



**Diskursverfahren
„Konfliktfall
Demenzvorhersage“
2017-2019**

**JOINT POSITION STATEMENT
OF THE GERMAN STAKEHOLDER CONFERENCE ON
CONFLICTS IN PREDICTIVE DEMENTIA DIAGNOSTICS**

Göttingen, Germany, December 2018

SHORT VERSION

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Preamble

New biomarker-based diagnostic tools aim at predicting asymptomatic individuals' risk of developing dementia. To date, however, these remain imprecise regarding their predictive accuracy. Further, there are still no widely acknowledged therapies for preventing or delaying the onset of dementia symptoms. At the same time, however, public and scientific interest not only in the early diagnosis of dementia in individuals with mild symptoms but also in the prediction of healthy individuals' morbidity risk is high. Once tests with better predictive accuracy become available in the future, the following considerations should be taken into account.

Desiderata for the Social and Ethical Discourse

- Accurate biomarker-based dementia prediction in asymptomatic individuals raises both aspects of potential harm as well as potential benefit. Harm could arise, for example, in the form of psychological destabilization and stigmatization in the event of the discovery of a high morbidity risk. Benefits can come from the potential incentive to pursue a healthier lifestyle or to prepare constructively for the possibility of future cognitive impairment.
- The individual right of informational self-determination must be protected during patient counseling on dementia prediction such that individuals control their *right to know* as well as their right *not to know*. This applies also to family members. The emergence of incentive structures, stemming, for example, from market economics or health insurance policies that could bias the decision either for or against a dementia test should be prevented.
- Society needs to work toward a common understanding about dementia in which individuals who have dementia are valued as much as healthy persons.

Desiderata for Patient Counseling

- Standards and framework agreements should be developed for all professions providing individual counseling prior to predictive dementia diagnostics.
- Access to counseling services should be facilitated. To the extent necessary, a right to counseling should be legislatively mandated.
- Counseling in the context of dementia prediction must provide individuals a basis for well-considered decision-making. It must encompass medical, psychosocial, and legal aspects and address issues of participation in social life despite physical or mental impairment.
- Counseling should take place in the setting preferred by the person seeking advice. Ideally, family members should be included if they so desire and with the consent of the person seeking counseling.
- Counseling before, during, and after diagnostic testing should be offered and funded. Counseling should be multidisciplinary. It should not be dependent on those who provide testing.

Desiderata for Research

- There is a need for high-quality social science research as well as for randomized, controlled clinical studies on patient-relevant harm and benefit of predictive dementia diagnostics.
- Future tests must possess high reliability and diagnostic accuracy.

- There is a need for randomized, controlled studies that investigate diagnostic testing procedures in combination with healthcare-delivery pathways.
- Research on counseling in the context of dementia should be encouraged. Existing and future research specifically addressing the counseling environment must be utilized in order to design more appropriate and evidence-based approaches, guidelines, and decision aids for counselors in the context of risk communication.
- Patient-relevant endpoints should be broadly operationalized to include quality of life aspects.

Recommendations for Patients with Mild Cognitive Impairment (MCI)

- Basic standards and minimum requirements should be formulated for the diagnostic procedures used to identify patients whose MCI is due to Alzheimer's disease. These should include patient education goals and address the preparation, administration, and interpretation of diagnostic procedures.
- Diagnostics should be preceded by quality-controlled, standardized patient counseling that covers medical and psychosocial aspects and includes assessments of depressive tendencies, depression, and especially suicide risk.
- The qualifications required by persons offering patient counseling (and the coursework necessary for acquiring these qualifications) should be specified.
- Laboratories conducting the analysis of diagnostic tests should be certified and required to demonstrate adherence to quality standards. They should be required to participate in interlaboratory comparisons.



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