Images of ageing and stakeholder engagement in emerging diagnostics for Alzheimer’s Disease

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Alzheimer’s disease is associated with ageing. Many elderly people experiencing loss of cognitive functioning start wondering whether this signals the onset of this dreaded disease. Although such worries are often unfounded, the boundary between ‘normal, ageing related cognitive decline’ and ‘Alzheimer’s disease’ is not clear at all and has been varying historically. Technology development is an important driver in shifting this boundary. As Ballenger (2006) has shown, the definition of Alzheimer’s disease in the past century has co-evolved with the technologies available for diagnosing and treating the disease, as well as with the medical and social scientific approaches dominant in scientific research. These technological and scientific developments have been guided by images of ‘normal’ and ‘diseased’ ageing, but also changed them. Thus, novel technologies for diagnosing Alzheimer may also impact the way society views and deals with ageing. However, this ‘soft’ type of impact (difficult to delineate, let alone to quantify) is hardly acknowledged in the more traditional technology assessments of novel technologies related to Alzheimer’s disease.

We will argue how to include such ‘soft impacts’ in the ethical and social assessment of emerging novel forms of diagnostics for Alzheimer’s disease. In cooperation with the Dutch LeARN-project (a Dutch consortium of researchers, clinicians and medical technology enterprises that currently develops new tools for AD diagnostics), we investigate how such innovations could proceed in a responsible way. One of our main questions is how the proposed technological developments may affect current views of Alzheimer’s and ageing, and how these in turn may impact future society and culture.

We will focus here on two steps to answer this question: conceptual analysis and stakeholder engagement. Conceptual analysis of the ideas underlying the technological developments may show how the diagnosis produced will redraw the boundary between Alzheimer’s disease and normal ageing. A question that is specifically interesting here is how these developments will affect the balance between biologically and socially oriented approaches of ageing.

In addition, a broad set of stakeholders (patients, families, medical professionals, medical industry, policy, insurance) will be engaged, to enable deliberation on the potential future impact of the technological developments on society and culture and to formulate criteria for responsible innovation in this specific context. To include potential impact on views of ageing in these deliberations, vignettes or scenarios might be written, depicting possible futures of ageing.

Finally, we will discuss the value and limits of this combination of conceptual analysis, stakeholder engagement and scenario exercises for exploring the potential soft impacts of emerging technologies on society and culture.