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

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HEALTH SCIENCES

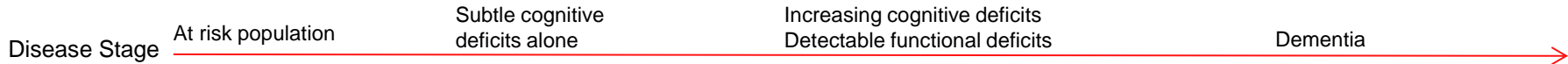
 OECD
BETTER POLICIES FOR BETTER LIVES

 Global Coalition on Aging

 UNIVERSITY OF
OXFORD

Advanced Dementia: Research Priorities

for the Next Decade



Evidence on Risks
And how to influence them

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

Discipline	Broad Research Objectives	Specific Examples
Intervention	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	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
Health policy/services	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	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)
Implementation	Conduct projects to implement proven interventions and policies	Demonstration project of evidence-based advanced dementia care intervention into nursing home practice
Measurement	Develop new advanced dementia-specific instruments for outcomes currently lacking valid measures Better establish psychometric properties of existing instruments	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)

RCT = randomized, controlled trial.

Susan L. Mitchell & AI, Advanced Dementia: State of the Art and Priorities for the Next Decade. Ann Intern Med 2012;156:45-51
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

Scattered DATA

Using Technology to Harmonize Data

Evidence-based IT in Healthcare

- CLINICAL CARE:
 - Use of Electronic Health Records improved the quality of Diabetes Care¹
- 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

1. **Cebul RD et al.** Electronic Health Records and Quality of Diabetes Care. N Engl J Med 2011;365:825-833.

2. **Wilson D. Pace & Al.** An Electronic Practice-based Network for Observational Comparative Effectiveness Research. Ann Intern Med. 2009;151:338-340.

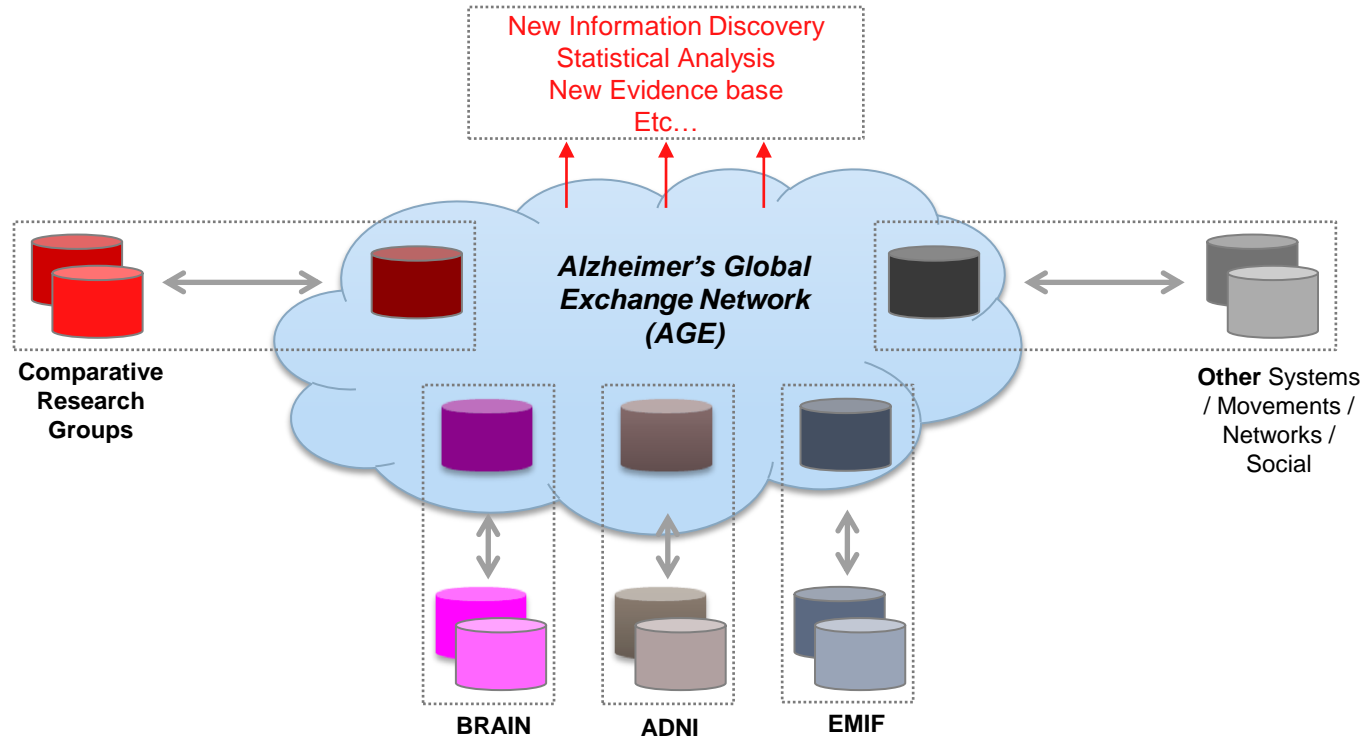
Health Information Exchange

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



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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