Accelerating Innovation in Alzheimer’s Through Digital Research & Care Networks

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## Advanced Dementia: Research Priorities for the Next Decade

### Disease Stage
- **At risk population**
  - Subtle cognitive deficits alone
  - Increasing cognitive deficits
  - Detectable functional deficits
  - Dementia

### Evidence on Risks And how to influence them

### Table 2. Priorities for Advanced Dementia Research Over the Next Decade

<table>
<thead>
<tr>
<th>Discipline</th>
<th>Broad Research Objectives</th>
<th>Specific Examples</th>
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<tbody>
<tr>
<td>Intervention</td>
<td>Design and conduct RCTs of interventions to promote high-quality, goal-directed care across health care settings Design and conduct RCTs of interventions to reduce disparities in end-of-life care</td>
<td>RCT of an intervention to reduce hospital transfers for nursing home residents with advanced dementia whose goal of care is comfort RCT of a clinical pathway to reduce feeding tube insertions in hospitalized patients with advanced dementia RCT of culturally sensitive video decision aids that use visual images (vs. verbal explanations) to illustrate treatment options</td>
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<tr>
<td>Health policy/services</td>
<td>Identify policies that incentivize high-quality, cost-effective end-of-life care Test strategies to increase access to hospice care and palliative care programs Conduct comparative effectiveness research of treatment strategies</td>
<td>Develop and evaluate nursing home quality indicators for end-of-life care Examine effect of introducing payment for hospice during receipt of skilled nursing facility care Determine the incremental cost-effectiveness ratio of not hospitalizing nursing home residents with advanced dementia for suspected pneumonia (e.g., incremental changes in quality-adjusted outcomes relative to costs)</td>
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<tr>
<td>Implementation</td>
<td>Conduct projects to implement proven interventions and policies</td>
<td>Demonstration project of evidence-based advanced dementia care intervention into nursing home practice</td>
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<tr>
<td>Measurement</td>
<td>Develop new advanced dementia-specific instruments for outcomes currently lacking valid measures Better establish psychometric properties of existing instruments</td>
<td>Measure of stress among family members of nursing home residents with advanced dementia Develop utility-based measures of health-related quality of life in order to conduct comparative effective research Determine minimally clinically important difference for Symptom Management at the End-of-Life in Dementia Scale (30)</td>
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**RCT** = randomized, controlled trial.

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Oracle Analysis
Status Quo

Current Status on Alzheimer’s & Knowledge Sharing

+ Multiple Advanced Research Networks
+ Silo-ed Knowledge
+ Silo-ed Investments
+ Insufficient or low evidence-base
Using Technology to Harmonize Data
Evidence-based IT in Healthcare

- **CLINICAL CARE:**
  - Use of Electronic Health Records improved the quality of Diabetes Care\(^1\)

- **CER:**
  - Electronic Practice-based Networks deliver significant value to CER (DARTNet)\(^2\)

A meaningful use of technology (Information Exchange) could accelerate global Innovation on Alzheimer’s and help sustain the 2020 objectives

Health Information Exchange
Standards solve common challenges

- How to identify the data source uniquely and unambiguously?
- How to leverage many messaging and document standards (HL7 v2, CDA, CCD, etc) and combine in a summary view?
- How to deal with many terminology (ICD, LOINC, SNOMED) standards and combine in a summary view?
- How to create a unified research dataset?
- How to ensure security, privacy and allow for rigorous consent management?
- How to leverage existing clinical data without copying them centrally?
- How to scale to cope with regional and longitudinal volumes?
- How to avoid and treat missing data in CER and Clinical Trials? (data quality)
Global Collaboration with Confidence and Control

Alzheimer’s comes to AGE

New Information Discovery
Statistical Analysis
New Evidence base
Etc…

Alzheimer’s Global Exchange Network (AGE)

Comparative Research Groups

Other Systems / Movements / Networks / Social

BRAIN
ADNI
EMIF
AGE Attributes

- HIPAA-Compliant
- Provides participants full control over their data
- Protects Institutional IP
- Supports Patient-Consent
- Enables global, real-time information-sharing and collaboration
- Scalable
- Sustainable
How to Implement AGE?

Critical Success Factors

Objectives being well-defined…

- Create ‘Working Groups’ (data sources: CER, Care givers, policy-makers, etc…)
- Define ‘What Data to Share?’
- Define the Standards to use to share Data
- Define the Owner of AGE (PPP?) and User Profiles
- Define Information Privacy and Security Policies
- Define Roadmap & Milestones for AGE
- Determine what AGE shall not be used for
THANK YOU

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