JL – none

32 AN – none

33 MS – none

34 ZT – none
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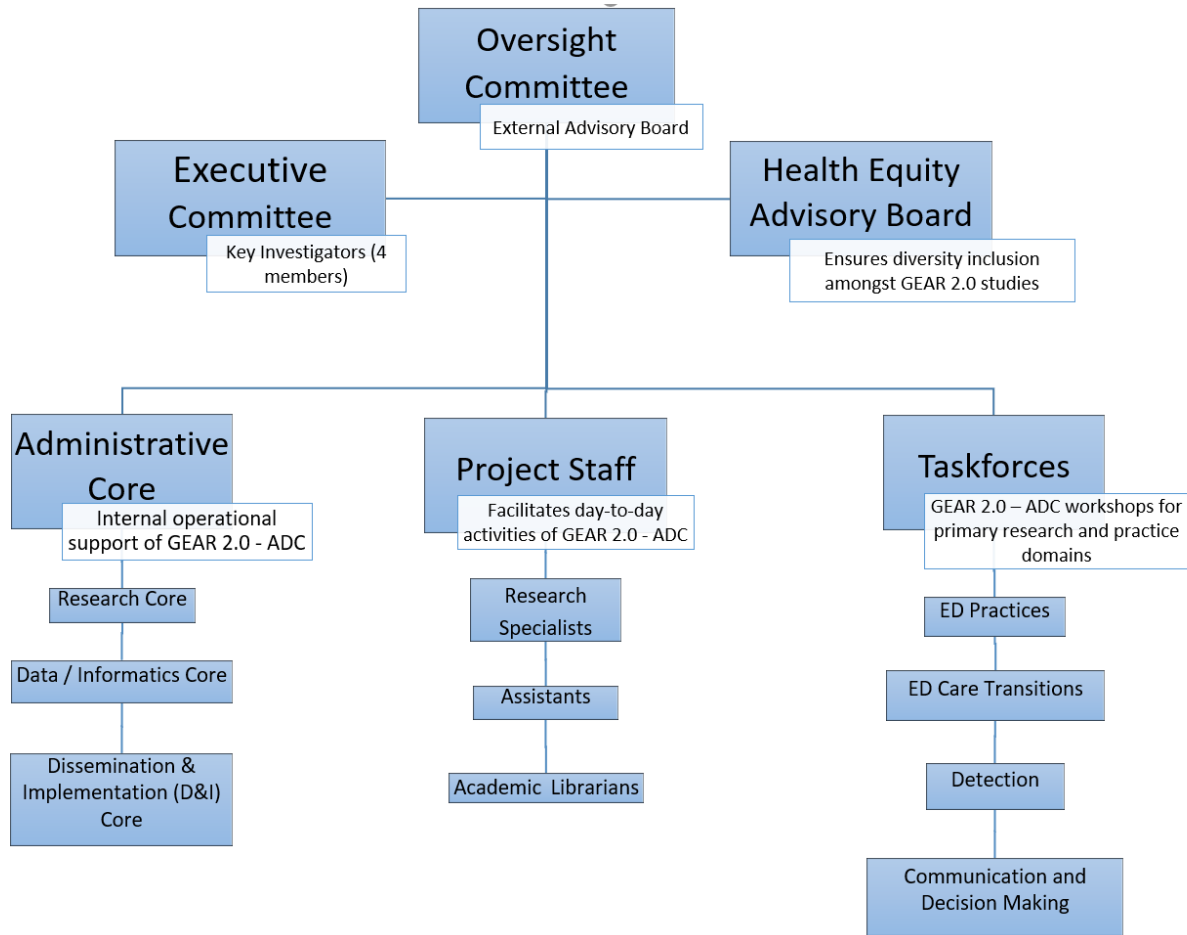
Figure Legends

Figure 1. GEAR 2.0 ADC Organizational Structure

Figure 2. GEAR 2.0 ADC Taskforce Composition

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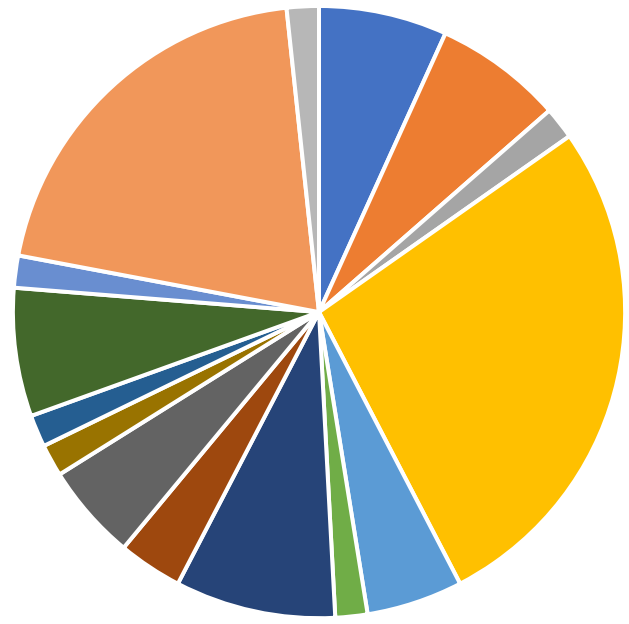


New only

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GEAR 2.0 Stakeholders

- Advocate
- Care Partner
- Educator
- Emergency Physician
- Funder
- Geriatric Psychiatrist
- Geriatrician
- Neuropsychologist
- Nursing
- Pharmacist
- Physical Therapist
- Person Living With Dementia
- Psychologist
- Researcher
- Student



review only

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	3-4
6-7INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	6-7
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	6
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	5
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	13-15
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	14
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	14
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	14
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	15
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	15
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	n/a



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	n/a
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	n/a
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	n/a
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	n/a
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	n/a
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	n/a
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	n/a
Limitations	20	Discuss the limitations of the scoping review process.	n/a
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	n/a
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	22-23

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473. doi: [10.7326/M18-0850](https://doi.org/10.7326/M18-0850).



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The Geriatric Emergency care Applied Research (GEAR) Network Approach: A Protocol To Advance Stakeholder Consensus and Research Priorities in Geriatrics and Dementia Care in the Emergency Department

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Keywords:	Dementia < NEUROLOGY, ACCIDENT & EMERGENCY MEDICINE, GERIATRIC MEDICINE

SCHOLARONE™
Manuscripts

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The Geriatric Emergency care Applied Research (GEAR) Network Approach: A Protocol to Advance Stakeholder Consensus and Research Priorities in Geriatrics and Dementia Care in the Emergency Department

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58 On behalf of The GEAR* and GEAR 2.0** Networks
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For peer review only

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Keywords: Emergency Medicine, geriatrics, dementia, research priorities, stakeholder, consensus

Word Count: 3978

ABSTRACT

Introduction

Increasingly, older adults are turning to emergency departments (EDs) to address health care needs. To achieve these research demands, infrastructure is needed to both generate evidence of intervention impact and advance development of implementation science, pragmatic trials evaluation, and dissemination of findings from studies addressing the emergency care needs of older adults. The Geriatric Emergency Care Applied Research Network (<https://gearnetwork.org>) has been created in response to these scientific needs – to build a transdisciplinary infrastructure to support the research that will optimize emergency care for older adults and persons living with dementia (PLWD).

Methods and Analysis

In this paper we describe our approach to developing the GEAR Network infrastructure, the scoping reviews to identify research and clinical gaps, and its use of consensus-driven research priorities with a transdisciplinary taskforce of stakeholders that includes patients and care partners. We describe how priority topic areas are ascertained, the process of conducting scoping reviews with integrated academic librarians performing standardized searches and providing quality control on reviews, input and support from the taskforce, and conducting a large-scale consensus workshop to prioritize future research topics. The GEAR Network approach provides a framework and systematic approach to develop a research agenda and support research in geriatric emergency care.

Ethics and dissemination

This is a systematic review of previously conducted research; accordingly, it does not constitute human subjects research needing ethics review. This review will be prepared as a manuscript and submitted for publication to a peer-reviewed journal, and the results will be presented at conferences.

Open Science Framework registered DOI: [10.17605/OSF.IO/6QRYX](https://doi.org/10.17605/OSF.IO/6QRYX), [10.17605/OSF.IO/AKVZ8](https://doi.org/10.17605/OSF.IO/AKVZ8),
[10.17605/OSF.IO/EPVR5](https://doi.org/10.17605/OSF.IO/EPVR5), [10.17605/OSF.IO/VXPRS](https://doi.org/10.17605/OSF.IO/VXPRS)

Strengths and limitations of the study:

- The inclusion of transdisciplinary stakeholder participants as part of the scoping review and consensus process to identify research gaps and priorities.
- Cross coordination with medical librarians of scoping review searches.
- Creation of a Health Equity Advisory Board to ensure meaningful inclusion of diverse populations in studies focused on the emergency care of people living with dementia.
- A well-defined search strategy created by a team of academic research librarians to search a broad group of databases.
- Small body of published literature in topic areas.

INTRODUCTION

Increasingly, older adults are turning to emergency departments (EDs) to address health care needs.^{1,2} Older adults (aged 65 and older) in the United States visit the ED at a rate of 51.1 per 100 persons per year.³ Recommendations to transform EDs to better care for older adults have included redesigning services and processes.⁴⁻⁶ Geriatric emergency care and Geriatric EDs (GEDs) have emerged over the past decade as innovative solutions to better provide emergency care for older adults.^{4,6-8} However, many of the processes, protocols, and care models targeting older patients with emergency care remain untested in the unique ED setting. Consequently, *the impact of geriatric emergency care for older adults is unknown.*^{9,10} Further, novel interventions and best practices tailored to the ED setting need to be developed for both older adults and persons living with dementia (PLWD). To achieve these research demands, infrastructure is needed for GEDs to both generate evidence of intervention impact and advance development of implementation science, pragmatic trials evaluation, and dissemination of findings from these studies.¹¹

The Geriatric Emergency Care Applied Research (GEAR) Network was created in response to these scientific needs – to build a transdisciplinary infrastructure to support the research that will optimize emergency care for older adults and PLWD.¹² The GEAR Network (<https://gearnetwork.org>) is supported by the National Institute on Aging (NIA) and partner organizations, The Gary and Mary West Health Institute and The John A. Hartford Foundation (jointly on The Geriatric Emergency Department Collaborative grant (Award number N/A) with two phased awards: GEAR (R33 AG058926 add dates) and GEAR 2.0 - Advancing Dementia Care (GEAR 2.0 ADC) (R61 AG069822 September 2020 – June 2022). In the first phase of both

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3 awards, key stakeholders from emergency medicine, geriatrics, nursing, psychiatry, pharmacy,
4
5 social work, individuals representing health care systems, clinicians, researchers, medical
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7 specialty organizations, advocacy organizations, caregivers, older adults, and people living with
8
9 dementia to identify consensus-driven research priorities that will improve the care of older
10
11 adults (GEAR). GEAR 2.0 ADC added PLWD and care partners to the team. The second phase
12
13 consists of pilot grant funding to support investigators that advance research priorities
14
15 identified by stakeholder consensus.
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20 The original GEAR project (hereafter referred to simply as GEAR) is dedicated to
21
22 improving ED care of the older adult and focused on the priority topics of: care transitions,
23
24 cognitive impairment – delirium, medication safety, elder abuse, and falls. Four of the five GEAR
25
26 research priorities have already been published using this approach.¹³⁻¹⁶ GEAR 2.0 ADC is
27
28 focused on optimizing emergency care for persons living with dementia and their care partners
29
30 in the priority areas of: ED practices, ED care transitions, detection, and communication and
31
32 shared decision making.
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37 In this paper we describe the Phase 1 methods used by GEAR 2.0 ADC to identify
38
39 consensus-driven research priorities, which were based on methods used for GEAR. We
40
41 describe how we identified the priority topic areas, conducted scoping reviews in each topic
42
43 area while integrating input from a transdisciplinary stakeholder taskforce, integrated academic
44
45 librarians in the review process to perform standardized searches and provide quality control,
46
47 and conducted a large-scale consensus conference to prioritize future research. The GEAR
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51 Network approach may be valuable for other specialties, disciplines, and organizations
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3 attempting to identify research and practice gaps, generate evidence, build collaborations, and
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5 target high-yield research questions to optimize the care of older adults.
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10 **METHODS / DESIGN**

11 **GEAR 2.0 ADC Design and Structure**

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17 Like GEAR, GEAR 2.0 ADC is a phased program that provides infrastructure to the
18 support mission of increasing transdisciplinary research to improve emergency care for persons
19 living with dementia and their care partners. The organizational structure of GEAR 2.0 ADC
20 (Figure 1) consists of committees that guide operations, a taskforce of stakeholder members
21 that join workgroups and participate in the consensus conference during the first phase (2
22 years), and Cores that support training and expert consultation for pilot studies that will be
23 conducted during the second phase (3 years). GEAR 2.0 ADC is from June 1, 2020 to May 31,
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40 The Executive Committee

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42 GEAR 2.0 ADC is operationally coordinated by the Executive Committee that oversees
43 and guides the program and activities in both phases. The Executive Committee is led by
44 geriatric emergency medicine investigators who also lead one of the 4 priority topic
45 workgroups. Each of these leads were selected based on geriatric emergency medicine
46 expertise and the concurrent engagement of local Alzheimer's disease Research Center faculty
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3 at their sites. These investigators supervise the GEAR 2.0 ADC efforts and meet virtually on a
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5 biweekly basis.
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10 The Oversight Committee

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13 The Oversight Committee consists of content experts in geriatrics, emergency medicine,
14
15 and Alzheimer's disease and Related Disorders (ADRD) that provides high-level guidance to the
16
17 Executive Committee during quarterly meetings. Representatives from the NIA also participate
18
19 in these meetings to hear updates and progress of GEAR 2.0 ADC activities. The Oversight
20
21 Committee provides interdisciplinary guidance on the project direction, content and research
22
23 approaches, and future directions to address cross-disciplinary gaps highlighted by the
24
25 American Geriatrics Society conference series.¹⁷
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32 Health Equity Advisory Board

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35 To address the need for greater equity in emergency care research in geriatrics and
36
37 dementia care both with regards to PLWD, care partners, and researchers, a Health Equity
38
39 Advisory Board (HEAB) was created. The HEAB provides guidance and feedback on GEAR 2.0
40
41 ADC activities, to ensure meaningful inclusion of diverse populations based on race, gender,
42
43 ethnic/religious affiliation, sex identification, along with the impact of social determinants of
44
45 health in studies focused on the emergency care of people living with dementia. HEAB
46
47 members include PLWD, their caregiver and care partners, advocates, and stakeholders all from
48
49 underrepresented populations or groups. Current board members include individuals that are
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51 African American, Hispanic, Asian, and lesbian. The HEAB will follow the NIA Health Disparities
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3 Research Framework¹⁸ approach and will work with partner organizations like the IMPACT
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5 (Imbedded Pragmatic Alzheimer's disease and AD-Related Dementias Clinical Trials)
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8 Collaboratory, an organization that is developing strategies to address diversity and inclusion in
9
10 studies focused on PLWD.¹⁹ This includes addressing the four key levels of analyses related to
11
12 the NIA health disparities priorities of environmental, sociocultural, behavioral, and biological
13
14 disparities in health for older minority populations. We will incorporate the lifecourse
15
16 perspective, which is a "multidisciplinary approach to understanding the mental, physical, and
17
18 social health of individuals, which incorporates both life span and life stage concepts that
19
20 determine health trajectory and influence population-level health disparities."¹⁸
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28 Project Team Staff

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30 GEAR 2.0 ADC activities are supported by smaller project teams where each of the
31
32 Executive Committee leads are located. Local project team members include a research
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34 coordinator and academic medical school librarian to facilitate GEAR 2.0 ADC activities, the bulk
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36 of which includes including conducting the scoping reviews. Additional activities of the
37
38 research coordinators include coordinating communication with all members, and organizing
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40 meetings (including presentations, recordings, minute preparation).
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47 *Patient and Public Involvement Statements:*

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49 Throughout the Methods, the involvement, inclusion, and representation of patients,
50
51 and public partners are described. The GEAR 2.0 ADC Taskforce and Workgroups are
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53 transdisciplinary groups of stakeholders committed to improve the emergency care of PLWD.
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3 Members were identified to participate based on content expertise, their positions in partner
4 organizations, and referrals from other invited members. The Executive Committee invited
5 participants to ensure diversity of background and expertise while ensuring a manageable
6 group size. They include emergency physicians, geriatricians, neurologists, psychiatrists,
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8 neuropsychologists, nurses, social workers, pharmacists, physical therapists, patient advocates,
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10 and most importantly PLWD and their care partners.
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20 GEAR 2.0 ADC Taskforce and Workgroups

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22 The GEAR 2.0 ADC Taskforce is a transdisciplinary group of stakeholders committed to
23 improve the emergency care of PLWD. Members were identified to participate based on
24 content expertise, their positions in partner organizations, and referrals from other invited
25 members. The Executive Committee invited participants to ensure diversity of background and
26 expertise while ensuring a manageable group size. They include 47 individuals who identified
27 themselves as emergency physicians, geriatricians, neurologists, psychiatrists,
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29 neuropsychologists, nurses, social workers, pharmacists, physical therapists, patient advocates,
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31 and most importantly PLWD and their care partners. (Figure 2 GEAR Taskforce Composition)
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42 Taskforce members participate on one or more workgroups that represented research
43 and clinical practice priorities in four topics (see below for how these topics were chosen):
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- 47 1. Optimal ED care practices for PLWD and their caregivers (ED Practices)
- 48 2. Optimal ED care transitions for PLWD and their caregivers (ED Care Transitions)
- 49 3. Approaches to identify ED PLWD (diagnosed and undiagnosed ADRD) (Detection)
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3 4. Approaches to communication and shared decision making in ED treatment and
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5 disposition for PLWD and their caregivers (Communication and decision making).
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13 **Approach**

14 15 16 17 18 GEAR 2.0 ADC operational overview

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20 During the first phase, GEAR 2.0 ADC identified and prioritized research by completing
21 scoping reviews in each of the priority topics and then held a two-day consensus conference of
22 key stakeholders who discussed and voted on research priorities to optimize emergency care
23 for PLWD. The GEAR Network Consensus Conference approach is modeled after the Cornell
24 Institute for Translational Research on Aging (CITRA) process for developing stakeholder-based
25 translational research agendas in aging.²⁰ Unlike CITRA, the GEAR Network approach has more
26 extensive preparatory work prior to the consensus conference that includes completion of
27 scoping reviews in pre-selected priority areas prior to the Consensus Conference. Completion
28 of the scoping review required: 1. Proposing initial research priorities in each of the domains. 2.
29 Using a Population, Intervention, Comparison, Outcome (PICO) framework for the research
30 questions to conduct structured literature searches with academic librarians to identify
31 publications related to the domains (Round 1 priority research questions), 3. Summarizing the
32 most recent scientific reviews of ED-based trials, observational, and/or retrospective studies (if
33 any) that address the priority area, 4. Extracting major conclusions from relevant literature
34 identified or other systematic reviews related to the PICO question. The results of the scoping
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3 reviews were then used as the basis for discussion and considerations of research priorities at
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5 the consensus conference.
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8 During the second phase, GEAR 2.0 ADC will fund pilot studies that encourage
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10 transdisciplinary collaboration to address the research priorities ranked by the stakeholders
11
12 from the first phase.
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14 15 16 17 18 Priority Domain Determination

19
20 GEAR 2.0 ADC Taskforce members ranked priority topics in December 2019 during the
21
22 grant proposal preparation process. The Executive Committee proposed the multiple priority
23
24 topics which the Taskforce ranked. These were then emailed as a survey to Taskforce members
25
26 to rank the importance of each topic and the top ones were selected to be the focus of GEAR
27
28 2.0 ADC activities. Based on past experience in GEAR, the decision was made to limit efforts to
29
30 four workgroups based on capacity and workload.
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38 Workgroup Pre-Conference Activities

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40 Each workgroup was led by an Executive Committee member lead and supported by the
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42 Project Team Staff. At the study kickoff meeting, Taskforce members were invited to participate
43
44 in any of the four workgroups representing research and practice priority domains. Taskforce
45
46 members joined workgroups based on their interests and expertise, noting their preferences
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48 through an online survey. Though most requests were honored, some respondents were
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50 assigned to non-primary choices to ensure diversity of background and maintain workable
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3 group sizes of 12-14 participants. While participants were encouraged to only engage with one
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6 group, a number engaged in multiple groups.
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8 Each workgroup's leader developed a charter document that consisted of a description
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10 of the workgroup's topic, goals, meeting dates, membership list, as well as expectations of both
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12 group leadership and participants. All workgroups met monthly for one hour, while work
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14 continued asynchronously through emails moderated by the group leadership. Files are
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16 accessible through cloud-based file sharing tools and servers to provide a single source of
17
18 information for all members. These workgroup meetings served to review the progress of the
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20 project, to discuss and reflect on project findings, and to frame project directions. Workgroups
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22 particularly had extensive discussions to develop key questions and identify research gaps using
23
24 the PICO approach.²¹
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32 Phase 1: Scoping Review Process

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34 In preparation for the GEAR 2.0 ADC Consensus Conference, scoping reviews were
35
36 conducted in the four domains. We followed the PRISMA ScR – Scoping review checklist process
37
38 to explore both the breadth of literature in this area and identify the knowledge and practice
39
40 gaps.²² Scoping reviews are preferred for this type of work as they incorporate a wider range of
41
42 literature than systematic reviews and can provide more synthesized ideas for future
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46
47 systematic reviews.^{22, 23}
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52 *Development of PICO Research Questions*

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54 Each workgroup brainstormed potential PICO questions within their domains. The
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workgroups iteratively refined and reviewed the questions and then submitted them to the Executive Committee for review. Each workgroup had approximately 20 questions. The Executive Committee, through joint discussion among the workgroup leads, ensured that questions were distinct. The full Taskforce ranked questions for each workgroup via an online survey (Qualtrics). A respondent weighting system was used to identify the top research questions with workgroup members' ranking weighted double that of other taskforce members. The top two questions were then formatted using the PICO approach.²¹ (Tables 1-4)

Table 1. Communication and Decision-Making PICO Research Questions

Preliminary PICO Questions	Final Two PICO Questions
<ol style="list-style-type: none"> 1. As a decision-making strategy, does accelerated triage for patients with severe dementia improve the process or outcomes of ED care? 2. How does "communication and decision-making" differ for persons with dementia compared to persons without dementia (examples: obtaining information, ascertaining pain severity)? 3. How should presenting complaint, dementia severity, underlying frailty/vulnerability or other patient-level factors influence the ED communication strategy? 4. Are there specific medical communication strategies (such as "Teach Back" or next day telephone follow-up) that improve the process or outcomes of ED care in persons with dementia? 5. Is safe, effective, and efficient Shared Decision Making possible in persons with dementia or other cognitive impairment? 6. How frequently (and to what extent) do overlying sensory deficits (hearing impairment, vision problems) confound patient-physician communication during episodes of emergency care in persons with dementia? 7. Are members of the healthcare team (nurse, social worker, physician extenders, pharmacist, and/or physicians) who receive specific training in how to communicate with and treat dementia patients able to communicate more effectively with dementia patients and their caregivers? 8. Do patients and care partners who are unaware of or seemingly in denial of a dementia diagnosis benefit from rapid referral for a 2nd opinion to a dementia clinic (MDC or GAC)? 9. What approaches are effective and accessible (considering health literacy needs, etc.) for providing education to patients and caregivers in the ED about the diagnosis of dementia and accessible local resources in the community? 10. How can emergency medicine providers ascertain when the caregiver does or does not understand the patient's baseline condition or vulnerability to stresses of 	<p>Question 1: How does communication and decision-making differ for persons with dementia compared to persons without dementia?</p> <p>Question 2: Are there specific medical communication strategies (such as "teach-back" or next day telephone follow-up) that improve the process or outcomes of ED care in persons with dementia?</p>

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4 illness or injury (or pharmacological interventions)?
5 11. When (and how) do emergency medicine providers seek additional details from
6 caregiver?
7 12. What cognitive impairment diagnosis or findings should be communicated by
8 emergency department providers to inpatient providers and primary care physicians
9 regarding concerns about dementia?
10 13. What specific resources (home safety assessment, fall prevention, geropsych
11 follow up, social work abuse assessment, Alzheimer's Association, etc.) should be
12 communicated (and how) to the patient and caregiver to improve quality of care and
13 prevent future ED visits/hospitalizations?
14 14. What is the potential role(s) of Observation units (short stay visits) in assisting
15 communication and medical decision making in dementia care? Could they reduce
16 the number of ED visits and/or the time patients stay in the ED?
17 15. How can lack of cultural understanding by ED healthcare providers limit alignment
18 of communication of options and ascertaining comprehension of options?
19 16. How do patients' cultural differences influence how dementia resources may be
20 accepted, available and/or followed and how should communication strategies differ
21 among various populations that come to the ED to acknowledge these differences?
22 17. How does the presence of dementia interact with inequities in emergency
23 medicine healthcare delivery?
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Table 2. Detection/ Identification of Dementia/Cognitive Impairment PICO Research Questions

Preliminary PICO Questions	Final Two PICO Questions
<ol style="list-style-type: none"> 1. Which ED patients (diagnosed vs. undiagnosed, by age group) should be screened for cognitive impairment? (mild cognitive impairment (MCI), dementia)? Are there differences by race and ethnicity? 2. How can the ED best identify cognitive impairment? (Best in terms of sensitivity, reliability, practicality, ease and speed of completion, etc.) Are there differences by race or ethnicity? 3. 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.) 4. Can educational programs improve detection of dementia in ED patients? 5. Who in the ED should complete cognitive impairment screenings or assessments? (ED clinicians (physicians, nurses, etc.), non-clinicians (technicians, research assistants, etc.), patients completing self-assessments on interactive tables, etc.) 6. Is there an objective bedside diagnostic test in the ED (i.e., plasma test, bedside EEG, etc.) to improve dementia screening accuracy? (e.g., plasma test) 7. When in the ED care continuum should cognitive screening be done? (before, during, after the ED visit) 8. Can the ED screen for undiagnosed dementia and refer patients for further assessment? Are there differences by race and ethnicity? 9. How to account for language and cultural differences with diverse ED population in existing screening tools for cognitive impairment? 10. Is the electronic health record optimized to alert healthcare providers of patients already diagnosed with dementia? 11. Does identification of patients with dementia change ED outcomes for these patients? 12. What outcomes are associated with undiagnosed dementia in the ED? 13. What outcomes are associated with undetected dementia in the ED? 14. What is the impact (positive / negative) of ED dementia screening? 15. In cases of known dementia, does detection include assessment for patient and caregiver support? 16. What are the ethical responsibilities of the ED clinicians to convey information about screening results versus diagnoses? 17. What are the repercussions about reporting dementia detected in the ED and their impact on subsequent care, patient stigma or anxiety? 18. How do symptoms of cognitive impairment without a diagnosis affect persons with dementia, particularly since diagnostic uncertainty frequently occurs in emergency medicine? 	<p>Question 1: How can the ED best identify cognitive impairment? (Best in terms of sensitivity, specificity, reliability, practicality, easy and speed of completion, etc.) Are there differences by race or ethnicity?</p> <p>Question 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.)</p>

Table 3. Care Transitions PICO Research Questions

Preliminary PICO Questions	Final Two PICO Questions
<ol style="list-style-type: none"> 1. What interventions (e.g., Electronic Medical Record, coaching, follow up; to be defined in the PICO) delivered to ED patients with impaired cognition improve ED to home transitions? (or to other settings like Skilled Nursing Facility/Nursing Home/hospice) 2. What components of interventions delivered to ED patients with impaired cognition improve ED to home transitions? 3. What interventions delivered to caregivers of ED patients with impaired cognition improve ED to home transitions? (or to other settings like Skilled Nursing Facility/Nursing Home/hospice) 4. What components of interventions delivered to caregivers of ED patients with impaired cognition improve ED to home transitions. 5. What elements of care transitions have the greatest negative impact when it comes to the care of PLWD transitioning from ED to a new place (home, facility, unit) 6. What are patient-centered metrics of quality transitions for ED patients with impaired cognition? 7. What predicts an ED patient with impaired cognition for needing support with care transitions / having poor outcomes from care transitions? 8. Would prioritizing ED care for patients with impaired cognition (similar to trauma/stroke) lead to a more positive transition to home (or to other settings)? 9. What are characteristics of the care partner that enable or impede effective care transitions? 10. What are interventions that can be applied across multiple transitions longitudinally that improve the care of PLWD? 11. How do PLWD, care partners, and other stakeholders define care needs and goals specific to ED transitions? 12. Who are the essential personnel required to optimize ED care transitions for PLWD (social work, nursing, ED physician, primary care/inpatient team, care partner, others)? 13. What decisions around care transitions should cognitively impaired patients make? 14. How can ED providers determine if the patient has a safe living environment and, if needed, improve the living situation? 15. What is the most effective form of follow-up for persons with dementia and at what time interval? 16. What interventions optimize ED physician communication to inpatient and primary care providers regarding concerns related to cognition of ED patients? 	<p>Question 1: What interventions delivered to ED patients with impaired cognition and their care partners improve ED discharge transitions?</p> <p>Question 2: What measures of quality ED discharge transitions are important to varying groups of ED patients with impaired cognition and their care partners?</p>

Table 4. Optimal ED Practices PICO Research Questions

Preliminary PICO Questions	Final Two PICO Questions
<ol style="list-style-type: none"> 1. How do emergency care needs differ for PLWD differ from other patients in the ED? 2. What components of ED care improve patient-centered outcomes for PLWD? 3. Possible components may include: ED environment, patient length of stay in the ED, evaluation and identification of delirium, assessment and treatment of pain, management of agitation, scheduling outpatient follow-up, etc. 4. What patient-centered metrics best measure the impact of ED interventions for persons with dementia? 5. Does optimal ED care prevent incident delirium for PLWD in the ED? 6. How does severity of dementia and presence of other health issues impact the optimal delivery of ED care for PLWD? 7. How do social determinants of health such as race, ethnicity, wealth, and access to medical care impact delivery of optimal ED care for PLWD? 8. How frequently are PLWD evaluated for delirium in the ED? 9. How accurately do ED clinicians identify delirium in PLWD in usual practice? 10. What is the accuracy of delirium identification tools for PLWD in the ED? 11. How can rapidly progressive dementia be identified in the ED? Should patients with rapidly progressive dementia be admitted for expedited workup? 12. What are the best pharmacological and non-pharmacological strategies to manage agitation and other behavioral concerns for PLWD in the ED? 13. How adequately is pain controlled in the ED for PLWD? 14. How frequently are alternative measures for pain assessment such as the Behavioral Pain Scale, or Critical Care Pain Observation Tool used in the ED for PLWD? 15. How frequently are alternative measures for pain assessment such as the Behavioral Pain Scale or Critical Care Pain Observation Tool taught to emergency clinicians? 16. How accurate are screening techniques which are commonly used ED for PLWD? Commonly used screening techniques may include techniques to identify delirium, pain, depression, and abuse. 17. What are the knowledge and training gaps for emergency clinicians and nonclinical staff regarding optimal care of PLWD? Non-clinical staff may include personnel such as security, and registration. 18. How can emergency clinicians best interact with care partners to provide optimal ED care for PLWD? 19. How does care partner involvement impact ED care for PLWD? Are these impacts different when care partners are present compared to paid caregivers? 20. What are the impacts of pragmatic approaches to providing acute unscheduled care such as home care, community paramedicine, telemedicine, or 3D telemedicine on patient-centered outcomes for PLWD? 21. How do emergency clinicians best connect PLWD with community resources? 22. When concern for dementia or cognitive impairment is identified in the ED, how do clinicians address concerns with patient autonomy and capacity? Should these concerns be reported to anyone? For example, the patient's family, primary care clinician, or adult protective services. 	<p>Question 1: <i>What components of emergency department care improve patient-centered outcomes for persons with dementia?</i></p> <p>Question 2: <i>How do emergency care needs for persons with dementia differ from other patients in the emergency department?</i></p>

Medical Librarian Collaboration

Medical librarians from each workgroup leads institution working together developed a standardized core search strategy for the workgroups, as well as topic specific modifications for the scoping reviews. Prior studies have demonstrated this collaboration style creates higher quality search strategies and minimizes review bias.²⁴⁻²⁶ To confirm the search strategies developed would capture the articles sought after, exemplar articles were identified. The searches were reviewed to ensure inclusion of these articles. The only exclusion filter applied to the search was to limit the focus to an adult patient population. No other publication type, language, or date filters were applied.

The librarians worked together to identify relevant bibliographic databases to maximize capture of relevant articles while limiting duplication. Databases searched included Medline (Ovid), Embase, Cochrane Central Register of Controlled Trials, CINAHL, PsychINFO, PubMed Central, Web of Science, and ProQuest Theses and Dissertations. For a list of databases used by the Workgroups, see Table 5. Databases searched by Workgroups. Each site librarian conducted the literature search, identified article duplication, and uploaded the results to Covidence, a systematic review software (Veritas Health Innovation, Melbourne, Australia. Available at www.covidence.org). Search strategies began at the earliest year databases began indexing until March 2021 and focused on emergency care and The scoping reviews for each group are registered on Open Science Framework.²⁷⁻³⁰

Table 5. Databases searched by Workgroups

Database searched	Workgroup
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	Detection	Communication	Practices	Transitions
MEDLINE (Ovid)	X	X	X	X
Embase	X	X	X	X
Cochrane Central Register of Controlled Trials	X	X	X	X
CINAHL (Ebsco)	X	X	X	X
PsycINFO (Ebsco)	X	X	X	
PubMed Central	X	X	X	X
Web of Science	X	X	X	X
ProQuest Theses & Dissertations		X		

The workgroup lead and a trained research associate from each workgroup independently screened the titles and abstracts of all articles uploaded into Covidence for relevance. Each workgroup created unique inclusion and exclusion criteria based on workgroup consensus. Future publications will present the findings of the workgroups. The reviewers adjudicated any disagreements. If they did not agree, a third-party reviewer made the final decision. The full text of articles identified as potentially relevant were then reviewed in the same manner. Data were abstracted from the articles deemed relevant. To ensure consistency in the conduct of the scoping reviews, workgroup leads and project team members discussed progress at the biweekly meetings and communicated frequently through email correspondence.

Phase 1: GEAR 2.0 ADC Consensus Conference

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3 The culmination of the scoping review process resulted in presentations of these
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5 synthesized results from each domain at a two-day consensus conference of the full GEAR 2.0
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7 ADC Taskforce in September 2021. At the conference, Taskforce members were mixed and
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9 distributed across smaller groups to discuss the findings of the scoping reviews. The goal of
10
11 these small groups was to provide stakeholder insight and recommendations on the current
12
13 knowledge base and to provide suggestions for future research and pilot grants. After small
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15 group discussion, there was an opportunity for shared debrief of these breakout sessions. Each
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17 workgroup then incorporated the feedback and themes heard from the small group discussion
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19 to prepare five research priorities, based on the scoping review results and transdisciplinary
20
21 stakeholder recommendations. The full taskforce then ranked these research priorities using an
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23 online survey (Polleverywhere.com). Taskforce members unable to attend the conference were
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25 asked to vote asynchronously, for 100% participation by all Taskforce and Health Equity
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27 Advisory Board members. Results of each scoping reviews, their search methodology, data from
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29 included manuscripts, and ranked research priorities will be published separately.
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40 Copies of the GEAR and GEAR 2.0 ADC Consensus Conference Summaries are available on the
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42 GEAR website: <https://gearnetwork.org/manuscripts-publications/>
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47 Phase 2: GEAR 2.0 ADC Pilot funding

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49 During the second phase, pilot funding opportunities will be made available to
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51 investigators. Proposals for pilot studies must address the research priorities recommended by
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53 the GEAR 2.0 ADC Taskforce and HEAB members from the GEAR 2.0 ADC Consensus
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3 Conference. During this phase, the GEAR 2.0 ADC Cores will become active and support early
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5 research addressing research gaps and priorities recommended by the GEAR 2.0 ADC Taskforce.
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8 In addition to pilot funding, the Research Core, Data and Informatics Core, and Dissemination
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10 and Implementation Core will provide guidance to pilot awardees as they conduct their studies,
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12 including training sessions to enhance and increase transdisciplinary collaboration within and
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14 across the GEAR 2.0 ADC Network. These will be held as virtual training webinars, conferences
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16 and office hours, and bi-monthly research progress meetings where awardees will have the
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18 opportunity to share their study progress with each other.
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25 GEAR 2.0 ADC pilot funding opportunities can be found on the GEAR website:

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27 <https://gearnetwork.org/grants-and-funding-opportunities/>
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32 **DISCUSSION**

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35 In this paper we present a framework establishing an infrastructure to advance geriatric
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37 emergency medicine research. The value of this framework, and more importantly the
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39 representation of key stakeholders, is unique and critical to guide optimally future research
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41 addressing practice gaps that matter to all those engaged in all facets of emergency care for
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43 PLWD and their care partners. It differs from other previous agenda setting processes directed
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45 at geriatric emergency care³¹⁻³⁴ in the following ways: 1. The inclusion of stakeholder
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47 participation as part of the scoping review and consensus process to identify research gaps and
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49 priorities, 2. Cross coordination with medical librarians of scoping review searches, 3. Creation
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51 of a Health Equity Advisory Board to ensure meaningful inclusion of diverse populations in
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3 studies focused on the emergency care of people living with dementia, and 4. Provision of pilot
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5 funding to initiate research in the recommended consensus research priorities.
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8 A significant strength of the GEAR Network approach is the inclusion of patients,
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10 individuals that use the healthcare system, and care partners as part of the process. It is a
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12 priority of the GEAR Network to include their experiences and perspectives and to learn what
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14 matters to them about the emergency care they receive. Further, GEAR Network strives to
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16 share with these stakeholders' reasons why health and medical care occurs the way it does, to
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18 enable them to engage meaningfully, and to integrate their critical feedback and
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20 recommendations on the topics throughout the entire GEAR Network approach. For GEAR 2.0
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22 ADC, this has even greater relevance coupled with challenges faced by PLWD, all of whom have
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24 cognitive impairment with varying degrees of severity. While the PLWD who participate in
25
26 GEAR 2.0 ADC are in the early stages of dementia and remain high functioning, they, along with
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28 care partners and many other stakeholders who are not researchers nor clinicians, are not as
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30 familiar with taskforce or agenda setting research processes.
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37 Preparatory background steps by the GEAR 2.0 ADC Project Team with these non-
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39 research and non-clinical stakeholders are necessary to support their full engagement.
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41 Following the Empowering Partnership principals of and working with the Livewell Dementia
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43 Specialists organization,³⁵ GEAR 2.0 ADC set up several working sessions with the non-
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45 researchers and non-clinicians Taskforce members, including separate preparatory video
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47 conferences, providing printed folders of all conference materials in advance of the meeting,
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49 and providing opportunities for feedback about conference format and to address any
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51 questions they might have prior to the conference. There was also an additional debrief
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3 session after the GEAR 2.0 ADC Consensus Conference to gather additional suggestions and
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5 feedback about the conference from these individuals. When working with PLWD with early to
6
7 middle stage dementia, it is important to recognize there may be varying degrees of cognitive
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9 function that may impact tasks and activities. For example, the survey ranking many potential
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11 questions initially proposed by workgroups required significant mental focus to complete for
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13 individuals of all levels of cognitive function. This was even more challenging for some PLWD
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15 members who found the survey format difficult to comprehend fully. To incorporate their
16
17 input, once the top four choices were identified, their thoughts on each were discussed
18
19 separately with them. Concurrently, other PLWD members did not express any difficulty with
20
21 the survey. It is important that researchers consider the potential limitations of PLWD in
22
23 research engagement and find ways to enable their full participation.
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30 Another innovative feature of the scoping review process in GEAR 2.0 ADC was the
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32 collaboration of research librarians from four different institution sites and their inclusion early
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34 in PICO question development. Each workgroup's assigned librarian participated in meetings
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36 when PICO question development was occurring. This provided unique insight and
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38 understanding as to the group's thought process that allowed the librarian to craft the
39
40 appropriate search strategy. It was decided that the four librarians would develop a
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42 standardized search for the elements consistent between the groups and then tailor the
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44 remaining elements for their specific groups. By cooperating on core search development, the
45
46 librarians were quickly able to develop a highly effective search strategy, minimizing bias.²⁶ The
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48 standardization of the common elements helped ensure consistency in articles identified
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50 between groups.²⁵
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As part of its mission, GEAR 2.0 ADC has also prioritized addressing equity through diversity and inclusion in its research agenda. The concern is multifactorial as it includes the diversity and composition of the workgroups, the defining of the questions, and implementation in the future pilot grants to be offered by GEAR 2.0 ADC. Despite continuous efforts to increase diversity of the taskforce and while equally split in member gender, the workgroups and PLWD representatives are overwhelmingly Caucasian. This is a challenge for many organizations attempting to increase diversity in representation and health equity with research, especially for PLWD. Within the workgroups, Diversity Equity and Inclusion was discussed in terms of the patients seen in the ED. The discussions included race, gender, ethnic/religious affiliation, sex identification, along with the impact of social determinants of health. Identifying additional workgroup members whose participation would broaden the groups' diversity would have taken more time than the groups had, thus the decision was made to create a "Health Equity Advisory Board"(HEAB) of members from underrepresented and disenfranchised groups to review and provide input on the output of the workgroups and GEAR 2.0 ADC processes. The GEAR 2.0 ADC PIs along with the workgroup leads have developed a framework for the board that includes quarterly meetings that preview consensus conference materials to incorporate feedback before the conference and sharing materials and will involve the HEAB when selecting GEAR 2.0 ADC pilot studies to fund.

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Finally, perhaps the most significant and unique feature of the GEAR Network research infrastructure is its provision of pilot funding for the research priorities generated by its consensus stakeholder process. Support is directed to build preliminary research and evidence in clinical and research gaps identified by scoping review processes that were voted by

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3 transdisciplinary members of the field and by patients and their care partners. This novel
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5 approach targets funding for stated and ranked priorities by “putting money where our mouth
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7 is.” It is hoped that the funding from these pilot studies will foster interest and research in
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9 needed areas of geriatric- and dementia-related emergency care, increase and diversify the
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11 pool and foci of researchers, and generate preliminary evidence and data for larger scale study
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13 proposals that are critically needed to advance the science of geriatric emergency care.
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18 In summary, the GEAR Network approach provides a framework and systematic
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20 approach to review the literature for research and practice gaps. Further, the GEAR Network
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22 approach gives insight as to how to engage key stakeholders from all facets of caring for older
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24 adults and persons living with dementia to define and state what research priorities matter.
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26 This approach may be used by other disciplines, professions, and specialties to advance
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28 research priorities in aging.
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3 Statements/Declarations
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6 *Authors' contributions:*
7

8 All authors read and approved the final manuscript.
9

10 CRC conceived the approach, provided methodological guidance, oversaw the implementation
11 and operations of the approach, and provided review and edits in the writing____
12
13

14 SD organized the implementation and operations of the approach and was a major contributor
15 in writing
16

17 JD organized the implementation and operations of the research approach and was a major
18 contributor in writing the manuscript.
19
20

21 AG organized the implementation and operations of the research approach and was a major
22 contributor in writing the manuscript.
23
24

25 LH organized the implementation and operations of the research approach and was a major
26 contributor in writing the manuscript.
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29 UH secured funding, conceived the approach, organized the infrastructure and partnerships,
30 organized the implementation and operations of the approach, was a major contributor in
31 writing and overseeing the manuscript.
32
33

34 JL organized the implementation and operations of the research approach and was a major
35 contributor in writing the manuscript.
36
37

38 AN organized the implementation and operations of the research approach and was a major
39 contributor in writing the manuscript.
40
41

42 MNS secured funding, conceived the approach, organized the infrastructure and partnerships,
43 organized the implementation and operations of the approach, was a major contributor in
44 writing and overseeing the manuscript.
45
46

47 ZT organized the implementation and operations of the research approach and was a major
48 contributor in writing the manuscript.
49

50
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52 This work and the GEAR Networks are funded and supported by the following organizations,
53 each of which fosters and supports the development of research infrastructures to promote
54 studies that address the research and clinical gaps in the aging process and related health fields
55 through: (1) research performed and proposed through contracts; (2) a program of research
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3 grants and individual and institutional pilot awards; (3) cooperation and collaboration with
4 other Departmental agencies, voluntary organizations, and other institutions; and (4) collection
5 and dissemination of the findings of aging and dementia related studies.
6
7

8 National Institute on Aging [R33 AG058926 (Hwang)]
9

10 National Institute on Aging [R61 AG069822 (Hwang, Shah)]
11
12

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14

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16
17

18 The John A. Hartford Foundation [The Geriatric Emergency Department Collaborative]
19
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23
24 *Competing interest statements:*

25 CRC – none

26 SD – none

27 JD – none

28 AG – none

29 LH – none

30 UH – none

31 JL – none

32 AN – none

33 MS – none

34 ZT – none
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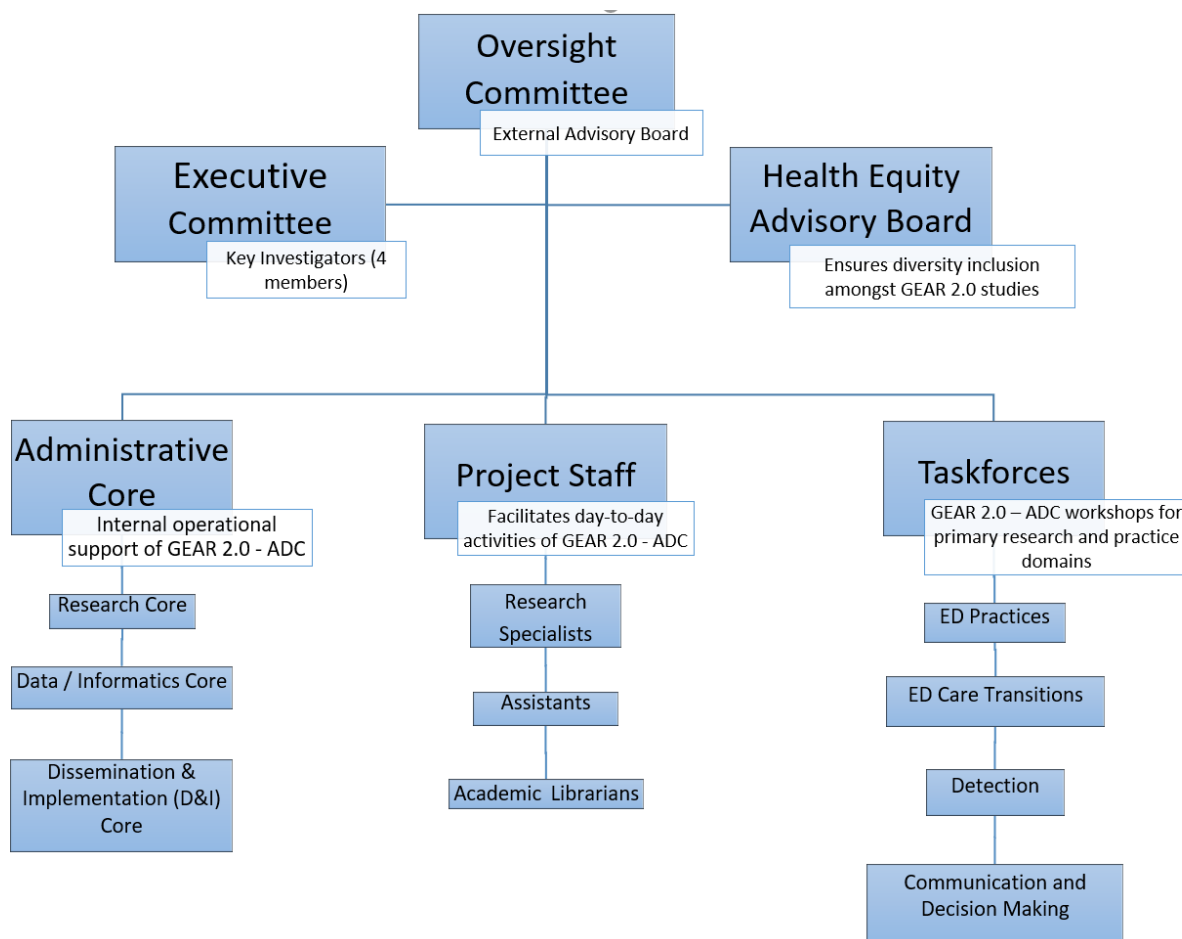
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Figure Legends

Figure 1. GEAR 2.0 ADC Organizational Structure

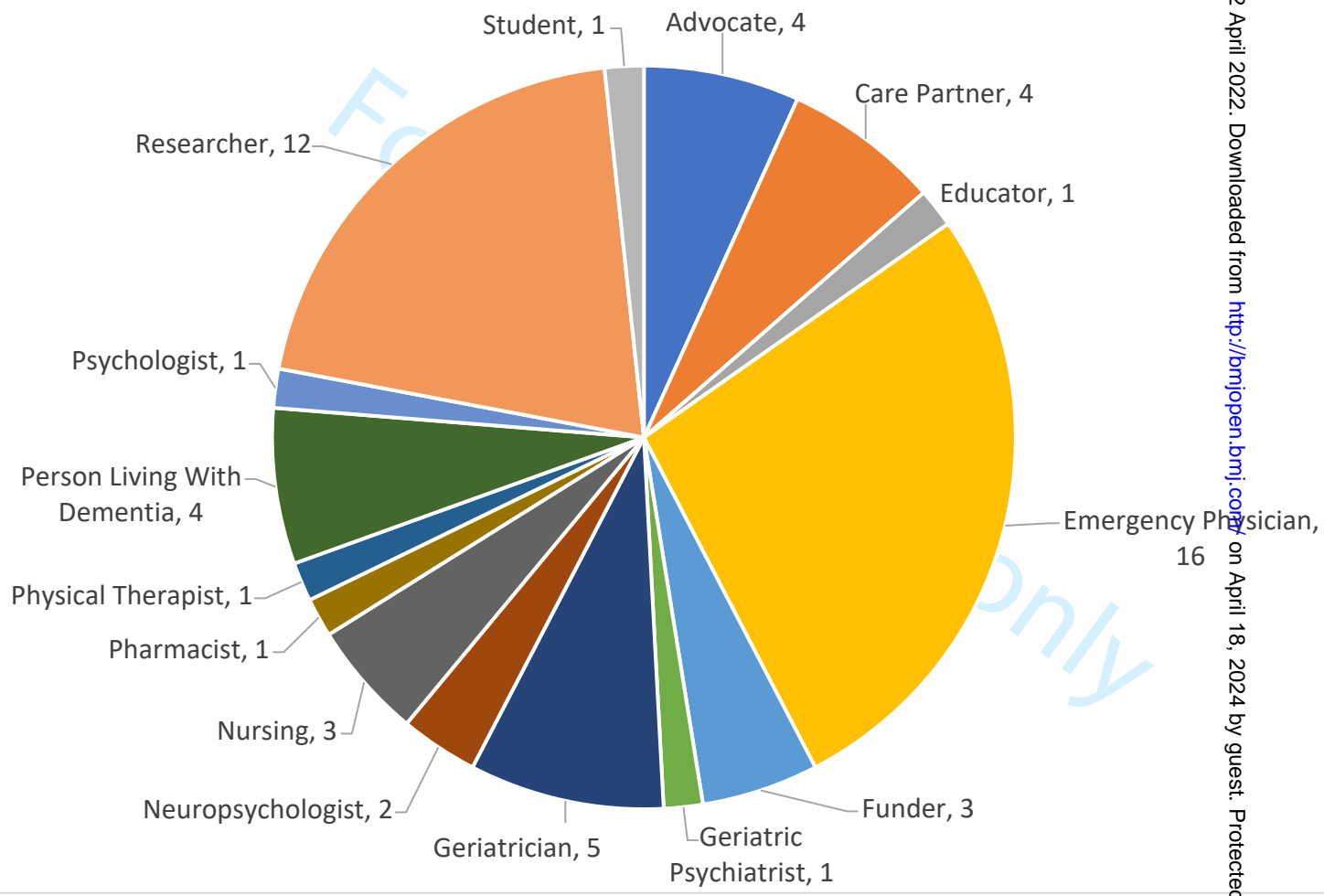
Figure 2. GEAR 2.0 ADC Taskforce Composition

For peer review only



New only

GEAR 2.0 Taskforce Composition (n=47 individuals*)



* Identification categories not mutually exclusive

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	3-4
6-7INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	6-7
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	6
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	5
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	13-15
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	14
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	14
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	14
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	15
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	15
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	n/a



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	n/a
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	n/a
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	n/a
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	n/a
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	n/a
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	n/a
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	n/a
Limitations	20	Discuss the limitations of the scoping review process.	n/a
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	n/a
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	22-23

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473. doi: [10.7326/M18-0850](https://doi.org/10.7326/M18-0850).

