



Dementia Methods Pre-Summit Summary and Recommendations

October 2017

Prepared by:
**Patient-Centered Outcomes Research Institute
Leaders Engaged on Alzheimer's Disease**

Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.



DEMENTIA METHODS PRE-SUMMIT SUMMARY AND RECOMMENDATIONS

June 7-8, 2017
Arlington, Virginia

October 2017



Contents

Background and Goals for the Meeting.....	1
Importance.....	2
Relevant Definitions.....	3
Input Collected from Participants.....	5
Meeting Sessions – Day 1	9
Discussion of Major Themes, Day 1	10
Meeting Sessions - Day 2	11
Discussion of Major Themes, Day 2	12
Feedback on Meeting Summary and Recommendations:.....	16
Summing up: Recommendations from the Pre-Summit.....	17
Appendices.....	21
Appendix 1: Dementia Methods Pre-Summit Agenda.....	21
Appendix 2: Steering Committee.....	23
Appendix 3: Links to Background Materials	24
Appendix 4: Session 3 Panelist Summaries.....	25
Appendix 5: Summary Document for Discussion with Stakeholder Group for Individuals Living with Dementia.....	28
References	29

Sponsored by the Patient-Centered Outcomes Research Institute.
The Pre-Summit organizers gratefully acknowledge partial meeting support from the LEAD
Coalition.



Patient-Centered Outcomes Research Institute
1828 L St., NW, Suite 900
Washington, DC 20036
info@pcori.org www.pcori.org
(202) 827-7700

Background and Goals for the Meeting

The goal of the Dementia Methods Pre-Summit was to efficiently drive the field toward a **methods research agenda**, by focusing stakeholder attention on strengths and limitations of methods currently used in dementia intervention research. The outcome of the Pre-Summit is recommendations *to be addressed at the October 2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers (referred to as October Summit)*.

Pre-Summit participants were encouraged to think of this goal as a “roadmap” for specific action steps, as suggested by Dr. Zaven Khachaturian (OECD 2013; see also Khachaturian 2012). A roadmap view will help to make goals feasible and practical, and to comprehensively capture the content of both research and administrative goals.

The participants represented experts of many different types: researchers whose careers are devoted to the study of interventions and/or to the study of research methods; people experiencing dementia themselves and those experiencing it through a loved one; and federal health policy makers; health and aging policy advocacy organizations; and research funders. The opportunity that this meeting provided for joint conversation and collaborative agenda setting is unique.

A key focus of this meeting was on patient engagement in research, consistent with the patient-centered comparative effectiveness research that PCORI funds. See [Appendix 1](#) for the meeting agenda, [Appendix 2](#) for a list of Dementia Methods Pre-Summit Steering Committee members and [Appendix 3](#) for links to background readings for the Pre-summit. Throughout this document we use the term “persons living with dementia” instead of “patient” consistent with terminology used by the October Summit Steering Committee and stakeholder groups. The term “patient” is used when part of terms such as “patient-reported outcome” and “patient and public involvement (PPI)” as used by specific fields of inquiry such as health outcomes research or as used by major funders and when discussing non-dementia specific healthcare consumers.

Importance

People with dementia and those affected by dementia need the help of dementia care and dementia services. There is tremendous room for improvement in understanding what dementia care works for whom, which requires ongoing research on interventions and care delivery models. There is also a need for ongoing dissemination and translation research, to improve the spread of effective interventions and to guide translation of effective interventions to a range of settings for a range of people. The evidence needed to accomplish these goals requires a strong empirical foundation, based on solid research methods. The goal of this Pre-summit is to identify how best to improve methods to strengthen this chain from research to care improvement.

The James Lind Alliance was presented as an example of patient-involved research prioritization. It is a group funded through the UK National Institute of Health Research that “brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise 'unanswered questions'... to help ensure that those who fund health research are aware of what matters to both patients and clinicians.”

All participants were asked: Why do we not have answers to some of the questions in [Appendix 3](#) of the pre-read for Session 1 (the questions elicited by the Lind priority setting exercise)? Is the problem poor design of studies, lack of trust in the results, and/or failure to communicate the results? How are obstacles to dissemination contributing to the limited uptake of interventions with good evidence?

The Lind experience, and the experience of Dendron, presented in the pre-read, provide evidence that engaging people with dementia and their caregivers in research can work.

The Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) is a UK-based patient-and public-involvement network which addresses research issues like trial recruitment and language used in patient communication, as well as providing PPI for specific studies (Iliffe

Connection to Summit Goals:

The goal of the October 2017 Research Summit on Dementia Care is to identify what we know and what we need to know in order to accelerate the development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia, families, and other caregivers. The summit is focused on research that is needed to improve quality of care and outcomes across care settings, including quality of life and the lived experience of persons with dementia and their caregivers.

This Pre-Summit was convened to yield recommendations for consideration at the October 2017 Summit based on conclusions about research methods in care and services research and implications for funders, policymakers, and the research and patient and caregiver communities.

A specific focus of this Pre-Summit was on the current state of the art of engaging stakeholders in dementia care and services research. Recommendations from the Pre-Summit will inform **Summit Session III, Involving Persons with Dementia and Caregivers as Members of the Research Team; Session IV, Involving Persons with Dementia as Study Participants;** and **Session V, Research on Care Coordination and Care Management.**

Sources of Summit Research Recommendations

- Plenary summit speakers, and co-chairs
- Summit audience members
- Summit stakeholder groups
- Pre-summit activities
- Summit listening sessions
- Background papers and issue briefs

et al. 2011). The James Lind Alliance is funded by the NIHR to help identify and prioritize questions for further research (James Lind Alliance, 2016).

Relevant Definitions

Definitions are important. **Patient-centered outcomes research** can be defined as the *evaluation of questions and outcomes meaningful and important to patients and caregivers* (Frank et al. 2014).

Engagement in research can be defined as: the meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from topic selection through design and conduct of research to dissemination of results. (*PCORI: What We Mean by Engagement*, accessed May 30, 2017. pcori.org/funding-opportunities/what-we-mean-engagement). Patient engagement in research refers to partnership in production of the evidence, rather than patients as a source of data as research subjects.

Doctor David Reuben’s PCORI-funded project *Developing Patient-Centered Outcomes for Dementia: Goal Setting and Attainment* was presented as an example of research engaging with people living with dementia, and it involves collection of individual level goals for the purposes of measuring intervention effectiveness. Work that PCORI funds, like this project, is intended to answer questions important to patients and other health care stakeholders and provide information needed to inform health care questions.

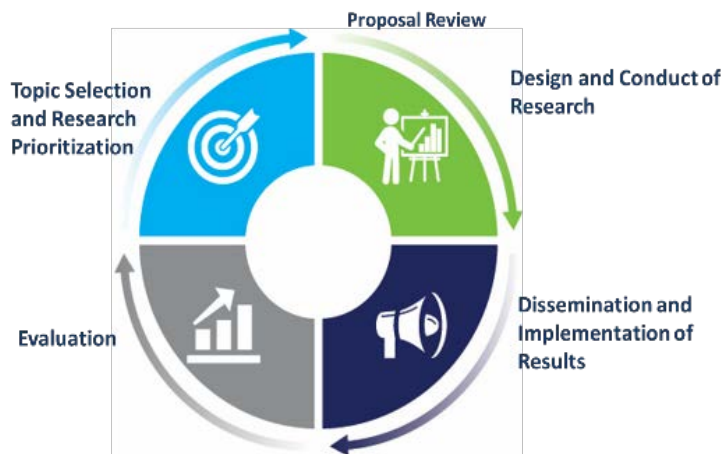


Figure 1. Summary of the PCORI Engagement Model

The PCORI model of stakeholder engagement is implemented from topic identification and research topic prioritization for funding, through to merit review which involves stakeholder engagement, to conduct of the research, which requires stakeholder engagement, to dissemination of results. See Figure 1 for a summary of the PCORI engagement model.

Reporting back to those who provide input is important to the stakeholder advisors for the summit, as it is to many research partners. The Pre-Summit Steering Committee have taken the draft recommendations from this meeting to the stakeholder advisors for review and input, both the advisory group of people living with dementia and the advisory group of caregivers.

Researchers from PCORnet were among the meeting participants and provided perspectives from the network for caregivers and people with dementia, the Patient & Caregiver-Powered Research Network (AD-PCPRN). PCORnet is the infrastructure initiative from PCORI intended

to 1) improve the nation's capacity to conduct clinical research faster, more efficiently and less expensively, with greater power; 2) establish a large, highly representative, national patient-centered clinical research network with a focus on conducting randomized and observational comparative studies; and 3) support a learning US healthcare system, which would allow for large-scale research to be conducted with greater accuracy and efficiency within real-world care-delivery systems.

This Network intends to 1) enroll an increasingly large number of subjects into this patient-centered network with a minority recruitment focus; 2) obtain self-reported information and measures of cognition at baseline and longitudinally; 3) screen & refer subjects for clinical trials; and 4) test computable patient phenotypes. (See <http://pcornet.org/patient-powered-research-networks/national-alzheimers-dementia-patient-caregiver-powered-research-network-phase-ii/>.)

Work by Brian Mittman, one of the meeting co-chairs and a member of the PCORI Methodology Committee, has advanced understanding of translation of clinical research into practice through implementation research. Elements of implementation research were referenced throughout the meeting, including in the recommendation-setting process at the Summit, providing a roadmap for ways to implement recommendations that will improve feasibility of the recommendations.

Additional terms for which shared understanding of definitions is important were reviewed:

- **Research:** A systematic investigation designed to develop or contribute to generalizable knowledge. (*National Institutes of Health, Research Involving Human Subjects*, accessed May 30, 2017. humansubjects.nih.gov/glossary).
- **Research subject:** Human subject, as it pertains to research involving human subjects in the HHS regulations. A living individual about whom an investigator conducting research obtains: data through intervention or interaction with the individual, or identifiable, private information. (*National Institutes of Health, Research Involving Human Subjects*, accessed May 30, 2017. humansubjects.nih.gov/glossary)

As noted above, engagement in research refers to partnership in evidence development, in distinction to serving only as a source of data as a research subject.

- **Research partner:** Individual who is not a researcher, but who works with researchers to conceptualize, design, implement, analyze data, and/or disseminate results of data, in order to bring their perspective to the research.
 - **Patient partners** include patients (i.e., individuals with the lived experience of conditions under study), their family members and caregivers, and organizations that represent patients and caregivers.
 - **Stakeholder partners** include clinicians, researchers, purchasers, payers, health care industry, hospitals and health care systems, policy makers, and training institutions. (See Sheridan et al., 2017.)

The concept of *engagement in research* is distinct from the concept of **engagement in clinical care**, which can be defined in terms of patient activation and engagement.

- **Patient activation** refers to a patient’s knowledge, skills, ability, and willingness to manage his or her own health and care.
- **Patient engagement** is a broader concept that combines patient activation with interventions designed to increase activation and promote positive patient behavior, such as obtaining preventive care or exercising regularly. Patient engagement is one strategy to achieve the “triple aim” of improved health outcomes, better patient care, and lower costs (James, 2013).

Finally, when discussing work with individuals with impaired cognition, either as research subjects or as engaged research partners, the following concepts are relevant:

- **Capacity to participate as a research subject** “Consent capacity” describes an adult’s ability to understand information relevant to making an informed, voluntary decision to participate in research. (*National Institutes of Health, Research Involving Individuals with Questionable Capacity to Consent*, accessed May 30, 2017. <https://grants.nih.gov/grants/policy/questionablecapacity.htm>)
- **Capacity to participate in treatment decisions** Capacity describes a person’s ability to make a decision. In a medical context, capacity refers to the ability to utilize information about an illness and proposed treatment options to make a choice that is congruent with one’s own values and preferences. (Karlawish J. UpToDate, “Assessment of Decision-Making Capacity in Adults,” accessed May 30, 2017. uptodate.com/contents/assessment-of-decision-making-capacity-in-adults)
- Of interest, the concept of **capacity to participate as a research partner** has no known definitions. *Creating a definition will help focus the field on engagement in research and will provide guidelines for research in dementia that can support respect for autonomy of people living with dementia and caregivers while protecting vulnerable individuals.*

Input Collected from Participants

A four item survey was posted via Survey Monkey for meeting participants ten days prior to the meeting. A total of 18 people provided comments by Day 1 of the meeting: 16 via the online portal and two via email. The survey portal was left open after the meeting and attendees were encouraged to respond. A total of 30 responses were received. The questions and a summary of responses are provided below.

1. Engaging people with dementia and their caregivers in research: In your opinion, what are the major challenges to active and meaningful engagement in research for people with dementia and their caregivers? Please list any successful examples of engagement in research that would be helpful for all participants to know about.

Challenges to engagement:

- Resources: Time and money
- Lack of awareness of importance of research

- Lack of accurate diagnosis in chart
- Misperceptions about “capacity to partner”

Examples of engaged research provided by the participants included:

- Video-interactive technology
- ADPCPRN (www.alzheimerspcprn.org) involves people living with dementia and caregivers as part of governance council

Suggestions for encouraging engaged research included:

- Use of a mental health nurse as recruiter for engagement
- Establish ongoing contact and support so that the person with dementia is familiar with research team
- Establish clear expectations and reinforce what is expected
- Establish alternative models where studies can be conducted in community settings (see <https://www.nia.nih.gov/research/initiatives/approved-concepts-may-2017>)

2. What are barriers to use of dementia care research information by clinicians? By payers?

Barriers to use **by clinicians**:

- Resources: time limitations for reviewing research and for implementing recommendations.
- Emphasis on pharmacologic research results to the detriment of care and services research results
- Concerns about credibility of research results (for example due to researcher bias or due to reliance on study samples that are not applicable to community providers)

Barriers to use **by payers**:

- Relevance: Need to show how effective dementia care and services interventions align with payer priorities
- Feasibility of adoption: Interventions are too costly; need to demonstrate business case
- Perception of lack of research relevance to real-world practice
- Concerns about credibility of results (e.g., potential researcher bias)
- Limited translation of research findings into potential economic benefit –
 - results not expressed as costs, lack of economic data and
 - lack of evidence of business case
- Reimbursement models that don’t match intervention complexity

Most respondents noted the need for translation channels – clear ways for vetted research information to be relayed to those who should see it - and some called for better training for researchers in communicating potential uses of research findings.

“Research on care and services has lower status than research on prevention and cure” (Submitted 6/5/17)

“... Improved outreach and messaging may help to make clinicians and payers aware of the research ...Engaging community clinicians and payers in the process earlier (e.g. at the point of design) would help with these barriers. Developing a pipeline to start these conversations between researchers and other stakeholders is also critical.” (Submitted 6/12/17)

“Creating more measures that show patient- and family-centeredness may appeal to both clinicians and payers.” (Submitted 6/2/17)

3. In research on dementia care and dementia services interventions, what topics or domains are suitable for self-report by people with dementia?

Suggestions for topics or domains suitable for self-report by people with dementia included:

- Care satisfaction
- Care preferences
- Care quality
- Quality of life
- Subjective experiences (pain, mood)
- Goals of care

Comments also indicated that all domains are appropriate, provided that the severity of disease is considered and domains assessed depend on stage of disease

“Existing measures for ADCS-ADL [activities of daily living] can be used with people with dementia at various stages. We definitely need better measures for NPS [neuropsychiatric symptoms], which may preclude other symptoms and offer insight into risk” (Submitted 6/1/17)

“Patient Reported Outcomes (PRO) are a huge donut-hole in the longitudinal data completeness. An effective easy-to-use PRO that can be easily integrated with an electronic medical record is a very good way forward” (Submitted 6/2/17)

“For reports of internal states, such as depression or anxiety, loneliness, self-efficacy, quality of life, and satisfaction with services, I believe self-report measures are essential.” (Submitted 6/6/17)

“To suggest that some topics or domains are "suitable" is to assume that people living with dementia are incapable of providing input. Rather than asking what topics or domains are suitable, a better question would be: What is the best way to incorporate input from people living with dementia in intervention research?” (Submitted 6/16/17)

“Would like to see card sort methods exploited much more fully for prompted self-reports - could greatly extend the range of topics and domains that can be assessed” (Submitted 6/4/17)

4. What study designs are likely to yield the most promising and actionable information for dementia care and services in the future? What are obstacles to implementing specific study designs (e.g., randomization, analytic methods to address observational designs)?

Suggestions for study designs included:

- Mixed methods
- Pragmatic trials
- Simulation models

“... using comparative effectiveness designs likely most helpful to create actionable item at a systems level.” (Submitted 6/2/17)

“All designs have promise- we should not identify any one design as more important than others. We also need to recognize the limitations in each design. Mixed methods and pragmatic trials are promising because they (mixed methods) provide qualitative data which helps us understand why something works and they (pragmatic trials) bring us closer to translation (actionable information).” (Submitted 6/3/17)

“#1: Stepped wedge designs (if contamination of later-entering cohorts) are under-used in this field I think #2: Issues of refusal of consent. These can be addressed with relative ease when researcher or researcher-proxy has an ongoing relationship with individual/cg. #3: Essential to get large health care systems to invest in research partnerships regardless of designs” (Submitted 6/4/17)

“Randomized block design, Latin square design, randomized cluster design should all be reexamined and optimized---cross-collaboration the field of drug epidemiology may provide innovative solutions.” (Submitted 6/6/17)

“Data standards (literally what are the variables captured and all the needed metadata and how are they labeled to get to the endpoints). Two groups are working on this, a subgroup at DIA [Drug Information Association] and CDISC [clinical data interchange standards consortium]. What they do not yet tie to but should: how this is rolled in to electronic health records (EHR) and in studies. Involve the Office of National Coordinator (ONC) which gave vague EHR guidance but could enforce something specific. If CMS ties reimbursement to the measures/data it will be there. This will be beyond the Sentinel current data captured but PCORnet would be a good place to talk/test/try!” (Submitted 6/7/17)

“Features of successful designs: Those that have input from all relevant stakeholders, researchers to maintain a quality design as well as payers, patients, families, clinicians and other users to keep a practical eye on the situation.... At times we rely on researchers to wear too many hats (e.g., small business owners, CEOs, managers, educators, clinicians, policy roles,

community outreach, legal issues, etc.). Often researchers are not trained for all these roles and their staff is too small to successfully navigate each of these areas... There is a need to improve efficiency of science and its translation. - Partnerships with technology companies ... may provide critical access to infrastructure, and resources-- including novel ways to assist with implementation..." (Submitted 6/12/17)

Other observations submitted:

- Leverage technology
- Strengthen data infrastructure
- Design must be comprehensive—inclusive of PWD, clinicians, primary caregiver, as well as immediate family members
- Address caregiver data
- Use simulation models

Research design considerations submitted:

- Baseline status – analysis cannot be just about group-level change
- Stage of disease/ cognitive status
- Living situation (home vs. care facility)
- Socioeconomic status
- Degree of family involvement
- Capture of relevant confounders

Meeting Sessions – Day 1

<p>Session 1: <i>Engaging People with Dementia and their Caregivers in Research: Selecting Research Priorities, Selecting Outcomes that Matter.</i></p> <p>Chair: Lee Jennings, MD, MSHS</p> <p>Discussants:</p> <ol style="list-style-type: none"> 1. Jason Karlawash, MD 2. Angela Lunde, MA 3. David Reuben, MD 4. Teresa Webb, RN: providing perspective of person living with dementia 	<p>Session 2: <i>Engaging decision makers: How can 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?</i></p> <p>Chair: Brian Mittman, MD</p> <p>Discussants:</p> <ol style="list-style-type: none"> 1. Shari Ling, MD 2. Doris Lotz, MD, MPH 3. Eleanor Perfetto, PhD, MS 4. Jennifer Reck, MA
--	--

The Session 1 discussion was focused on addressing these three questions:

- How can people with dementia and family caregivers be involved in identifying important topics for research?
- How can multi-stakeholder panels be guided in research topic prioritization activities?
- How can input from persons living with dementia and their caregivers be incorporated into selection of outcomes in research projects?

The discussion in Session 2 was focused on addressing these questions:

- What information do health care system decision makers need for dementia care decisions?
- How do different stakeholders access and use information for decision making?

Discussion of Major Themes, Day 1

Discussion at the conclusion of the first day of the meeting yielded the following themes:

- Face the complexity of interventions and outcomes and figure out implications for measurement and trial design
- Develop consistent guidelines/standards for dementia care and services research
- Expand requirement for engagement in research to other funders
- Innovate on study funding (e.g., partner among funding agencies to expand study length)
- Isolate successful elements of interventions
- Think in terms of “micro-innovations” and “mini-improvements”
- Think about unintended effects/impacts beyond stated target.
 - Consider the Housing First movement as a model. Housing First posits that providing stable housing can be a means of supporting the delivery of health services by removing barriers to delivery and receipt of those services. For dementia, such context-based approaches may provide a way to address dementia-relevant needs that may not be the immediate purview of dementia researchers but which impact dementia care meaningfully.
 - Aggregate anecdotal evidence,
 - Signal search
 - How to publish this work?
 - Create new forums for communication/networks
- Accurate reporting – purposeful and requiring minimal processing
 - Examine incentives to misrepresent (e.g., for reimbursement of services)
- Increase efforts to include in research those populations not well represented in current dementia care and services research
 - Missing rural population
 - Missing atypical dementias
 - Missing those with limited access to healthcare
- Messaging for decision makers
 - Simplify goal (e.g., delay nursing home placement)
 - Be honest about consequences

- Efficiency: creating standards for a minimum data set to be used across trials, expanding range of outcomes assessed to add to evidence base and include patient-reported outcomes (Macleod et al. 2014).

Meeting Sessions - Day 2

<p>Session 3: <i>Disease impact and disease progression: How can persons with dementia be involved as participants in research on dementia care and services?</i></p> <p>Chairs: Lisa Gwyther, MSW, LCSW and Darby Morhardt, PhD, LCSW</p> <p>Discussants:</p> <ol style="list-style-type: none"> 1. Soo Borson, MD 2. Rebecca Logsdon, PhD 3. Lonni Schicker, EdD, MHSA, RN – providing perspective of person living with dementia 4. Nancy Wilson, MA, MSW 	<p>Session 4: <i>Study design and implementation: What research methods can be used to test interventions and programs to help people with dementia and their families?</i></p> <p>Chair: David Meltzer, MD</p> <p>Discussants:</p> <ul style="list-style-type: none"> • Joshua Chodosh, MD, MSHS • Kate de Medeiros, PhD • Deborah Paone, DrPH, MHSA • Quincy Samus, PhD
---	--

The Session 3 discussion was focused on addressing these three issues:

- What is known about the strengths and limitations of self-report in cognitive impairment?
- For what domains is caregiver and clinician report preferable and why?
- How can technology expand collection of information direct from persons living with dementia or cognitive impairment?

Summary of Session 3 Pre-read:

- Need to clarify the term “people with dementia”
- Factors for consideration
 - Heterogeneity in dementia types
 - Variability in symptom presentation
 - Individual differences before the illness
 - Different stages of disease progression
- Key points from literature
 - Need for conceptual framework for self-report
 - Include the person with dementia perspective in conceptual framework development
 - Need to address informant report, self-report and the use of both
 - Need for more longitudinal designs

- Enhancing self-report with non-verbal information
- Align the research so that persons with dementia can participate

See [Appendix 4](#) for a detailed summary of the presentations in this session.

The Session 4 discussion was focused on addressing these 2 methodological issues:

- What study designs have been effective in dementia care and services research?
- How can observational designs be optimized?

Discussion of Major Themes, Day 2

At the conclusion of the second day, the themes identified after Day 1 were revisited. Additional points raised involved:

- PCORnet/AD-PCPRN as test bed for interventions. The intention of building the PCORnet infrastructure is to provide infrastructure for rapid and large-scale studies of interventions, at the level of individuals, populations, and health systems.
- Goal Attainment Scaling: Goal attainment scaling is an approach to measuring an individualized outcome in a way that can be standardized across a group (i.e., the goal is individual but the measurement of attainment is standardized). This approach to measurement allows the consideration of a common outcome (goal attainment) across a heterogeneous population of persons with dementia.
 - GAS also allows the measurement of outcomes relevant to an individual (goals for care) that span conditions as dementia occurs in the setting of multi-morbidity for most persons.
 - Methods needed to address heterogeneity – from study design to data collection to data analysis.
- Fluctuating Capacity:
 - Measurement of meaningful change via:
 - Distribution-based methods, in which statistical characteristics of the data, such as standard error of the mean, are used as the basis for determining meaningfulness of score changes;
 - Anchor-based methods, in which external referent, such as patient- or clinician-judgement of meaningfulness, is used as the basis for identifying meaningful score changes. (For example, see Redelmeier et al., 1996, and Revicki et al., 2008.)

With that in mind, the group reviewed each of the four main themes to add detail and to check if those themes comprehensively captured the main points of the Summit. Two additional themes were added at this stage.

1. Research funding and efficiency
2. Deciding what to measure – who and what – *added after Day 2 discussion*

3. Measuring impact accurately
4. Effective communication of findings – *added after Day 2 discussion*
5. Reporting to decision makers
6. Creating infrastructure for massive testing and scaling up

Detail for each of those categories discussed during this wrap-up session is provided below.

1. Research funding and efficiency
 - Change funding structure
 - Add engagement resources
 - Invest in successful models
 - Add interactions with those outside the researcher community
 - At professional meetings
 - Evaluating funding applications/deciding where money goes
 - On research teams
 - In outreach
 - Review plans with NIA Division of Behavioral and Social Research, which attends to health economic and policy issues related to reimbursement for services
 - Get payer comments on research and pursue active payer engagement
 - Involve all relevant end-users and stakeholders, such as payers, advocates, providers, and those in the settings where programs are to be implemented. Reference the CDC Framework (<https://www.cdc.gov/eval/framework/index.htm>) and principles of CBPR.
 - Require study of care effectiveness as requirement for insurance coverage. Examine pros and cons of doing so.
 - Consider partnership/co-funding possibilities with humanities based research, as through the National Endowment for the Humanities.
 - Set up more networks for funding and partnerships.
 - Civil money penalty reinvestment project funding from Office of Health Care Quality (OHCQ) has an implementation focus; connect to efforts there.
 - Address gaps in the existing patchwork of service delivery. Consider health services research to test innovations to coordinate care
 - Consider building into funding ways to address obstacles to adoption of good models of service delivery.

Private funding options were discussed. A point was raised about the potential for venture capital funding with reference to some models for home care already in place, pointing to the research/business interface.

2. Deciding what to measure – *added after Day 2 discussion*
 - Make sure unit of analysis for effectiveness is not overly narrowly defined.
 - Endorse use of logic models to make explicit the assumptions, inputs, interim outputs and longer term impacts expected from the research; gather stakeholder and end-user perspectives on the draft logic model.
3. Measuring impact accurately
 - Accuracy of self-report
 - Domains and reporters
 - Technology for data collection – unobtrusive measurement
 - Data analysis – signal searching
 - PROs in clinical practice. There was skepticism expressed about the value of PROs for use in dementia care and services research, given concerns about reliability of self-report, particularly at moderate to severe levels of cognitive impairment. After discussion there was consensus toward the value of appropriately selected PROs, matched to disease severity. Some self-reported domains could be reliably reported into late-moderate stages of disease. Other self-report is state-dependent (e.g., pain) and may be reliable at later stages of disease. Work should continue to improve interpretability and communication to clinicians and persons living with dementia about PRO data. GAS was mentioned as a promising method for dementia
4. Effective communication of findings – *added after Day 2 discussion*
 - Consider the value proposition for key stakeholders – start at the end and work back.
 - Consider translation issues upfront – include a range of settings and population subgroups to guide adaptations, avoid Type II error.
 - Potential for usability/dissemination, as well as research planning and design, would be greatly enhanced with formative or developmental evaluation baked in to the process. Consider an embedded evaluator who can capture the key implementation factors.
5. Reporting to decision makers - getting the message out
 - Dealing with ambiguity without undercutting the message
 - Strength of evidence and policymaking
 - What does CMS need to see? Statutory focus on benefit to identified “patient” – how to address caregiver needs?
 - Statutory requirements
6. Creating infrastructure - for massive testing, and scaling up infrastructure

The following existing infrastructure was cited as promising channels for dementia care and services research:

- PCORnet experience with the AD-PCPRN (<https://www.alzheimerspcprn.org/>) and the PCORnet Front Door (<http://www.pcornet.org/>) for research proposals
- Alzheimer Disease Research Centers (ADRCs) (<https://www.nia.nih.gov/health/alzheimers-disease-research-centers>)
- VA projects

In addition, participants recommended attending to levels of evidence existing infrastructure can generate.

The group turned to using goal formulations to guide recommendations. Sample goal statements were discussed:

- Goal: Reduce translation timeline from research to clinical setting (set concrete target)
- Goal: Increase community participation in research by XX% (set concrete target)
- Goal: Create communication channels from research to stakeholders (implementation research can inform this goal)

Additional themes were nominated for inclusion in the recommendations:

- Safety/efficacy of interventions
- Feasibility of interventions
- multidimensional model of health-related quality of life; reference work of M Powell Lawton
- Overemphasizing focus on scales to detriment of effectiveness demonstration
- Message all people in health systems to be involved in research – include all stakeholders
- Biomedical model doesn't work for scaling intervention research – what are options?

Feedback on Meeting Summary and Recommendations:

From the leadership of the Stakeholder Group for Individuals Living with Dementia

On August 9 the PCORI staff convener of the pre-summit (Lori Frank) presented a one page summary to the Stakeholder Group for Individuals Living with Dementia to provide feedback on the proceedings and to collect input on recommendations that should flow from this Pre-summit to the October 2017 Summit (See [Appendix 4](#) for the summary document).

These four stakeholders expressed appreciation for the Pre-summit, in which two of the stakeholders participated. They encouraged attention to nomenclature and shared a document on “outcomes that matter” that includes reference to nomenclature. They also had specific suggestions for additional recommendations:

- 1) Consider an inclusive rather than exclusive approach to trial enrollment. They mentioned interested people being denied the opportunity to participate in research studies due to a lack of a care partner who would enroll with them. They pointed out that individuals who live alone or otherwise lack a care partner should be able to join studies on their own. For many individuals, asking a friend to accept the burden and disruption of serving as a study participant is challenging. Enrollment criteria that excludes these individuals, feeds into the stigma about what individuals with dementia can and cannot do. Are there questions that participation of these individuals, even without care partners, could help address? Similarly, some study age requirements are excluding individuals because they are too young. The group suggested a reexamination of the rationale for age restrictions.
- 2) Actively examine steps that can make study participation more feasible for more people. For those that live at a distance from research centers, could some or all of the study visits be completed remotely?
- 3) Engagement in research by people living with dementia and caregivers is very promising. Among the ideas this group offered for consideration by the Summit group: create opportunities to allow more interaction between researchers and those they are interested in including in research studies and on research teams, a kind of “speed dating” to facilitate matching of researchers and research partners. The interactive nature of the PCORI Pre-summit was praised, with the meeting and also conference dinner involving mixing of people living with dementia, caregivers, and researchers. These types of interactions change the relationship from one of person as “lab rat” to person as partner.
- 4) Regarding the first recommendation to “Fund more research on how people living with dementia and their caregivers can be partners with researchers”, clarify that the intention is to have individuals who are not researchers but who are affected by the condition contribute ideas about the content of research studies and help set up the questions being studied.
- 5) The group suggested adding a recommendation to address the need for data sharing policies and transparency, to permit cross-study sharing and efficiency, so that new research is not “starting at ground zero.”

Summing up: Recommendations from the Pre-Summit

The recommendations that emerged from this Pre-summit are presented in the form of an action plan, with specific steps related to the following five areas: 1) scientific issues, 2) research infrastructure needs, 3) regulatory needs, 4) administrative issues, and 5) financial requirements for both research funding and care reimbursement to support research. Each area is discussed below.

1. **Scientific issues:**

The Pre-summit provided an overview of some examples of innovative dementia care and services research; however, research is lacking in two areas:

- Knowledge translation, to take effective or promising models and transfer them to other settings and/or to other populations; and
- Empirical information on how to optimize research engagement to enhance decision-making, both about research and about care.

Existing models for dissemination and implementation research can be usefully applied to dementia care and services research on a broader scale than has been done to date.

New research on best methods for engaging people with dementia and caregivers across phases of research is needed. Adding to the evidence base is required to address skepticism about the feasibility of engagement of people with dementia in research, and the value of such engagement remains to be demonstrated across settings.

Scientific Recommendations:

- Commit to “research done differently” and focus on engagement, moving beyond existing schemas. Specifically:
 - Use research engagement and research partnership models to enhance decision making about research.
 - Address inclusion of people living with dementia and caregivers in governance for research. Value and seek out diversity to ensure novel perspectives and ideas inform research.
 - Engage people living with dementia not just as research subjects in research studies but also as research partners, to provide input on developing interventions.
- Tackle high priority conceptual issues:
 - Actively reference the culture of science in review of funding, particularly the relative valuing of care and services research vs. prevention/cure/pharmacologic research. How can care and services research funding be improved? How can its value to end users – care providers, caregivers, people living with dementia, payers – be summarized and communicated?

- Create conceptual frameworks for measurement that address the challenges of heterogeneity of dementias, within-individual fluctuations in symptoms and capabilities, and differences in disease course. Also address range of relevant outcomes and incorporating differences within the same trial, e.g., via goal attainment scaling. Be explicit about purpose of obtaining input from persons living with dementia, whether to capture what they value and how they feel or whether to capture performance concerns.
 - Be clear about measurement target: people living with dementia and caregivers as dyads, caregiving activities distinguished from other elements of the relationship between the person living with dementia and a caregiver.
 - Recognize caregiving for the cost driver it is when designing interventions.
- Create a methods research agenda to address the following points:
 - Recognize the value of observational and other types of research, such as qualitative research, to informing methods and approaches.
 - Improve the efficiency of longitudinal research: explore robust funding models, including funding partnerships and hand-offs, to build on existing infrastructure and support longitudinal study.
 - Tackle use of informant vs self-report. Invest in research on how to optimize measurement through multiple data sources, understanding when to weight informants more heavily than people living with dementia and vice-versa.
 - Expand use of alternative methods to get report direct from individuals. Address methods for non-verbal data collection.
 - Address the value of “laboratory” vs. real-world measurement, especially of functioning but also of cognition.
 - Account for population heterogeneity and different and overlapping types of dementia.
 - Invest in goal attainment scaling as a method.

2. **Research Infrastructure:**

Research infrastructure built through PCORnet is an important foundation; however, additional data infrastructure linkages are required. While the call for “Research Done Differently” (www.PCORI.org) should be heeded in terms of building infrastructure that engages stakeholders in the process and in the resulting research, there is a need to “Organize Research Differently” as well. How can research infrastructure be set up to avoid discontinuities in funding, with the resulting inefficiencies, between different funders and across different organizations like academic research centers?

Research Infrastructure Recommendations:

- Identify models for public/private partnerships for infrastructure.
 - Existing plans of action (e.g., NAPA [<https://aspe.hhs.gov/national-alzheimers-project-act>], International Brain Health Initiative) should be amended to provide appropriate attention to care and service needs, supplementing the heavy emphasis on diagnosis and drug development.
 - Recognize the value of observational and other types of qualitative research that can help inform current methods and approaches.
- Incorporate specific policy recommendations about care and services into national and international plans. There is no National Program for health services research in dementia, but this is needed.
- Take methods research agenda and look for ways to incorporate it into existing research (e.g., fund methods “add-ons” to examine real-world vs. in clinic measurement of functioning).
- Enhance workforce development, as part of translating effective interventions.
- Improve research prioritization activities through cross-agency coordination, inclusion of people with dementia and caregivers and others from the public. Reference successful models from other therapeutic areas and from other countries already prioritizing dementia research topics.
- Set up real-time evaluation and real-time feedback systems for health systems. This is more complex for services research than for research on drug treatments.
- Build from the PCORnet experience; expand networks and fund a broader range of goals.

3. Regulatory issues:

Drug and device regulatory practice in the United States is increasingly incorporating patient and consumer views (see for example the FDA’s Patient-Focused Drug Development program, <https://www.fda.gov/ForIndustry/UserFees/PrescriptionDrugUserFee/ucm347317.htm>). Expanding this patient-centric emphasis into dementia research will strengthen the evidence base for research engagement in dementia.

Regulatory recommendation: Strengthen requirements for engagement of persons living with dementia in drug and device development and regulatory product review.

4. Administrative requirements:

Coordinating infrastructure is a key administrative requirement for this agenda, as is establishing efficiency strategies to provide for continuity of research programs across funders and mechanisms for sending research funds to promising innovations.

Administrative recommendations:

- Convene multiple funders to develop plan to explicitly address cross-agency co-funding and continuity plans.
- Create streamlined communication channels to respond to changes in funder ability to support new and ongoing research, ensuring partnerships that can avoid wasteful disassembly of productive research programs.

5. Financial requirements for this agenda:

A major challenge to improving methods in dementia care and services research relates to structuring funding for research. As noted above under infrastructure, PCORnet and other network initiatives are promising models for generating and testing hypotheses relatively quickly. What other funding models are needed to leverage these, e.g., parallel or serial funding initiatives. For parallel or co-funding initiatives, how can research dollars be used most efficiently? For serial funding initiatives, how can coordinated funding be set up to leverage investments as one funder's contribution ends, without inefficient loss of research infrastructure as another funder's contributions begin? Health insurance demonstration projects will require regulatory change to implement.

Recommendations for financing research: Consider models of coverage with evidence development and a focus on reimbursement models to support priority research.

Appendices

Appendix 1: Dementia Methods Pre-Summit Agenda



Agenda

Dementia Methods Pre-Summit

June 7-8, 2017

Residence Inn
Arlington Capital View
2850 South Potomac
Avenue
Arlington, VA 22202

Day 1	Wednesday June 7, 2017
12:00PM	Lunch and Arrivals
1:00PM	Welcome and Foundation Setting for Pre-Summit
1:30 PM	<i>Session 1: Engaging People with Dementia and their Caregivers in Research</i> Chair: Lee Jennings, MD, MSHS <ul style="list-style-type: none">• How can people with dementia and family caregivers be involved in identifying important topics for research?• How can multi-stakeholder panels be guided in research topic prioritization activities?• How can input from patients with dementia and their caregivers be incorporated into selection of outcomes in research projects? Discussants: Jason Karlawish, MD; Angela Lunde, MA; David Reuben, MD; Teresa Webb, RN
3:00 PM	Break
3:15 PM	<i>Session 2: Engaging Decision Makers in Dementia Care and Services Research</i> Chair: Brian Mittman, PhD <ul style="list-style-type: none">• What information do health care system decision makers need for dementia care decisions?• How do different stakeholders access and use information for decision making? Discussants: Shari Ling, MD; Doris Lotz, MD, MPH; Eleanor Peretto, PhD, MS; Jennifer Reck, MA
4:45 PM	Integration discussion for Sessions 1 and 2
5:45 PM	Adjourn for dinner



Agenda

Dementia Methods Pre-Summit

June 7-8, 2017

Residence Inn
Arlington Capital View
2850 South Potomac
Avenue
Arlington, VA 22202

Day 2	Thursday June 8, 2017
8:00 AM	Recap of Day 1 and Introduction to Day 2
8:30 AM	<p>Session 3: <i>Measuring Disease Impact: Collecting Information from People with Dementia and their Caregivers</i></p> <p>Co-chairs: Darby Morhardt, PhD, LCSW and Lisa Gwyther, MSW, LCSW</p> <ul style="list-style-type: none">• What is known about the strengths and limitations of patient self-report in cognitive impairment?• For what domains is caregiver and clinician report preferable and why?• How can technology expand collection of information direct from patients? <p>Discussants: Soo Borson, MD; Rebecca Logsdon, PhD; Lonni Schicker, EdD, MHSA, RN; Nancy Wilson, MA, MSW</p>
10:00 AM	Break
10:15 AM	<p>Session 4: <i>Study Design and Implementation: Testing Interventions for People with Dementia and their Families</i></p> <p>Chair: David Meltzer, MD, PhD</p> <ul style="list-style-type: none">• What study designs have been effective in dementia care and services research?• How can observational designs be optimized? <p>Discussants: Joshua Chodosh, MD, MSHS; Kate de Medeiros, PhD; Deb Paone, DrPH, MHSA; Quincy Samus, PhD</p>
11:45 AM	Integration discussion for Sessions 3 and 4 and creation of methods research recommendations for dementia care and services research
12:45 PM	Recommendation review and prioritization
1:15 PM	Adjourn with box lunch

Appendix 2: Steering Committee

Arlene Bierman, MD, MS

Agency for Healthcare Research and Quality (AHRQ)

Chris Callahan, MD

Indiana University-Purdue University Indianapolis

Elena Fazio, PhD

National Institute on Aging (NIA)

Laura Gitlin, PhD

Johns Hopkins School of Nursing; Johns Hopkins School of Medicine

Lisa Gwyther, MSW, LCSW

Duke University

Lee Jennings, MD, MSHS

University of Oklahoma Health Sciences Center

Ian Kremer, JD

LEAD (Leaders Engaged on Alzheimer's Disease) Coalition

Katie Maslow, MSW

Gerontological Society of America (GSA)

David Meltzer, MD, PhD

PCORI Methodology Committee, University of Chicago

Brian Mittman, PhD

PCORI Methodology Committee, Veterans Affairs Greater Los Angeles Healthcare System,
Kaiser Permanente

Darby Morhardt, PhD

Northwestern University

David Niebuhr, MD, MPH

Agency for Healthcare Research and Quality (AHRQ)

Kim Wittenberg, MA

Agency for Healthcare Research and Quality (AHRQ)

Mary Kay Margolis, MPH, MHA

Patient Centered Outcomes Research Institute (PCORI)

Lori Frank, PhD

Patient Centered Outcomes Research Institute (PCORI)

Appendix 3: Links to Background Materials

Nicholson, G, & Andersen, C. (2017). Dementia Methods Pre-Summit Materials: Session 1: Engaging People with Dementia and their Caregivers in Research. Retrieved from <https://www.pcori.org/sites/default/files/PCORI-Dementia-Methods-Pre-Summit-Session1-June-07-08-2017.pdf>

Frazier, K, Kary, W, Cowans, T, Keller, Q, & Frentzel, E. (2017). Dementia Methods Pre-Summit Materials: Session 2: Engaging Decision Makers in Dementia Care and Services Research. Retrieved from <https://www.pcori.org/sites/default/files/PCORI-Dementia-Methods-Pre-Summit-Session2-June-07-08-2017.pdf>

Frentzel, E, Kary, W, Keller, Q, Paez, K, & Ying W. (2017). Session 3: Measuring Disease Impact: Collecting Information from People with Dementia and their Caregivers. Retrieved from <https://www.pcori.org/sites/default/files/PCORI-Dementia-Methods-Pre-Summit-Session3-June-07-08-2017.pdf>

Nicholson, G, & Andersen, C. (2017). Dementia Methods Pre-Summit Materials: Session 4: Study Design and Implementation: Testing Interventions for People with Dementia and their Families. Retrieved from <https://www.pcori.org/sites/default/files/PCORI-Dementia-Methods-Pre-Summit-Session4-June-07-08-2017.pdf>

Nicholson, G, & Andersen, C. (2017). Dementia Methods Pre-Summit Materials: Session 4: Study Design and Implementation: Testing Interventions for People with Dementia and their Families. Retrieved from <https://www.pcori.org/sites/default/files/PCORI-Dementia-Methods-Pre-Summit-Session4-Part2-June-07-08-2017.pdf>

Lepore, M, Shuman, S, Wiener, J, Gould, E, & RTI International. (2017). Summit Report on Challenges in Involving People with Dementia as Study Participants in Research on Care and Services. Retrieved from <https://aspe.hhs.gov/basic-report/challenges-involving-people-dementia-study-participants-research-care-and-services>

Appendix 4: Session 3 Panelist Summaries

Melanie (Lonni) Schicker

Person living with mild cognitive impairment

- Services and treatment research must consider the stigmatizing effects of language around diagnosis. For example, Lonni lives in limbo between diagnoses of “moderate” MCI and early Alzheimer’s disease and it has been her experience for the public and professionals to confuse cognitive impairment with mental illness.
- Research is needed on how best to address public and professional awareness regarding the unique impairments in early stage dementias. Professionals and the public tend to discount or trivialize non-trivial symptoms of cognitive decline and their effects on daily life.
- Research is needed on how to buffer or reduce the devastating financial impact of early diagnosis, particularly for single persons with younger onset dementias facing job, income and insurance coverage losses.
- Research should address gaps in community-based programs offering opportunities for persons with early stage dementias to find purpose and meaning in volunteer or advocacy opportunities. For example, the Alzheimer’s Association included her as a speaker, teacher and advocate; however, local senior centers offer few meaningful participatory roles for people with early stage dementia.

Soo Borson

- Make no assumptions: No person living with dementia should be automatically excluded as a source of information about themselves and their experiences without verifying that they cannot provide the necessary information. (This is often done by means of a cognitive screening test, without verifying that the screening test truly indicates that the information to be sought can’t be obtained. (Taylor, DeMers, Vig, & Borson, 2012). Without verifying the screening test as a valid indicator, then the information in question cannot be obtained reliably from the person living with dementia.
- While specific cognitive deficits can interfere with valid verbal responses, this varies considerably from person to person, type of impairment, stage of cognitive decline. When necessary, alternate methods of obtaining information may be effective. One example of this would be tailoring queries so they can be responded to (or understood) by non-verbal or motor means.
- Expression of emotional/non-verbal and visual rather than verbal responses should be properly classified and standardized for research purposes.
- Make queries personally relevant and anchor them to an individual experience and/or the values of the person living with dementia. (It is difficult to respond to abstractions).
- For the field, create an encyclopedia of tools that have been well validated for use by people with dementia, those for which self- and proxy reports have been compared, and those that have been evaluated across dementia stages. The best example is Rebecca’s QoL-AD. This thorough methodological approach is a beautiful example for the field.

Rebecca Logsdon

1. Why do we need self-report from PWD?
 - a. Respect for our research partners
 - b. To facilitate participation
 - c. It is the best way to obtain information regarding subjective states, values and beliefs.
 - d. An exclusive reliance on informants may be misleading as informant responses will be affected by caregiver burden, depression, the current and prior relationship and the amount/level of contact (Martyr, Nelis & Clare, 2014.)
 - e. Many persons with dementia do not have an informant or caregiver available and they are excluded from research.
2. What influences self-report from PWD?
 - a. Individual characteristics
 - Cognitive-comprehension, language, memory
 - Insight, understanding, acceptance of diagnosis and prognosis
 - Education, health literacy, cultural norms, perceived consequences
 - Disease progression and changes over time support the need for longitudinal studies. The good days/bad days aspects of cognitive decline could strongly affect cross sectional or one point in time self-reports.
 - b. Characteristics of measure
 - Design and complexity
 - Support for sensory and cognitive challenges; for example, large print, cues for response options
 - c. How collected
 - Questionnaire, interview, in-person, over phone
 - Level of detail
3. Multi-step, can it be broken into smaller components; e.g., poor-fair-good-excellent – could be broken into mostly good (good or excellent) or not so good (fair or poor).
 - a. Nature of information
 - Subjective: opinion, value, feeling
 - Objective: ADL, IADL, specific tasks
 - Memory requirements; e.g., ‘in the past week...’ vs. right now
4. Future Directions
 - a. How can we make existing measures more user-friendly, such as magnet boards? (Orsulic-Jeras, Whitlatch, & Szabo, 2016)
 - b. Carefully decide what outcomes are essential and consider task analysis or human factors research to ensure they are useable – persons with dementia must be involved in this process.
 - c. Technology – objective, observable behaviors including ADL, IADL; e.g., activity monitors are more sophisticated, user-friendly and inexpensive (Kaye, 2007).
 - d. Cell phone use – GPS, patterns of use
 - e. Facial expression / eye movements

Nancy Wilson

- When we do not include the person with dementia in self-report of subjective state we run risks of not addressing key treatable and common conditions like anxiety or depression. Many family caregivers err on attributing everything to dementia and they may not be the best informants about the person's subjective needs, fears and serious anxiety symptoms. Identifying anxiety with the input of the person living with dementia makes it possible to help both members of the dyad learn skills and strategies to address the disabling aspects of dementia (Bradford et al, 2013; Snow et al, 2012; Stanley et al, 2013).
- In the Partners in Dementia Care trial, staff were trained to conduct research interviews by telephone with veterans and caregivers--and approximately 8% of the trial subjects were self-report only due to absence of a caregiver participating. A simple cognitive screen with non-traditional scoring (Blessed) was used. However, more research is needed to determine the best instruments and approaches for determining whether a person is able to report their subjective experience (Bass et al,2014).
- Addressing these issues that focus on inclusion of the person with dementia in research has important implications for practitioners and clinicians; that is, to assure the person living with dementia is considered throughout the illness course.

Summary of Recommendations from the Dementia Methods Pre-Summit, June 2017

The Patient-Centered Outcomes Research Institute (PCORI) funds research. In June, PCORI held a meeting about methods for dementia research. The attendees were dementia researchers, people living with dementia themselves and their loved ones, state and federal health policy makers, and research funders. The goal was to determine what is working well and what to do next, to improve the study of dementia care.

The two day meeting was divided into four sessions:

The **first** session was about engaging people living with dementia and their caregivers in research. They can be research partners who help plan the studies and decide what research questions should be answered, instead of serving only as research subjects. PCORI requires that the research it funds include people affected by the condition in the planning, conduct, or communication about the research. This is a unique requirement in the United States. The PCORI-funded research network, called the Alzheimer's Disease Patient- and Caregiver-Powered Network, was discussed during this session.

The **second** session was about the engagement of other types of stakeholders in research, particularly policy makers. So far, this does not happen very often.

The **third** session was about the best ways to get information about dementia care directly from people living with dementia.

The **fourth** session was about challenges researchers have with figuring out what dementia care types work and why.

The recommendations that we plan to share at the Summit in October involve ways to improve the efficiency of research funding for dementia care and ways to *bring the voice of those living with dementia into more research*.

There is no coordinated national program for health services research in dementia. One should be created!

Here are specific recommendations:

1. Fund more research on how people living with dementia and their caregivers can be partners with researchers.
2. Fund more research on how to communicate findings of research so more people can benefit.
3. Funders should work together to fund longer-term studies.
4. Funders should add research on dementia care to studies on drug treatment.
5. More studies should compare what people living with dementia say to what others around them say about their dementia care.
6. More research is needed in the "real world" instead of in laboratories.
7. Large networks for research have been promising and should continue to be supported.

References

- Bass, D. M., Judge, K. S., Snow, A. L., Wilson, N. L., Morgan, R. O., Maslow, K., Kunik, M. E. (2014). A controlled trial of Partners in Dementia Care: veteran outcomes after six and twelve months. *Alzheimers Res Ther*, 6(1), 9. doi: 10.1186/alzrt242
- Bradford A, Brenes GA, Robinson RA, Wilson N, Snow AL, Kunik ME, Calleo J, Petersen NJ, Stanley MA, Amspoker AB. (2013). Concordance of self- and proxy-rated worry and anxiety symptoms in older adults with dementia. *J Anxiety Disord*. 27(1):125-30. doi:10.1016/j.janxdis.2012.11.001.
- Frank L, Basch E, Selby JV; Patient-Centered Outcomes Research Institute. (2014). The PCORI perspective on patient-centered outcomes research. *JAMA*. 312(15):1513-4. doi: 10.1001/jama.2014.11100. PubMed PMID: 25167382.
- Iliffe S, McGrath T, Mitchell D. (2013). The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): case studies. *Health Expect*. 16(4):351-61. doi:10.1111/j.1369-7625.2011.00728.x.
- James, J. (2016). Health Policy Brief: Patient Engagement. Retrieved September 19, 2017, from <http://www.rwjf.org/en/library/research/2013/02/patient-engagement.html>
- James Lind Alliance. (2016). "About the James Lind Alliance." Retrieved September 19, 2017, from <http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/>
- Kaye J. (2008). Home-based technologies: a new paradigm for conducting dementia prevention trials. *Alzheimers Dement*. 4(1 Suppl 1):S60-6. doi:10.1016/j.jalz.2007.10.003.
- Khachaturian, Z. S. (2012). Perspectives on Alzheimer 's disease: Past, Present and Future. In Carillo MC, Hampel H. *Alzheimer's disease – Modernizing concept, biological diagnosis and therapy*. *Adv Biol Psychiatry*. Basel, Karger, vol 28:179-188.
- Macleod et al. (2014). Biomedical research: increasing value, reducing waste. *Lancet*. 11;383(9912):101-4.
- Martyr, A, Nelis, SM, & Clare, L. (2014). Predictors of perceived functional ability in early-stage dementia: self-ratings, informant ratings and discrepancy scores. *International Journal of Geriatric Psychiatry*. 29(8), 852–62. doi: 10.1002/gps.4071.
- OECD. (2013). Emerging Trends in Biomedicine and Health Technology Innovation: Addressing the Global Challenge of Alzheimer's. OECD Science, Technology and Industry Policy Papers, No. 6. OECD Publishing, Paris. <http://dx.doi.org/10.1787/5k44zcpt65vc-en>
- Orsulic-Jeras S, Whitlatch CJ, Szabo SM, Shelton EG, Johnson J. (2016). The SHARE program for dementia: Implementation of an early-stage dyadic care-planning intervention. *Dementia (London)*. DOI: 10.1177/1471301216673455. pii: 1471301216673455.

Redelmeier DA, Guyatt GH, Goldstein RS. (1996). Assessing the minimal important difference in symptoms: a comparison of two techniques. *J Clin Epidemiol.* 49(11):1215-9. PubMed PMID: 8892486.

Revicki D, Hayes RD, Cella D, Sloan J. "Recommended Methods for Determining Responsiveness and Minimal Important Differences for Patient-Reported Outcomes." *J Clin Epidemiol.* 2008; 68:102-9.

Sheridan S, Schrandt S, Forsythe L, Hilliard TS, Paez KA. (2017). Advisory Panel on Patient Engagement (2013 inaugural panel). The PCORI Engagement Rubric: Promising Practices for Partnering in Research. *Ann Fam Med.* 15(2):165-170. doi:10.1370/afm.2042.

Snow AL, et al. (2012). Psychometric properties of a structured interview guide for the rating for anxiety in dementia. *Aging Ment Health.* 16(5):592-602. doi: 10.1080/13607863.2011.644518.

Stanley, MA, et al. (2013). The peaceful mind program: a pilot test of a cognitive-behavioral therapy-based intervention for anxious patients with dementia. *Am J Geriatr Psychiatry,* 21(7), 696-708.

Taylor, J.S., DeMers, S.M., Vig, E.K., & Borson, S. (2012). The disappearing subject: exclusion of people with cognitive impairment and dementia from geriatrics research. *J Am Geriatr Soc,* 60, 413-419. doi: 10.1111/j.1532-5415.2011.03847.x.