

Ethics Issues and Health Policy for Alzheimer's Disease

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Purpose of Ethics Sub-committee

- Response to FACA member concerns
- Identify ethics implications of both AD and proposed health policies
- Prioritize topics by importance, impact
- Indicate persons/institutions and mechanisms needed to address identified issues
 - Providers, government, industry?
 - Education, regulation, reimbursement?

Work to date

- Members: Laurel Coleman, David Hoffman, Jennifer Manly
- Ruth Katz, Rohini Khillan, Linda Elam, Tia Powell
- Conference Calls
 - Identification of goals
 - Prioritizing topics
 - HIPAA and dementia



HIPAA educational project

- Developed slide presentation
 - Define HIPAA: valve, not blockage
 - Assessment of decision-making capacity
 - Case based instruction
 - Specific guidance
- Presented to HRSA-funded GEC centers May
- Ongoing creation of audio tape for slides
- Planned distribution broadly to GEC centers



HIPAA project additional steps

- Supporting documents
 - Published literature
 - Possible HHS FAQ
- Further Dissemination

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Additional Topics

- **Caregiver Issues**
- Support patient autonomy while noting interdependence of patient and care-giver
 - Access to web-based patient information portals
 - Robust inclusion in care plan, implementation
 - Support for patient AND family, not VS

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Research Issues

- Surrogate consent for research
- Consequences of research data in EMR
 - Benefit to patient care from data
 - Potential harm in lack of protected access to long-term care insurance, life insurance
- Big Data:
 - Balancing privacy protections and benefit of harnessing power of data
 - Promoting International collaborations
 - Coordinating best practices, guidance

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Severe Dementia and nutrition

- Feeding Tubes in severe dementia
 - No benefit duration, quality of life
 - Increased pressure sores
 - Choosing Wisely recommendation
- NAPA IOM Collaboration: Severe Dementia
- Ongoing work, completed 2015

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Future for Ethics Sub-committee

- Additional Topics?
- Completion of Health and Aging Policy Fellowship
- Continued need for ethics input

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