Population Screening Act: study of online lifestyle advice for reducing the risk of dementia

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Executive summary

Health Council of the Netherlands

The University Medical Centre in Groningen (UMCG) would like to investigate strategies for offering online lifestyle advice that focuses on reducing the risk of dementia, known as the DEMIN study. Based on the Population Screening Act (WBO), a permit from the Minister of Health, Welfare and Sport (VWS) is required for carrying out this research. The Committee on Population Screening of the Dutch Health Council has examined the permit application. The Committee advises the State Secretary to grant the permit under a number of conditions.

Permit application

The proposed scientific study focuses on adults in the age range 40 to 60 with a parent who was diagnosed with Alzheimer's Disease or vascular dementia less than six months ago. According to the applicant, these adults are more receptive to lifestyle recommendations that could possibly reduce the risk of them getting dementia. This target group will be offered the opportunity to take part in an online lifestyle programme that concentrates on a number of lifestyle factors that are associated with the risk of dementia and that can be influenced to a greater or lesser extent. Examples include smoking, lack of exercise, high blood pressure and depression. The researchers suggest that participants can lower their risk of developing dementia by a third by adopting a healthier lifestyle.

The primary goal of the research is to compare participation after active recruitment against participation after passive recruitment. In active recruitment, a member of the treatment team in person hands out an invitation to take part; in passive recruitment, the invitation is part of a general information package that is handed out at the front desk of the outpatient memory clinic. In addition, the applicant wants to investigate what effect the lifestyle recommendations have on the lifestyle factors.

The applicant will obtain a picture of the status of the lifestyle factors using validated questionnaires, physical examinations and blood tests. Participants must enter the findings of the physical examination themselves in a secure, online personal health profile. The participants receive feedback via that profile for each lifestyle factor in the form of a recommendation such as "keep it up" or "room for improvement". Subsequently, the participants receive fitted recommendations to adopt a healthier lifestyle. The applicant also wants to carry out cognition tests. There will be no feedback on the results of these tests.

Assessing conformity with the legal requirements

Scientific validity

The committee's opinion is that the research is scientifically valid, but the Committee does have a number of reservations. Firstly, the study has

been set up in such a way that it is only expected to yield new knowledge to a limited extent. This is because the difference between passive and active recruitment is not so large. The applicant is also not comparing participation within the DEMIN target group against participation within a target group that is not receptive to lifestyle recommendations for reducing the risk of dementia, leaving it unclear whether the receptive group is genuinely more likely to change its lifestyle than a non-receptive group. The breadth and depth of the extent to which lifestyle changes can actually reduce the risk of dementia are also not known. Related to that, the lifestyle for brain health (LIBRA) score – the key measure of outcome for the effect of lifestyle recommendations on lifestyle factors – has not been validated in a population that is comparable to the DEMIN target group.

Another reservation is about inputting the findings of the physical examination. The applicant proposes that the participants should do this themselves, which the Committee believes brings a risk of errors and a risk of lower participation among people with lower levels of literacy or computer skills. Finally, the Committee would like to point out that the cognition tests that the applicant wants to carry out are not included in the measures of outcome for the study.

Risk-benefit ratio

The Committee hereby issues a positive judgement on the risk-benefit ratio. The Committee believes that the scientific usefulness of the study is indeed not very great, but on the other hand that the lifestyle intervention can be beneficial for the health of the participants. After all, the majority of the lifestyle factors examined are also important in the occurrence of cardiovascular disease, diabetes and chronic renal damage. It has already been shown that a more healthy lifestyle reduces the risk of these conditions. Their effect on the risk of dementia is however unclear.

The study can also have disadvantages for the participants. Participants could for instance become worried about their risk of dementia, particularly because of the cognition tests, which they might see as a diagnostic test for dementia. In addition, the participants might get unrealistic expectations with respect to their own ability to affect their risk of dementia. Moreover, the medical findings from the research (such as elevated blood pressure, diabetes and elevated cholesterol) could also make the participants worried and lead to undue medicalisation.

Alignment with the rules for medical actions

The Committee believes that the information provided to the participants about the study is incomplete and not neutral. Too high expectations are generated with respect to the

possibilities participants may have for reducing their risk of dementia. There is no information about the pros and cons of medical findings from the research.

Recommendation

The Committee's judgement is that the expected scientific usefulness of the DEMIN study is relatively limited and that there is no direct evidence for the possibility of preventing dementia through an improved lifestyle. On the other side of the scales, some effect on the risk of dementia is to be anticipated and the lifestyle intervention can be beneficial to the health of the participants. The Committee therefore believes that the study is justified, as long as the participants receive appropriate information about the pros and cons of the research and as long as the risks are limited as far as possible. It therefore advises the State Secretary for VWS to grant the permit, under the key conditions that the applicant modifies all the information about the study in such a way that the pros and cons of participation are fully covered and that no cognition tests are carried out.

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