



Perspectives on Communicating Biomarker-Based Assessments of Alzheimer's Disease to Cognitively Healthy Individuals

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In clinical trials which target pathophysiological mechanisms associated with Alzheimer's disease, research participants who are recruited based on biomarker test results should be informed about their increased risk of developing Alzheimer's dementia. This paper presents the results of a qualitative focus group study of attitudes and concerns toward learning information about biomarker-based risk status among healthy research participants in the United Kingdom and Spain and people with dementia and their supporters/caregivers from countries represented in the European Working Group of People with Dementia of Alzheimer Europe. The study identified expectations related to learning risk status and preferences related to the content, quality, and follow-up of the disclosure process. The latter emphasize distinctions between risk and diagnoses, the importance of clear information about risk, and suggestions for risk reduction, as well as expectations for follow up and support. The implications of these preferences for practice are discussed. Providing details of research participants' experience and views may serve as a guide for the development of processes for the responsible disclosure of Alzheimer's disease biomarkers.

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