Healthcare innovations in an ageing society

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Objectives

To explore how values reinforce different assumptions about ageing users.

To identify how different kinds of value produce different forms of user involvement.

To study how value is co-constructed with ideas about the ageing user, in other words, to broaden the focus towards ageing user involvement in processes of healthcare innovation.

Ageing as a societal challenge

- Demographic change due to post WWII baby boom
- By 2025, elderly (>60 year) will constitute ~ 30% of population in Europe
- Advances in healthcare: fatal diseases became chronic
- Increasing demand for care for elderly
- New family structures, generations living apart
- More job-mobility: less voluntary care for elderly at home by family
- Independent elderly reduces costs, increasing satisfaction
- Shortage of personell in care sector

-> potential undersupply of elderly healthcare in future

Approach

- Products, services aiming towards improvement health and quality of life of elderly encounter acceptability problems.
- Handholds of gerontechnology for successful design of products for elderly user.
- Science, Technology & Innovation Studies provides insights towards rethinking current innovation processes, how values are co-constructed with the ideas of elderly users in innovation process.

Assumptions about ageing users

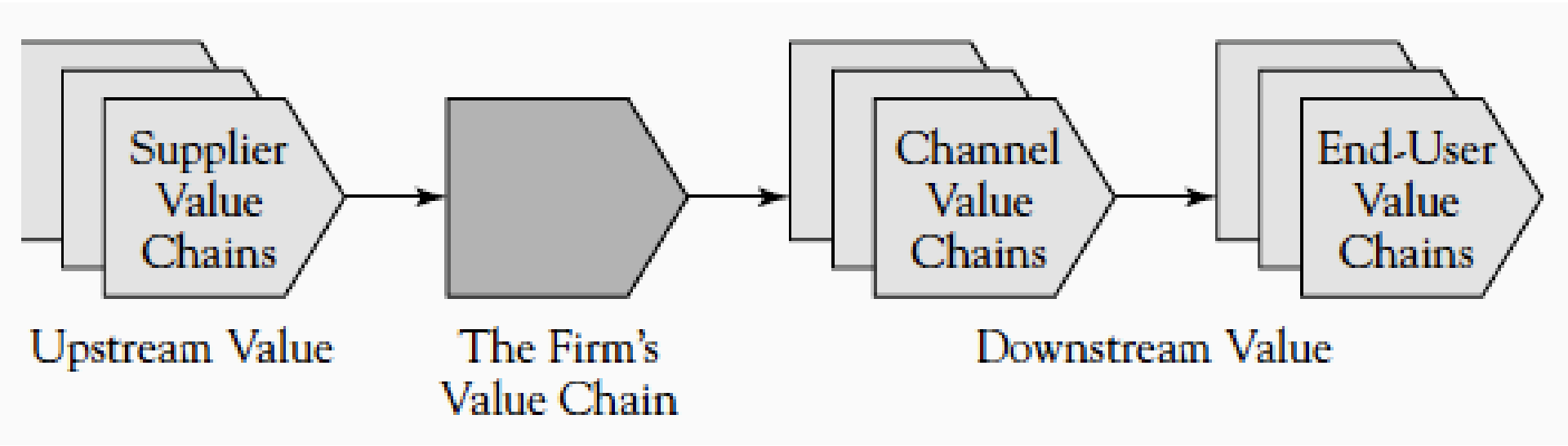
- Older persons are sick and disabled
- Elderly cannot properly interact with techology
- They don't like using technology, especially new technology: technology as burden vs. playful activity
- Elderly are not consumers in full sense of the word
- Elderly are likely to make mistakes when using technology
- …etc…

Question is: How are values co-constructed with these ideas of elderly users in innovation processes?

Focus on: **values** and elderly **user involvement** , **user-producer interactions**

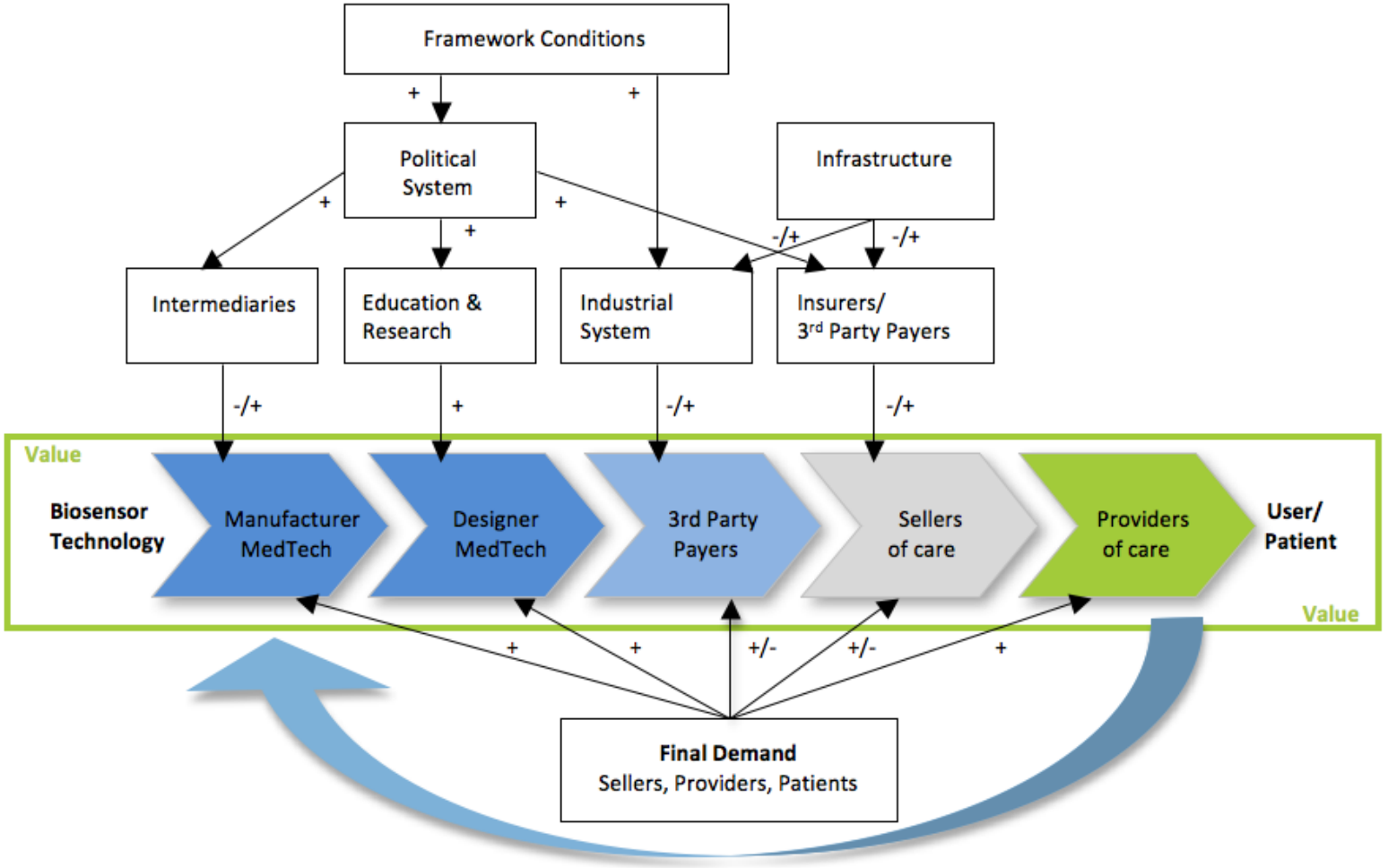
Health care Value Chain

Porter & Teisberg (2006) *Redefining Healthcare*
Christensen et al. (2008) *The Innovators Prescription*



Value chain & innovation system

Ten Kate, 2011



Values

Techno-economic Values

- Cost-effectiveness
- Clinical utility
- Diagnostic accuracy
- Technical accuracy
- Impact on entire health care value chain; care pathway

Social Values

- Good Life: Quality of Life and Healthy Ageing issues
- Healthy Aging
- Emotional quality
- Selft management
- Satisfaction
- Home care

Co-construction of Values & Users

- Different user involvement models
- Different types of user producer interaction
- User involvement can be beneficial to co-evolution processes
- Questions remain about values and representation

Five reasons for user involvement

- Overcoming market failure
- Employing experiential knowledge of users and their creative potential
- Instrumental to process, supporting boundary conditions of innovations
- 'Championing' innovations
- Increasing democratic/moral value of innovation processes

Boon *et al.* 2008

Types of user producer interactions

- Constructing linkages / learning by interaction
- Broadening, as being part of CTA
- Characterizing users, user representations
- Upstream involvement / demand articulation
- First user enrolment
- Feedback, scripts, framing
- Downstream innovation

Nahuis *et al.* 2012

Empirical field
Early diagnostics for Alzheimer Disease

AIM

- Systematic exploration of interactions between users and producers of healthcare innovations, in particular regarding early diagnostics for AD in the Netherlands

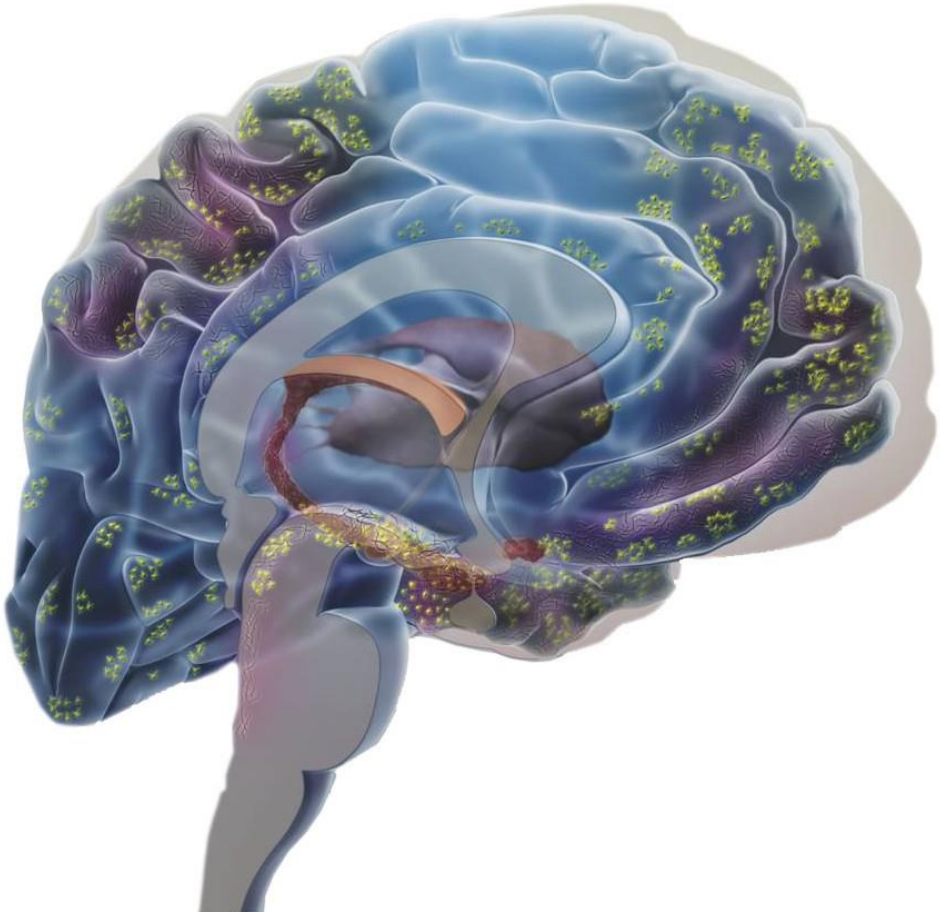
- Understanding co-creation of values and ageing user in early diagnosis technologies for AD.

- Two settings:
  - Health Technology Assessment practice
  - Alzheimer Cafe

Cuijpers, 2012

AD pathology

Brain atrophy and distribution of plaques and neurofibrillary tangles



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Early diagnosis of Alzheimer

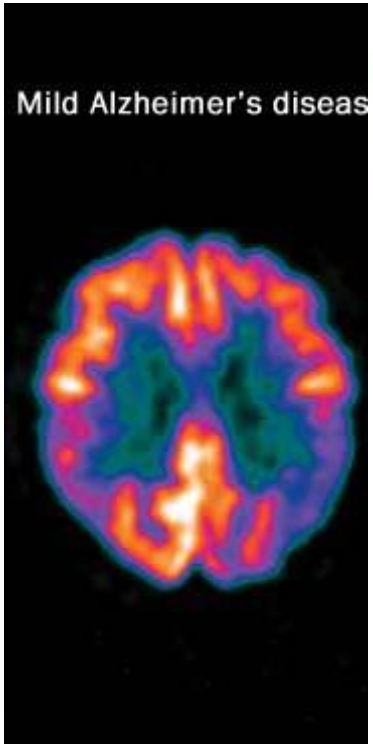
- New developments on early diagnosis AD going on
  - Molecular medicine, biomarkers
- Research project Leiden Alzheimer Research Nederland (LeARN)
  - Financed by Centre for Translational Molecular Medicine (CTMM)
  - Focussing on developing and determining clinical and economic value of various new diagnostic instruments
- Innovation also gives rise to societal, cultural and ethical questions
  - In general
  - Specific for practices around AD
  - Emergent biomedical development: high *expectations* + *uncertainties*

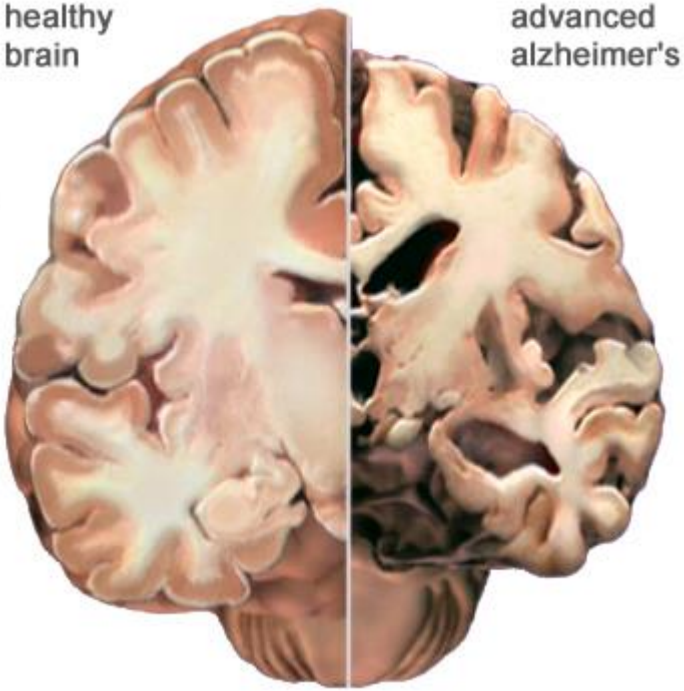
Why early diagnosis?

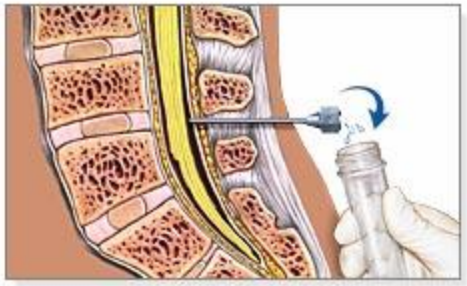
- Improvement of care planning
- Structure care and treatment
- Alleviate burden caregivers
- Advance directives and guidelines
- Driving restrictions
- Care/housing allocation

- Presymptomatic therapeutic treatment

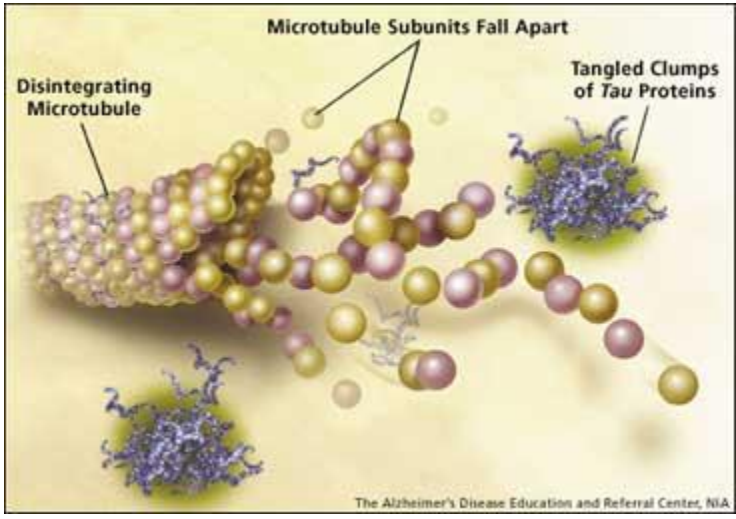
Boustani et al., Ann Int Med 2003





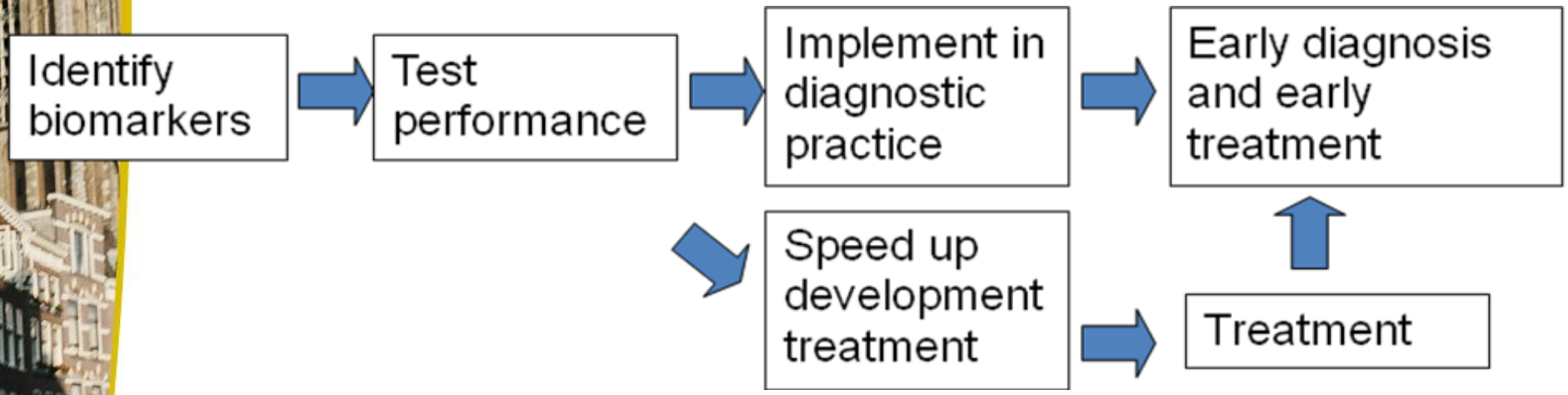


Spinal fluid
is collected
for testing



Early diagnosis of AD

Cuijpers,2012



Specifics of early diagnosis of AD

Cuijpers, 2011

Expectations	Uncertainties
Identify and monitor biomarkers	The innovation trajectory
Earlier and more specific diagnosis of AD	The future implementation / embedding
Contribute to development of disease – modifying treatment	Current knowledge on AD
Provide a way to deal with AD in aging western societies	The value of a diagnosis
	Visions on 'good diagnosis'
	Best way of dealing with AD in society?
	Disputed definitions

Consequences of early diagnosis

Increase understanding of disease & speed up the development of treatment / AD therapy.

Reduce uncertainty of patient and family & timely medical treatment, decisions, arrangements of care and support, increasing quality of life.

Reduce number of persons in nursing homes & reduce financial burden for society.

So: **How to assess the value of early diagnosis of AD?**

-molecular, medical, societal, cultural, ethical

The role of (informal) Technology Assessment, to better anticipate & shape future early diagnosis developments

Two case studies

Settings in which assessment of value of early diagnosis occurs:

- (Formal) Health Technology Assessment practice
- (Informal) Alzheimer Café

Analyzing cases

- *What is AD?*
- *What kind of futures are addressed?*
- *What is the role of early diagnostics?*
- *How are these local practices are related to the broader societal context of AD?*

Methods: participatory observations, document analysis, interviews

Case : Health Technology Assessment practice

- Clinical value of LEARN research on ED for AD
- Cost-benefit analyses:
  - Accuracy of different diagnostic instruments in a cohort.
  - Costs of health care consumed by these patients (model).
  - Patient outcomes (Quality of Life).
- Data: Project descriptions and publications, consensus meetings, interviews.

HTA values - adding complexity, growing uncertainty

1. Technical efficacy	(image) test quality; intra- and interobserver reliability
2. Test characteristics	Sensitivity/specificity after test (image) interpretation
3. Added value of a test	Change in diagnostic thinking if added to other tests
4. Clinical outcome	Effect on patient health
5. Cost-effectiveness	Societal costs and benefits

Case: Alzheimer Cafes

Example of multiple futures and informal TA in discursive space of the Alzheimer Cafés.

- Actors: AD patients, family, caregivers, volunteers, local professionals
- Monthly events
- Themes

Alzheimer cafe

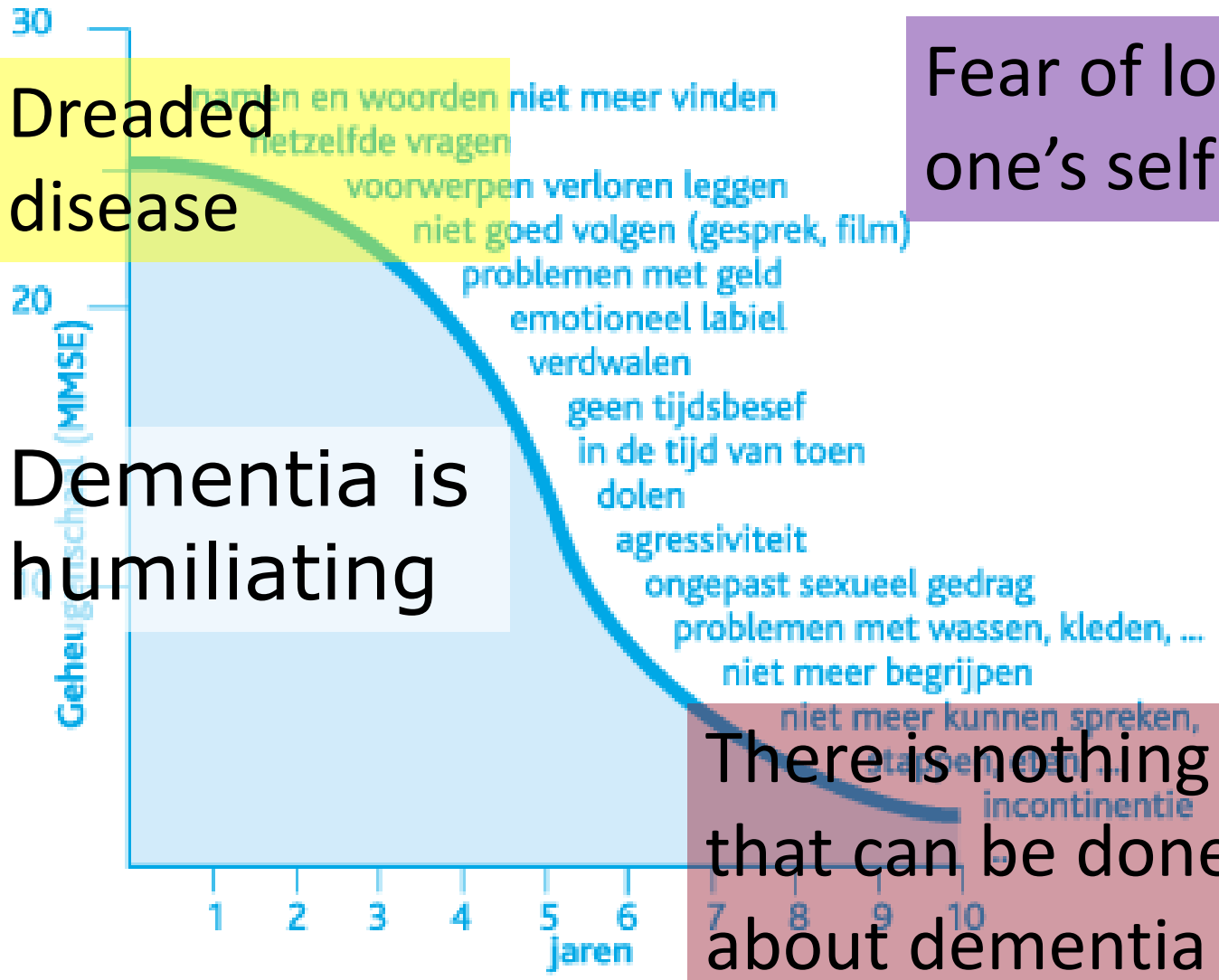
Alzheimer Nederland

Dreaded disease

Fear of losing one's self

Dementia is humiliating

There is nothing that can be done about dementia



Specifics of early AD diagnosis

- Emergent technology → expectations and uncertainties
- Development of early diagnostic instruments part of broader, changing AD landscape
- AD as a disease multiple
- Huge societal issue in many ways
- Complex development, involving many parties with their own ideas, concerns hopes and fears.
- Future images of (dealing with) AD tumble over each other

Co-creation values & users in early AD diagnostics

- Adequate linkages between users and ED developers are important for emerging AD diagnostics
- Alzheimer Nederland important intermediary organisation upstream between users and developer
- Alzheimer Cafes important places where concerted stakeholder interaction takes place, values and controversies about early AD diagnostics are articulated: Informal TA takes place
- Importance of shared research agenda building, feedback and broadening processes.

Concluding remarks

- Process of value creation in early AD diagnosis innovations is dynamic and interactive
- Values are heterogeneous and dependent on practice, application and point of use
- Intermediaries are loci of representing problems, needs, ideas, expectations; values
- Demand articulation is important learning process about demands: co-constructing values
- Future research on additional cases with elderly user involvement, values and demand articulation processes in innovations

Acknowledgements

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learn
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