

Dilemmas of Predictive Dementia Diagnostics

German Stakeholder Conference for
Improving Ethics Competence in Healthcare and Life Sciences

Presentation prepared for the 27th
Alzheimer Europe Conference, Berlin,
October 2-4, 2017

Panel "Ethical issues in dementia research"



Federal Ministry
of Education
and Research

Content

- I. Biomarker Prediction of Dementia: Emerging Ethical Issues
- II. The Social, Legal and Professional Issues involved
- III. Goals of the German Stakeholder Conference
- IV. Stages of the Communication Process
- V. Project Organization and Management Structure
- VI. Persons and Groups Involved
- VII. Expected Output

Biomarker Prediction of Dementia: Emerging Ethical Issues

- Biomarkers: A new window into one's *future* cognitive health
 - APOE ϵ 4, - Beta-amyloid plaques, total and phosphorylated-tau
- Issue Area 1: Professional Ethics
- Issue Area 2: Medical Law including Research Ethics
- Issue Area 3: General Ethical Questions

Goals of the German Stakeholder Conference

- To generate the participation of central stakeholders of national repute in the areas of healthcare and the life sciences
- To provide a forum and process for stakeholders to specify and explore problem areas
- To specify desired criteria for future legal and professional guidelines
- To elicit input from students in multiple healthcare professions and generate feedback from their perspectives
- To generate broad public interest
- To initiate and build on academic and public discourses about dementia

Stages of the Communication Process

Start
Oct 2017

Conference
Jun 2018

**Student
Seminars**
Fall 2018

**Educational
Tools**
May 2019

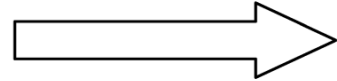
**Press
Conference**
Aug 2019

End
Sep 2019

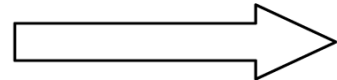
Management Team

- Text Production and Project Reports
- External Communication
 - Press relations
 - Press conference
 - Website
- Internal Communication
 - Federal Ministry
 - Advisory Counsel
 - Stakeholders
 - Students
 - University coordinators
- Stakeholder Conference
 - Securing participants
 - Organization
- Advisory Counsel
 - Organization
 - Support

Stakeholder Conference
Formulates Guidelines



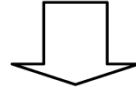
Organization



Editorial Responsibility

Draft of Criteria for Ethical Guidelines

- Patient information
- Consent diagnostics
- Consent research
- Privacy
- Living wills
- Right (not) to know
- Preventing stigma

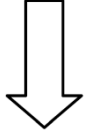


Case Discussions among Students
Use and modify guideline draft

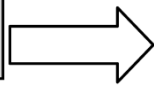


Advisory Counsel

- Nominates Stakeholder
- Advises Management Team
- Comments on ethical guidelines and educational material



Educational Material



Project Output =

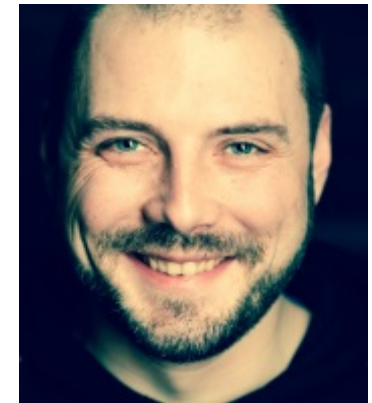
Steering Organs =

Discourses =

Persons and Groups Involved

	Advisory Counsel
Dr. med. Frank Bergmann	Association of Statutory Health Insurance Physicians Nordrhein Previous: German Neurologists' Association
Prof. Dr. Klaus Gerwert	Professor of Biophysics, Ruhr University Bochum Spokesperson, PURE - Protein Research Unit Ruhr within Europe
Prof. Dr. med. Hans Gutzmann	Former president of the German Society for Gerontopsychiatry and -psychotherapy DGGPP
Dr. Jürgen Gohde	Member of the Advisory Counsel of the German Alzheimer Society
Prof. Dr. Stefan Huster	Professor of Public Law, Social Security Law, Medical Law and Philosophy of Law, Ruhr University Bochum
Sabine Jansen	Executive Director, German Alzheimer Society
Prof. Dr. Martina Roes	Spokesperson and Group Leader, German Center for Neurodegenerative Diseases (DZNE), Witten

Project Team



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Expected Output

- Criteria for ethical guidelines for healthcare professionals
- Educational material for professional training (universities and vocational schools)
- Website for project communication, documentation and permanent archiving
- Public communication, e.g. press releases and texts for general media outlets
- Contributions to academic discussions

Project outputs will be made available here: www.praediadem.de

Selected References

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- Le Couteur D. G., Doust J., Creasey H. et al. (2013). Political drive to screen for predementia. Not evidence based and ignores the harms. *BMJ* 347, f5125.
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- Sperling R., Mormino E., & Johnson, K. (2014). The evolution of preclinical Alzheimer's disease. Implications. *Neuron*, 84(3), 608–622.