

New Directions in Measurement for Psychosocial Research on Dementia Care and Services

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#DementiaCareSummit

New Directions in Measurement for Psychosocial Research

- Conducted two pre-summit meetings
 - Alzheimer's Association International Conference
 - International Association for Geriatrics and Gerontology
- Goal: Bring together expert researchers in dementia care to discuss psychosocial measurement areas in an effort to create a framework where research can be guided with a unified understanding

Pre-Meeting Survey and Discussion

- Distributed to all invited participants in both locations
- Measurement areas, including outcomes for individuals with dementia and their caregivers
- Pros and cons of existing measures
- What Alzheimer's Association can do

Pre-Summit Meeting Participants

Sube Banerjee MBBS MD
Brighton and Sussex Medical School

Laura N. Gitlin, PhD
Johns Hopkins

Doug Pace, NHA
Alzheimer's Association

Soo Borson MD
University of Minnesota

Lisa P. Gwyther, MSW, LCSW
Duke University

James Pickett, PhD
Alzheimer's Society UK

Kate de Medeiros, PhD
Miami University

Beth Kallmyer, MSW
Alzheimer's Association

Joanne Pike, DrPH
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Murna Downs, PhD
University of Bradford

Katie Maslow, MSW
GSA

David B. Reuben, MD
UCLA

Patrick Doyle, PhD
Brightview Senior Living

Mary Mittelman, DrPH
NYU

Sheryl Zimmerman, PhD
University of North Carolina

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Darby Morhardt PhD, LCSW
Northwestern University

Pre-Summit Meeting Summary

- **Good measures exist in many areas, and good research is taking place**
- Rather than listing key measurement areas and measures, we need to step back and re-conceptualize approach because measurement may currently be:
 - Too myopic
 - Stem from a deficiency framework
 - Sometimes derived from biomedical research
 - Missing areas of importance
- Better measurement will allow more individualization and better outcomes
- Need to build a more complete conceptual model— domains, gaps, priority areas and measures

Principles for Re-Conceptualization

New directions in measurement should:

1. Address multiple levels of inquiry—individual, familial/relational, living environment, community
2. Capture perspectives of multiple stakeholders, acknowledging the primacy of the view of the person living with dementia
3. Recognize person-centeredness—the individual experience of change, impact of change, and adaptation to change
4. Focus on strengths, in addition to impairments
5. Take into account time as a variable because dementia is a progressive disease, and experiences differ along the course

Examples of Important Areas of Measurement Development

- Persons living with dementia: measures assessing engagement, optimism, preserved capabilities or development of goal elicitation techniques and methods of assessing goal attainment
- Caregivers: measures of readiness, resilience, family conflict and decision-making
- Measures related to implementation processes including systematic measures of contextual factors

Not comprehensive or developed by consensus

Next Steps

- Lead and convene workgroup to build conceptual model based on principles
- Convene larger expert group to:
 - Review model, identify gaps and establish priorities
 - Prioritize measurement areas and build consensus on specific measures
 - Identify gaps in measures
 - Work with partner organizations to build searchable database