

## **Dilemmas of Predictive Dementia Diagnostics: German Stakeholder Conference for Improving Ethics Competence in Healthcare and Life Sciences<sup>1</sup>**

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### **Background**

Research into new methods to predict dementia using biomarkers<sup>2</sup> may soon make it possible to cheaply test one's likelihood of contracting one of the major forms of dementia. Although dementia prediction represents a significant medical advance, it brings up ethical problems and potential psychosocial risks for individuals. Its potential advantages include more effective research and the ability of affected individuals to personally supervise their nursing care and estate planning. Possible problems lie in the mental burden of anticipating (potentially in error) the onset of dementia as well as in forms of social rejection. In addition, because test results are expressed as notoriously non-intuitive risk probabilities, informed consent and patient education are especially challenging.

### **Central Questions**

Biomarker-based dementia prediction is superficially similar to gene-based prediction, but it differs decidedly both in its methods and in the significance of its social and individual implications. It raises a number of ethical and legal questions that have yet to be thoroughly debated in German scientific and healthcare discourses. The "Dilemmas of Predictive Dementia Diagnostics" project, funded by the German Ministry of Education and Research, is intended to initiate and structure such debate. At issue are fundamental questions in three categories:

- the ethics of the healthcare professions involved in test counseling,
- legal issues in areas such as advance care planning and informed consent of participants in pharmacological studies, and
- general ethical issues such as stigmatization, discrimination, and healthcare finance.

### **Project Goals**

1. Ethical guidelines for learning to recognize and address problems in patient counseling, informed consent, and advance care
2. Educational materials for health professionals in training
3. Information for memory clinics and self-help groups
4. Resources for continuing the public debate

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<sup>1</sup> German title: *Entscheidungskonflikt prädiktive Demenz-Diagnostik: Diskursverfahren zu Beratungs- und Ethik-kompetenzen mit Stakeholdern und Studierenden*. Project number 01GP1770A.

<sup>2</sup> Substances in the human body that can be used to measure biological processes and states.

### **Project Leadership**

Professor Silke Schicktanz of the Department of Medical Ethics and History of Medicine of the University Medical Center Göttingen, is responsible for methodology, didactics, and analysis. The IEGUS Institute (Berlin/Bochum) is responsible for communications and logistics.

### **Advisory Board**

An interdisciplinary board of advisors provides constructive criticism regarding project methods and results and advises should unexpected problems arise. Its members are preeminent experts in fields directly relevant to dementia prediction and its implications:

- Dr. med. Frank Bergmann, Chair of the *Kassenärztliche Vereinigung Nordrhein* and former Chair of the Professional Association of German Neurologists.
- Prof. Dr. Klaus Gerwert, Professor of Biophysics at the Ruhr-Uni-Bochum and Speaker of the Protein Research Unit Ruhr within Europe (PURE)
- Dr. h. c. Jürgen Gohde, Chair of the Board of Advisors of the IEGUS Institute and former Chair of the *Kuratorium Deutsche Altershilfe*
- Prof. Dr. med. Hans Gutzmann, former President of the German Society for Geriatric Psychiatry and Psychotherapy
- Prof. Dr. Stefan Huster, Professor of Public Law, Social Welfare and Health Law, and the Philosophy of Law at the Ruhr University Bochum
- Sabine Jansen, Executive Director of the German Alzheimer Society
- Prof. Dr. Martina Roes, Site Speaker and Group Leader, German Center for Neurodegenerative Diseases (*DZNE*), Witten

### **Methods and Process**

The project will generate written and personal input from stakeholders from many disciplines and social groups and use this to create educational materials in a participatory process also involving students. For the purposes of the project, “stakeholders” are defined as persons, groups, and institutions who are responsible for or who are affected by decisions made in the field of biomarker-based dementia prediction and who could thus make a moral claim to be allowed to participate in how these decisions are formulated and made. Because prediction is a complex topic, experts in the field are not expressly excluded. When possible, however, organizations representing specific interests and claims are to be included rather than individuals with no mandate of representation.

The discourse method used in the project takes the form of an hourglass (see the figure below). To begin, a very broad spectrum of stakeholders will be requested to formulate their perspectives on dementia prediction and formulate these tersely on one written page. They are asked to identify the central concerns they have regarding improved prediction technology and how these should be addressed. Stakeholders may, but are not required to, formulate specific demands.

We expect the number problems and positions identified will be fewer than the number of participating stakeholders. Thus, from the written statements the project leadership team will distil and cluster common and contradictory positions. From among the organizations providing written statements, the project team will invite individuals to a stakeholder conference to deepen the debate face-to-face. Taking place on June 21-23, 2018 in Göttingen, the conference will bring together 20 to 40 individuals in several moderated discussions. Both written and oral arguments will flow into the project reports.

The intention of this method is to find a median between breadth of outreach and the effectiveness of face-to-face discourse. While a very large number of written statements by relevant stakeholders can be included, a limit to the number of participants invited to debate oral arguments is advisable in order to maximize the effectiveness of this form of communication. Project leadership shall justify to the project board of advisors and to the public its choices of participants and topics for debate. All stakeholder statements shall be published.

The results of the conference will be used to create teaching tools for relevant healthcare professions. These will be put to the test in principle-oriented, case-based discussions among circa 50 students in Göttingen and Bochum, and among memory clinic teams, who may then suggest changes. All inputs flow into a final criteria set and in educational and informational tools that shall be published for free download. The project will end in August, 2019 with a public presentation for a national and international audience.

### Project Timetable



**Figure: Project Methodology**

