



## On the personal utility of Alzheimer's disease-related biomarker testing in the research context

*Eline M Bunnik, Edo Richard, Richard Milne, Maartje H N Schermer*

Many healthy volunteers choose to take part in Alzheimer's disease (AD) prevention studies because they want to know whether they will develop dementia—and what they can do to reduce their risk—and are therefore interested in learning the results of AD biomarker tests. Proponents of AD biomarker disclosure often refer to the personal utility of AD biomarkers, claiming that research participants will be able to use AD biomarker information for personal purposes, such as planning ahead or making important life decisions. In this paper, the claim that AD biomarkers have personal utility for asymptomatic individuals is critically assessed. It demonstrates that in the absence of clinical validity, AD biomarkers cannot have personal utility and do not serve research participants' autonomy. Over the next few years, many research groups will be confronted with participants' preferences to learn the results of AD biomarker tests. When researchers choose to make results available upon explicit request, they should ensure adequate information provision and education, notably on the uncertain clinical significance of AD biomarker information. Routine disclosure of AD biomarkers to cognitively unimpaired individuals in research settings cannot be justified with an appeal to the personal utility of AD biomarker information.

**Journal of Medical Ethics**

Published **Online**

28 August 2018

<http://dx.doi.org/10.1136/medethics-2018-104772>

