

# Towards primary prevention of dementia

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## Impact paragraph

### **This thesis**

The overall aim of this thesis was to contribute to the growing consensus that lifestyle factors affect brain health and dementia risk and to disseminate this knowledge to the general public. More specifically, this thesis aimed to validate the Lifestyle for BRAin health (LIBRA) index, a risk score consisting of twelve potentially modifiable risk and protective factors (such as smoking, hypertension, or physical inactivity), for cognitive outcomes (functioning, impairment and decline) and structural brain markers on MRI. In addition, we aimed to assess knowledge of dementia risk reduction in the general population and raise awareness on this matter using two proof-of-concept studies: a 10-month public health awareness campaign and the *MijnBreincoach* app.

The results of this thesis provide us with several insights. First, this thesis contributes to previous work showing that higher (i.e., unhealthier) LIBRA scores are associated with lower cognitive performance and more cognitive decline. Additionally, this thesis provides first evidence for higher LIBRA scores being associated with lower structural brain volumes and more white matter hyperintensities, an indication for neurodegeneration and cerebrovascular damage. These results suggest that LIBRA is a useful tool to identify (groups of) individuals at-risk for dementia and monitor room-for-improvement over time, for example in primary care or lifestyle intervention trials. Second, this thesis provides information on the level of awareness of dementia risk reduction in community-dwelling individuals in the province of Limburg, the Netherlands, and shows that most people were unaware of the potential of primary prevention of dementia. Considerable gaps in knowledge existed for the vascular risk factors of dementia, such as hypertension and high cholesterol. The good news is that most people were eager to learn more about this topic and most participants were positive about using eHealth to improve (knowledge on) brain health. We subsequently conducted a 10-month public health campaign to promote awareness in the Province of Limburg, the Netherlands, which resulted in an increase in recognition of two out of the three campaign themes (“eat healthy” and “exercise regularly”). Unfortunately, population-level awareness did not change over time. Yet, the individuals (in the post-campaign assessment) that stated to have heard of the campaign were more aware of dementia risk reduction than the individuals that had not heard of the campaign. This campaign only had limited resources to reach

people and it is therefore recommended that future campaigns scale up to maximize exposure and engagement in the population. The *MijnBreincoach* app was investigated in another study. On the one side, this study showed us that most users rated the (concept of the) app positively and stated to have increased their knowledge on the topic. On the other side, this study uncovered technical issues of the app that caused users to drop-out and limited the use of several new functions of the app. Altogether, this study was designed as a proof-of-concept, aimed at identifying both the barriers and difficulties in the development of an mHealth tool for dementia risk reduction, as well as the advantages and gains, to improve our understanding of important factors that need to be considered in future studies. An elaboration on this, including optimizing the usability of the mHealth tool, was discussed in more detail in Chapter 6.

**Relevance: what does this thesis contribute to science and society?**

This thesis supports the increasing consensus that lifestyle affects dementia risk and that there is a need to inform the public about this matter. LIBRA is the only well-validated dementia risk score that focusses solely on the dementia risk fraction that is potentially modifiable through lifestyle interventions and optimized cardiovascular risk management. LIBRA could therefore be of added value in several research contexts, from epidemiological studies using LIBRA as a predictor variable for the risk of dementia and related conditions such as stroke, to lifestyle prevention trials and clinical trials using LIBRA as a surrogate outcome measure.

In 2018, we developed the *MijnBreincoach* app that uses LIBRA as a framework to identify room-for-lifestyle improvement and informs people about the relationship between lifestyle and brain health. *MijnBreincoach* was launched in March 2018, together with the 10-month public health awareness campaign in the Province of Limburg. With *MijnBreincoach*, we aim to bridge the gap between scientific research and society by offering this app free-of-charge to all Dutch inhabitants while doing research (with consent) on the anonymized usage tracking data. This provides us with the opportunity to raise awareness in the public about dementia risk reduction while at the same time fine-tuning the app based on direct user feedback.

To date, several national and international partners have adopted LIBRA, the public health campaign “*We zijn zelf het medicijn*” and *MijnBreincoach*.

For example, all visitors of the Healthy Brain Ageing Clinic at the Brain and Mind Centre in Sydney, Australia answer questions to obtain information on all LIBRA factors. LIBRA will also be used in two large-scale Dutch projects that have been launched in 2021. The Dutch FINGER-NL intervention trial, in which participants will receive a high-intensity or low-intensity lifestyle intervention for a duration of 24 months, uses LIBRA as a surrogate outcome measure. The ABAORD project will adapt the current LIBRA to a clinical setting for people with subjective cognitive complaints or mild cognitive impairment. LIBRA is also being used to detect room for improvement during a multiple risk behaviour change intervention on dementia risk literacy, launched in 2021 at Macquarie University, Australia. Hopefully our campaign can serve as a blueprint for a nationwide campaign aimed at increasing awareness of dementia risk reduction. Two municipal health services (*GGD West Brabant* and *GGD Haaglanden*) in the Netherlands are currently running a locally-adapted dementia awareness campaign with the *MijnBreincoach* app and the design and materials of our campaign. The Danish Alzheimer's Association and the Norwegian National Advisory Unit on Ageing and Health will use the web portal version of *MijnBreincoach*, in which individuals can complete the LIBRA test to identify room-for-improvement (but does not provide subsequent informative daily notifications). Our survey to measure awareness of dementia risk reduction, which was based on the British Social Attitudes survey and assessed awareness on all twelve LIBRA factors (e.g., "Do you agree or disagree (on a 5-point Likert Scale) that hypertension increases the risk of getting dementia?") is being used in several countries, such as Belgium and France.

**Target group: who could benefit from this thesis?**

The results of this thesis could be of added value for researchers, clinicians and policy-makers working in the public health domain in general, or specifically in the field of dementia risk reduction. The lessons learned and recommendations for future (research) projects provided in this thesis could be of benefit to these professionals and hopefully lead to multidisciplinary collaborations across fields. The results of this thesis are also relevant to community-dwelling individuals, especially considering the growing number of people with dementia worldwide and the absence of treatment options.

**Activities: how to inform and involve the target group?**

We published all of our scientific work in open access journals that are free-of-charge available and we have reprinted the campaign results (Chapter

5) in a Dutch scientific journal (*Tijdschrift voor Gerontologie en Geriatrie*) to facilitate collaborations within the Netherlands. Results of this thesis have been presented during the Alzheimer's Association International Conference in Los Angeles and the Alzheimer Europe Conference in The Hague, both in 2019.

A large part of the work in this thesis was aimed at disseminating scientific knowledge to the general public and, therefore, informing and involving this target group was in fact the essence of this thesis. We have used several strategies to inform the target group about dementia risk reduction, the awareness campaign and *MijnBreincoach* app. First, we strive to communicate our scientific results to the general public in lay-man's terms. During the campaign, we organized weekly educational events on dementia risk reduction throughout the Province of Limburg (e.g., lectures, workshops). We published a short booklet that provides information on the design, look-and-feel and results of the campaign and *MijnBreincoach* app, accompanied by attractive visuals. The booklet is free-of-charge available on request and can also be downloaded from our campaign website. The campaign results have been presented during a symposium for all "friends" of the campaign (more than 140 in total, e.g., national stakeholders, municipalities, health care centres, schools, supermarkets) at the provincial government (*Gouvernement*). The campaign friends received the short booklets during the symposium to distribute to their network. Our results were also presented during an educational event that is scheduled a few times a year in which researchers present their work in lay-man's terms to the general public ("*Dialogen rond Dementie*", organized by the Alzheimer Centre Limburg). With the help of several press releases, we have reached national and regional media (items in newspapers and on radio and TV). The *MijnBreincoach* app, which will remain available, will be further developed and has an increasing reach around the world, provides us with the opportunity to inform people about the potential of dementia risk reduction. The fact that the Dutch Ministry of Health, Welfare and Sport (*Zorg van Nu*) and the municipal health services (*GGD Appstore*) have incorporated *MijnBreincoach* on their website on innovations in health care, will hopefully lead to a "snowball effect" in the Netherlands. Next to informing the general public, we also aimed to involve them in our research by organizing client panels in which people with dementia, their caregivers and people with a general interest in dementia provided us with feedback on research ideas, custom questionnaires and products, such as *MijnBreincoach*.

