

# Dementia Methods Pre-Summit Materials

Session 2

Engaging Decision-makers

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## I. Introduction

The purpose of this document is to provide information from key communities of healthcare decision-makers, including policy makers, payers, and health care providers, to inform the national research agenda for dementia care and services. Semi-structured interviews were conducted with 11 stakeholders to inform the Dementia Methods Pre-Summit session discussion of how decision-makers from health care systems, employers, and payers be engaged in getting the information they need to support decisions about dementia care and services.

The interviewed representatives (key informants) hold a variety of leadership positions in diverse organizations such as multi-employer coalitions, integrated delivery systems, physician organizations, long-term care advocates, payers, and researchers. Each of the 30-minute interviews explored the following research questions:

1. What information do health care system decision-makers need for dementia care decisions?
2. How do these stakeholders access and use available information and how do they address knowledge gaps?
3. What strategies work for learning from these stakeholders about their unmet data needs?
4. What strategies can support their involvement in relevant research?

## II. Key Informant Interview Findings

### *Decision-makers' Information Needs & Usage*

Almost all of the interviewed informants had looked for information related to dementia care research and services. Table 1 describes the types of information they have sought; Table 2 describes their primary reasons for seeking the information.

**Table 1. Type of information sought by key informants**

Stakeholder	Tools/ Care Models/ Practices	Published Evidence	Stakeholder/ Expert Input	Consultant
National Advocacy/Service Provider	●		●	
Local Advocacy/Service Provider 1	●	●		
Local Advocacy/Service Provider 2			●	
Employer Coalition				●
Commercial Payer				
Federal Payer	●			
Integrated Delivery System 1, Clinical Arm				●
Multi-Specialty Physician Organization		●		
Integrated Delivery System 2, Research Center	●	●		
National Advocacy Group, Applied Research Center			●	
Integrated Delivery System 3, Research Center		●	●	

\*This table presents only those types of information that key informants mentioned during the interviews.

**Table 2. Key informants' use of information**

Stakeholder	Develop or Change Services Provided	Reduce Costs	Improve Outcomes	Develop Quality Measures	Remain current on Research
National Advocacy Group					
Local Advocacy/Service Provider 1					•
Local Advocacy/Service Provider 2	•		•		
Employer Coalition		•			
Commercial Payer	•		•	•	
Federal Payer				•	
Integrated Delivery System 1, Clinical Arm		•	•		
Multi-Specialty Physician Organization	•	•	•		
Integrated Delivery System 2, Research Center					•
National Advocacy Group, Applied Research Center			•		
Integrated Delivery System 3, Research Center					

\*This table presents only those uses of information that key informants mentioned during the interview.



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**Dementia care and services are not a priority for employers or commercial health plans.** The employer key informant reported that employers do not seek out information on this topic, which is a low priority for them. Their concerns are limited to their employees as caregivers for people with dementia and the extent to which that role may impact productivity. Employers view their employee assistance plans as responsible for offering caregiver support services. Similarly, commercial insurers give dementia a low priority since few dementia-related costs are covered by commercial plans.

... when you talk about dementia research, in general, in the commercial insurance world, it doesn't have very high relevance...Most drugs for dementia are not the high cost specialty drugs that everyone is trying to manage. There have been a few technology assessments we have done related to testing, such as genomic or imaging with respect to Alzheimer's and dementia, so that pops up sporadically but it's not a large focus. The huge resource issue in dementia is care. And no one is covering that except families and long-term care organizations, so I don't think you're going to see a lot of research about it from the payer community.

**Consultants are primary information sources for employers and integrated health delivery systems.** The employer and health system informants stated they typically rely on professional consulting companies such as Deloitte, Mercer, and PwC for needed information. A health system informant emphasized the legitimacy of the consulting firms. The informant noted that organization leaders view these firms as trusted information sources, with a preference for receiving information from these sources rather than through other sources, such as through the medical literature or otherwise directly from researchers.

**Identification of and Access to Information**

Key informants used various sources to obtain information about dementia care and services, as described in Table 3.

**Table 3. Information sources used by key informants**

Stakeholder	Journals	Conferences	Associations/ Coalitions	Consultants	Organizations' Members	Internet Searches	Business Meetings/ Presentations
National Advocacy Group	●		●			●	
Local Advocacy/Service Provider 1	●	●					
Local Advocacy/Service Provider 2			●				
Employer Coalition			●				●
Commercial Payer	●						
Federal Payer	●						
Integrated Delivery System 1, Clinical Arm				●			
Multi-Specialty Physician Organization		●					
Integrated Delivery System 2, Research Center	●	●					
National Advocacy Group, Applied Research Center			●		●		
Integrated Delivery System 3, Research Center		●	●				

\*This table presents only those information sources that key informants mentioned during the interview.

**Coalitions serve as trusted information sources.** Named coalitions included: the National Council on Aging; Rosalynn Carter Institute for Caregiving; Family Caregiver Alliance; American Society on Aging; Dementia Caregiving Network; and the SCAN Foundation.

**Journals.** Key informants identified the following publications as regular sources of research information: Journal of the American Geriatrics Society; Journal of American Medical Directors Association; Health Affairs; New England Journal; Aging and Health; and the Journal of Applied Gerontology.

**Conferences.** Informants attend conferences such as the Gerontological Society of America Annual Scientific Meeting; Alzheimer's Association International Conference; American Society on Aging's Aging in America Conference; American Geriatrics Society Annual Scientific Meeting; Rosalynn Carter Institute Annual Summit.

### ***Addressing Information Gaps***

**Decision-makers lack rigorous evidence on interventions in dementia care.** Overall, key informants were in agreement that there is a lack of rigorous evidence on care-based interventions for dementia. In accordance with the desire to adopt innovative care models and practices for populations with dementia, our key informants overwhelmingly voiced the need for evidence-based research to identify and implement interventions that have been demonstrated to improve outcomes and reduce costs for this population. As a researcher from a national advocacy group stated:

That's really where we are trying to make a difference: where things sound good but there's really not enough evidence behind it. What is the evidence behind what actually needs to happen in order to change practice and improve quality of life and cost to the provider?

**Evidence needed on knowledge translation, training, and outcomes.** In their call for more evidence-based information, key informants specified that they would like to see evidence related to: (1) translating interventions from research to practice, (2) training and engaging providers, and (3) outcomes (e.g., many behavioral interventions are used but are not evidence based). Key informants mentioned the following topics important to the care and services of people with dementia:

- Dementia diagnosis
- Modification of existing interventions for chronic diseases for co-morbidity with dementia
- Support for caregivers
- Community-based care
- Workforce training (e.g., assisted living and nursing home frontline staff—what trainings work best?)

### ***Approaches for Learning about Decision-makers Unmet Information Needs***

**Decision-makers are open to communicating with funders about their information needs.** Key informants suggested that the most effective way for PCORI to learn about their unmet information needs related to dementia was to establish a system of communication for organizations to share their ideas. The two key informants that discussed communicating about information needs with either a consultant or their membership both described an established relationship defined by continuous communication and information exchange. Alternatively, one key informant indicated that she had used her application for PCORI funding as a way to communicate her organization’s need for further information on dementia care.

### ***Supporting Decision-makers’ Involvement in Research***

The majority of key informants had participated in research in one form or another. The exceptions were the employer coalition, the commercial payer, and one of the integrated health system representatives. Those that did participate in research were involved in different capacities, as shown in Table 4.

**Table 4. Role that key informants have played in past research efforts**

Stakeholder	Fund	Design and Develop	Recruit	Implement or Collect Data	Disseminate
National Advocacy Group		●			●
Local Advocacy/Service Provider 1				●	
Local Advocacy/Service Provider 2			●		
Employer Coalition					
Commercial Payer					
Federal Payer	●	●			
Integrated Delivery System 1, Clinical Arm					
Multi-Specialty Physician Organization				●	●
Integrated Delivery System 2, Research Center				●	
National Advocacy Group, Applied Research Center			●		●
Integrated Delivery System 3, Research Center**					

\*This table displays only those roles that key informants mentioned during the interview.

\*\*Question not asked of this key informant.

**Key informants have research partnerships with many different organizations.** Key informants had worked with a variety of partners in the course of their involvement in research, including:

- Academic research centers
- Community agencies
- Medicaid / state government
- Health systems
- Centers for Medicare & Medicaid Services

Key informants tended to be positive about past partnership experiences. One exception was the key informant from a national advocacy group, who noted that their members had expressed reservations about partnering with academic research centers. In past partnerships, these members had “been burned” by the academic researchers: they were never given results from their work and they had not been able to learn from their experience. For these members, learning was an essential benefit to partnering in research.

Everything that you learn, all the information you gather helps you to improve. And if you don't continuously gather that information you have no benchmarks or know where to go, where to improve or what to stop. No way of setting priorities.

**Key informant suggested enhancing the research process to support research partnerships.** A key informant from an integrated delivery system suggested embedding experts in behavioral economics, branding, marketing, and dissemination within research projects in their initial stages. This would enable the research to be made relevant to, for example, health system executives who find research to be slow, segmented, not sustainable, and not scalable. He suggested:

Partner with Amazon, Apple, Facebook, all the ones between retail and tech. And partner with amazing marketing firms. Bring the researcher/designer from their side and you embed them early into the typical PCORI/NIH research the same way you embedded the patient (in PCORI research) and force the researcher to take into account the messaging, sustainability, scalability, and cost and distribution from the moment they go after a problem.

### III. Priority Issues and Information Needs

**Key informants are interested in research on providing quality care for people with dementia.** Overall, key informants expressed enthusiasm for participating in research on dementia care and services. They were particularly interested in research that would address the information needs they identified during the interview. The research topics that they were most interested in were:

- **Community-based care.** “We would be interested in helping to understand how people with this diagnosis live their best lives in the community and what does that mean related to their participation in arts, or what does that mean in terms of social stigma. Because our main area of focus is helping people live in community and on their family caregivers.”
- **Caregiver experience and supports.** “[We are] very interested in research that would help us understand the experience of family caregivers and would help us understand how to support family caregivers better.”
- **Workforce development.** “Our members are having a hard time recruiting and keeping people. And a lot of that has to do with how do you increasingly care for people with dementia because that’s so much of the population in these settings. So, it’s driven by their need.”

## Appendix: Methods

In collaboration with the Dementia Methods Pre-Summit Steering Committee, AIR identified 11 potential key informants representing a variety of stakeholder audiences. The group of individuals interviewed represented the communities of advocacy and service providers, researchers, payers, employers, health systems and physician groups.

AIR contacted all identified individuals and scheduled interviews with those who agreed to participate. AIR identified alternatives for individuals who declined participation or were non-responsive to recruitment efforts. A total of 11 interviews were scheduled over a three week time period. Using a protocol developed collaboratively between PCORI and AIR, AIR conducted 30-minute, semi-structured interviews with each key informant.

Prior to scheduled interviews, AIR developed profiles of key informants' research backgrounds and areas of expertise to focus the brief interviews on those topics that would leverage their knowledge and research experience.

Interview questions were pre-coded to the four research questions identified for Session 2 of the Pre-Summit. After reviewing notes from each interview and categorizing content by the research question, two investigators analyzed the data, independently reading and developing themes and patterns for each question.

**Table 1. Research Questions**

Overarching Questions	Structured Interview Guide Questions
Background information	First, I would like to hear about any of the current or recent work [your organization] has been involved in related to dementia care services [coverage]. Have you had any initiatives or other efforts related to dementia and healthcare? If yes, tell me about them
<ol style="list-style-type: none"> <li>1. What information do health care system decision-makers need for dementia care decisions?</li> <li>2. How do these stakeholders access and use available information and how do they address knowledge gaps?</li> <li>3. What strategies work for learning from these stakeholders about their unmet data needs?</li> <li>4. What strategies can support their involvement in relevant research?</li> </ol>	<p>Have you ever looked for research results to get ideas about developing new services or changing the services [company name] offers [covers]? Tell me about the situation.</p> <p>Who was interested in this information?</p> <p>What information were they looking for?</p> <p>What resources did you go to?</p> <p>Did you find what they needed?</p> <p>How did you use this information?</p> <p>Was the information useful? Explain.</p> <p>What makes information useful? Less useful?</p> <p>Do you want information that is actionable? If yes, what makes it actionable?</p> <p>In thinking about your organization’s information needs from research, what information is missing related to dementia care and services?</p> <p>What kind of information would you like to see more of?</p> <p>What would make it useful? More accessible?</p> <p>What are good strategies to learn from you about your unmet data needs?</p> <p>What makes you think information is credible? Not credible?</p> <p>What do you look for as a sign of credibility?</p> <p>Have you disregarded information because you felt it was not reliable? Tell me about it.</p> <p>In your current role, have you had opportunities to participate in any health care-related research?</p> <p>If yes, what were those opportunities? Were the opportunities ever related to dementia care?</p> <p>Has [YOUR ORGANIZATION] ever participated in research on dementia services? Tell me about the research and what your organization did.</p>

<ol style="list-style-type: none"> <li>1. What information do health care system decision-makers need for dementia care decisions?</li> <li>2. How do these stakeholders access and use available information and how do they address knowledge gaps?</li> <li>3. What strategies work for learning from these stakeholders about their unmet data needs?</li> <li>4. What strategies can support their involvement in relevant research?</li> </ol>	<p>For people whose organization has not participated in research:</p> <p>Has your organization ever thought about participating in research in general and more specifically in dementia research?</p> <p>If no, have you heard about PCORI--the Patient Centered Outcomes institute--prior to this interview?</p> <p>If yes, in what ways would [YOUR ORGANIZATION] like to be a part of research? In dementia research?</p> <p>For people who have participated in dementia research:</p> <p>Tell me about the research [on dementia care and delivery services] you have been involved in.</p> <p>As a reminder, when we ask about your “involvement in dementia research” we mean: Helping researchers to identify the information needs of companies like yours, developing research questions for a study, helping to disseminate results from a research study to your colleagues or other organizations, or helping to implement a new practice based on dementia research. This does not include research that you have participated in as a subject.</p> <p>How were you involved?</p> <p>What motivated you to become involved?</p> <p>What kinds of things did you do?</p> <p>How did you find the experience?</p> <p>Were there any challenges to participating? What would have made it better?</p> <p>Was anything done that made it easier to participate?</p> <p>If you had an opportunity to be a part of dementia research, what research would be most likely to interest you?</p> <p>What would be an information product from this research that you would find useful?</p>
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