

Research Article

# Are People Ready for Personalized Brain Health? Perspectives of Research Participants in the Lifebrain Consortium

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## Abstract

**Background and Objectives:** A healthy brain is central to physical and mental well-being. In this multi-site, qualitative study, we investigated views and attitudes of adult participants in brain research studies on the brain and personalized brain health as well as interest in maintaining a healthy brain.

**Design and Methods:** We conducted individual interviews with 44 adult participants in brain research cohorts of the Lifebrain consortium in Spain, Norway, Germany, and the United Kingdom. The interviews were audio recorded, transcribed, and coded using a cross-country codebook. The interview data were analyzed using qualitative content analysis.

**Results:** Most participants did not focus on their own brain health and expressed uncertainty regarding how to maintain it. Those actively focusing on brain health often picked one specific strategy like diet or memory training. The participants were interested in taking brain health tests to learn about their individual risk of developing brain diseases, and were willing to take measures to maintain their brain health if personalized follow-up was provided and the measures had proven impact. The participants were interested in more information on brain health. No differences in responses were identified between age groups, sex, or countries.

**Discussion and Implications:** Concise, practical, personalized, and evidence-based information about the brain may promote brain health. Based on our findings, we have launched an ongoing global brain health survey to acquire more extensive, quantitative, and representative data on public perception of personalized brain health.

**Keywords:** Cognition, Mental health, Lifestyle, Qualitative research, Lifebrain

Quality of life depends on the health of the brain. Diseases that directly affect the brain, like neurodevelopmental and neurodegenerative diseases, addiction disorders, psychiatric conditions, as well as diseases that affect the brain indirectly, such as cardiovascular disease or obesity, have severe consequences on health and well-being. In Europe, brain disorders account for approximately one-third of the total disease burden and have enormous societal, economic, and personal costs (Olesen et al., 2012; World Health Organization, 2016). The prevalence of poor cognitive health, manifested as cognitive impairment or dementia, is expected to increase markedly the next decades, in low- and high-income countries (Gorelick et al., 2017). On a global scale, a massive expansion of mental health treatment has been proposed to counteract the general neglect of mental health disorders and their stigmatization, especially in low-income countries (Horton et al., 2017).

Cognitive health refers to the ability to think clearly, learn, and remember whereas mental health is defined as “a state of well-being where every individual realizes their own potential, can cope with normal stresses of life, can work productively and fruitfully, and is able to make a contribution to their community” (World Health Organization, 2004). Increasingly, cognitive health and mental health are seen as closely intertwined, impacting the development of prevention and treatment strategies where cognitive and psychiatric problems are present in parallel (McDermott & Ebmeier, 2009). Depression, mood disorders, and severe anxiety are often associated with poor cognitive performance, particularly among elderly (Bierman, Comijs, Jonker, & Beekman, 2005) (Wilson et al., 2002). Moreover, risk and resilience factors for mental and cognitive health show considerable overlap (Livingston et al., 2017). There is an emerging trend to use the term “brain health.” There is yet no consensus definition of brain health, with some definitions stressing cognitive components related to brain health, such as “the ability to remember, learn, plan, concentrate and maintain a clear, active mind” (National Institute on Aging, 2019). In line with the notion of “brain maintenance” (Nyberg, Lövdén, Riklund, Lindenberger, & Bäckman, 2012), other definitions put more emphasis on developing and maintaining a healthy brain (Helse-og Omsorgsdepartementet, 2017), which is the foundation for cognitive function and preventing diseases and disorders related to the central nervous system.

Our understanding of the brain’s structure, function and neurochemistry, its development throughout the life span, and how it is affected by genetic, biological, and environmental factors has advanced significantly during the last decades (Fuhrmann et al., 2019; Walhovd, Tamnes, & Fjell, 2014). Nevertheless, public initiatives to maintain or improve brain health are not as well developed as for general physical health and often focus on specific target populations (World Health Organization, 2010). For example, most EU or global health policies focus on education and mental health in young age, nutrition, physical activity, pre- and perinatal health, socioeconomic status in

childhood, and drug and alcohol consumption. However, these policies often do not target risk factors for mental and cognitive health later in life. Similarly, policies on healthy ageing or dementia primarily focus on interventions among specific risk groups or middle age rather than propose a life-span approach for brain health maintenance (World Health Organization, 2017, 2019) and give limited attention to stimulate cognitive activities on brain health (Global Council on Brain Health, 2017). Only a few countries, for example, Norway, have national strategies for brain health (Helse-og Omsorgsdepartementet, 2017), or are in the process of forming National Brain Councils (The European Brain Council, 2019), although national strategies for dementia are being adopted globally (Cahill, 2019; Global Council on Brain Health, 2017).

In addition to large-scale public initiatives, maintaining brain health also requires continued action on an individual level. However, little is known regarding people’s perception of brain health and willingness to promote brain health by adopting a healthier lifestyle. Recent surveys in the United States show that respondents understand the importance of a healthy brain, but rarely engage in activities focusing on maintaining or improving brain health (Mehegan, Rainville, & Skufca, 2016, 2017; Mehegan & Rainville, 2018; Skufca, 2015). Similarly, other studies conducted in the Western world suggest that the public is often aware of the main risk factors for cognitive impairment (Friedman et al., 2015; Price et al., 2011; Wilcox et al., 2009) and mental health problems (Choudhry, Mani, Ming, & Khan, 2016). Nevertheless, a recent Australian study on people’s knowledge of and attitudes to dementia risk reduction, highlights that individuals may differ greatly concerning what they believe can be done to maintain and improve brain health (Smith, Ali, & Quach, 2014). Uncertainty regarding activities that benefit brain health may reduce people’s willingness and ability to improve personal brain health (Fiocco et al., 2019).

Development of predictive tests of individual risk for cognitive decline and dementia in later life is underway (Tang et al., 2015). Personalized or precision medicine integrates comprehensive genetic, lifestyle, medical history, and environmental information to determine an individual’s risk of developing a condition. Compared to the more prevalent “one size fits all” approach, personalized diagnosis could detect illnesses earlier and facilitate the tailoring of interventions on an individual level (Academy of Medical Sciences, 2015). Adapting medical and public health services to facilitate personalized medicine is a timely challenge and understanding the public’s perception of personalized health strategies is essential, particularly as they relate to the brain. For example, informing asymptomatic people about their individual risk for Alzheimer’s disease is currently not recommended due to the limited clinical validity of available tests (Milne et al., 2018). However, studies have shown that individuals with susceptible genetic variants are willing to change dietary habits, when informed about an increased

risk of developing Alzheimer's disease (Vernarelli, 2013). The application of reliable predictive tests for brain health, in combination with willingness to promote a healthy brain, might reduce health care needs and improve working capabilities over the next decades (Livingston et al., 2017).

In the present multi-site, qualitative study, we investigated the perspectives of adult participants in brain research studies in Norway, Germany, Spain, and the United Kingdom. Specifically, we explored their views on the brain and brain health, their interest in maintaining a healthy brain, their willingness to learn more about personal brain health, and their intention to promote good brain health and prevent development of brain disorders. Our study objective was to explore in-depth the views of brain research participants on brain health and prepare for the design of a larger, quantitative study—The Global Brain Health Survey (The Lifebrain Consortium, 2018).

This study is part of the Lifebrain project, a 5-year research project in the Horizon2020 program of the European Commission (Walhovd et al., 2018). The consortium combines data from 11 European cohorts to explore environmental, social, occupational, and lifestyle factors, affecting brain health.

## Methods

### Study Design and Sample Recruitment

The core study team included researchers from four Lifebrain partners: University of Oslo, Norway (Friedman BB, Budin-Ljøsne I), University of Oxford, United Kingdom (Suri S), Max Planck Institute for Human Development Berlin, Germany (Düzel A), and University of Barcelona, Spain (Solé-Padullés C). The four sites were selected because they hosted cohorts participating in Lifebrain and the participants could be re-contacted. With support from the principal investigators in the consortium, the research team designed an interview guide in English, which was discussed at a workshop in Barcelona, November 2017, with Lifebrain stakeholders, including representatives of key patient and interest organizations, brain health researchers, clinicians, research participants, and policymakers. Subsequently, the interview guide was piloted in the four countries, finalized, translated by the core study team into Spanish, Catalan, German, and Norwegian, and checked by other native speakers for accuracy. The interview guide included 26 questions covering three main topics of brain health: (i) perceptions of the brain and brain health, (ii) interest in maintaining a healthy brain, and (iii) willingness to learn more about personal brain health (see [Supplementary Material](#)). About half of the questions could be answered briefly while the other half required more substantive responses. One question purposefully invited participants to define brain health (Question A.2). The Regional committees for Medical and Health Research Ethics in Norway approved the study (2017/653/REK Sør-Øst B), and local ethics committee approvals were obtained at each study site.

Adult participants in the Lifebrain cohorts at the four research sites, who were not diagnosed with brain health disorders, were invited to join the study (Walhovd et al., 2018). Stratified sampling was used to recruit participants across age groups, sex, and a range of educational backgrounds. The local principal investigators and study coordinators helped to recruit participants, either by phone, email, local online channels, or in person. A leaflet was used to introduce the study and all participants signed an informed consent form.

### Data Collection and Analysis

The core study team conducted individual interviews at the four research sites from March to August 2018, using the same interview guide for all participants. The interviews were audio recorded and lasted approximately 40 min on average. Prompts and examples were used whenever needed to aid the flow of discussion. Participants also completed a short demographic paper questionnaire after the interview. The interviews were transcribed in the original language and translated into English for cross-country analysis and comparison.

The translated interview data were coded and analyzed using the NVivo qualitative data analysis software (QSR International Pty Ltd., version 11, 2015) and a content analysis approach (Elo & Kyngäs, 2008). First, a preliminary codebook structure was created before the analysis started, using the interview questions as a basis for outlining main categories of codes (e.g., Question C.22—help to implement lifestyle changes). Then, a selection of interviews was read to identify subcategories and codes emerging from the text for each question (e.g., Q 22—help from health care professionals, general guidelines, help from family and friends, no help). The codebook was revised after two to three interviews had been pilot-coded at each site to incorporate additional subcategories and codes whenever needed (e.g., Q 22—help from health apps). Each local researcher coded their own interviews using the same revised codebook, and the coding was cross-checked independently by a member of the research team at one of the other four research sites. Coding differences were discussed and reconciled by consensus. For instance, a clearer line was made between the measures done on purpose and consciously for brain health versus general measures for health—Question B.12). The coded interviews from the four research sites were merged in a master file, and the text pertaining to each coding category was condensed to its main content. The research team met at a workshop in Oslo in December 2018 to discuss the key findings summarized in a report.

## Results

Table 1 provides a summary of the participants' demographic characteristics. In total, 44 participants were interviewed: 9 participants in Spain, 11 in Germany, 12 in

**Table 1.** Demographic Characteristics

	N = 44	%
Participants		
Female	22	50
Male	22	50
Age of participants (years)		
18–25	2	4
26–40	11	25
41–60	6	14
61–70	3	7
>70	22	50
Education		
< University degree	20	41
University degree	24	59
Relationship status		
Not in a stable relationship	16	36
Married or in a stable relationship	28	64
Employment		
Employed for wages	15	33
Student/other	6	13
Retired	24	54
Employment and/or education in health care		
Yes	16	36
No	28	64

Norway, and 12 in the United Kingdom. The sample had an equal distribution of men and women. The largest group of participants were older adults (57%, age 61+) followed by young adults (29%, age 18–40), and middle-aged adults (14%, age 41–60). A majority of participants (59%) had a university degree and were married or in a stable relationship (64%). About a third (36%) of the participants had been educated or employed in health care-related fields.

Table 2 provides a summary of the results. No significant differences in responses could be identified between age groups, sex, and countries; results are therefore provided for the whole sample in one set.

### Perceptions of Brain Health

Most participants associated a healthy brain with intact memory and cognitive functions, for example, ability to think, move, learn, remember, concentrate, and perform daily tasks.

[Someone with a healthy brain is] one that is sharp, one that is functioning, one that is aware of things going on around and that is keeping the basic bodily functions ticking in an unobtrusive way (...).

Few participants referred to both cognitive and mental health.

A healthy brain is one that works, both the emotional part and the memory part. A person with a healthy brain is able to have healthy relationships with his/her

**Table 2.** Summary of Key Findings

Most participants associated brain health with cognitive function (e.g., memory) and cognitive and neurodegenerative diseases (e.g., Alzheimer's disease). Mental health was less often considered.

Most participants neither thought nor worried about their brain health.

Witnessing brain disease in the family or among friends triggered interest in brain health.

Participants were knowledgeable about the main factors influencing brain health but did little for their brain health and rather focused on general health and well-being. Those with an interest in brain health often picked one specific strategy (e.g., meditation or diet).

Participants were positive about undergoing brain health tests to learn about their risk of developing preventable brain diseases. There was less interest in learning about risk for non-preventable diseases.

Participants preferred personalized information and follow-up to maintain good brain health.

Participants were in demand of reliable, unified, and evidence-based guidelines about what to do to maintain a healthy brain.

environment. (...) And if you don't have memory you cannot make healthy relationships with other people either.

Some participants described brain health as an absence of illness, pain, or lesions.

[A person with a healthy brain is one with] no physical pain in the brain, (...) and no apparent pain inside your brain like headaches or dizziness (...).

When specifically asked to name brain diseases, participants primarily mentioned cognitive and neurodegenerative diseases such as Alzheimer's disease, dementia, and Parkinson's disease. Less frequently, and often only when prompted, they mentioned mental health disorders such as depression and schizophrenia, or brain injuries and tumors.

When asked to describe how the brain changes with age, many participants mentioned loss or reduction of memory and longer time to process information:

I do not actually know much about how it changes with age other than it seems to work less well particularly those bits relating to memory and retaining additional information.

Reduced capability to learn and concentrate, reduced mobility, and reduced hearing and vision were also mentioned. The participants explained that "the brain shrinks," "it loses brain cells," "it deteriorates," and used terms such as "neuro-connections" or "neuroplasticity" to describe changes occurring within the brain, although they were unsure of their exact meaning. Many admitted not being very knowledgeable about the physiology of the brain.

Some old participants said they applied strategies to compensate for reduced abilities, such as writing lists, or using daily reminders. In a few cases, participants reported that gaining life experiences can make up for losses in memory:

One learns things, and even though you have reduced brain cells, you can compensate for that with your experiences (...).

Participants also described the potential impact of specific life events (e.g., losing a partner) and phases (e.g., giving birth, retiring) on their brain health:

During the 3 years after I became a father, there have been periods with less sleep (...) I have thought about the connection between sleep and brain function. I concretely noticed that the brain functions differently when I am tired and suffer from sleep deprivation over time.

Most participants considered that a healthy body makes a healthy brain, although some reported that it is possible to have a well-functioning brain in a physically dysfunctional body. A few participants described a two-directional connection between mental health and body health:

I think there is a false line between mental health and health, it is like we have a soul and a body (...). But it is difficult to differentiate: if you have a healthy brain (...), it perhaps makes a healthy body. If you have a healthy body, that makes perhaps a healthier brain, (...) and then makes a healthy body again, it has a cyclic effect perhaps. (...) There is an extremely big correlation between a healthy body and the brain.

### Personal Interest in Brain Health

Most interviewees stated that they neither thought nor worried about their brain health and functioning. As explained by one participant: "most people, if they have a healthy brain, do not think about their brain." Some participants had a special interest in brain health due to their practice of activities such as meditation, mindfulness, memory games, or because of their professional background in the health care sector. Some of the research participants reported concerns regarding their ability to remember:

I think I forget rapidly, I think that's the only thing. Perhaps it is because I have a lot to do, I cannot concentrate as well as I used to, some things just disappear (...).

Most participants considered their cognitive health to be above or at least as good as average, and often referred to specific abilities like a good memory or ease to learn, compared to their peers:

When it comes to forgetting things, I am perhaps at the same level as the others, but I do so much compared with many I know. I believe that I use the brain more.

(...) I am quick in the head, I have been like this all my life.

A majority of interviewees said they were in control of their brain health but only to a certain extent, pointing out for instance the impact of genetics:

I believe there is some part I cannot control (...). If I have a genetic predisposition, I can logically not control it. The things I can control would be doing "gymnastics" of my brain, stimulating it.

Most participants already engaged in a number of activities to promote their general health and well-being. However, only a few engaged in these activities with the specific intent of improving or maintaining their brain health, although they believed these activities to be beneficial also for their brains. Those who intentionally aimed to take care of their brain often picked one specific strategy like intellectual stimulation (e.g., using language app daily for memory training), mental stimulation (e.g., meditation, reflecting on own life), or following a specific diet (e.g., eating blueberries or omega-3 fatty acid-rich foods).

### Willingness to Learn About Personal Brain Health

Participants were asked whether they would be willing to undergo a test to get information about their potential risk of developing brain diseases in the future. We explained that the test could range from a simple blood test, a genetic test, a cognitive assessment, up to a brain scan, and we did not provide examples of any specific brain disease. Most participants were willing to undergo such tests and stated that knowing their risk profiles would allow them to choose actions to prevent disease onset and plan for the future. As one participant explained: "the only way to plan is to have full knowledge."

When asked whether they would consider undergoing a test providing information about non-preventable brain diseases, opinions were more divided. About half of the participants thought such tests would be useful to plan for the future, whereas the other half preferred not to undergo them to avoid unnecessary worry and anxiety. Some participants expressed uncertainty regarding whether to undergo testing:

It depends a bit on what the test says. (...) If it is (...) that you may develop a dementia disease within 4 years, then I would be quite worried. It would worry me, honestly. Thinking, what about my children? What about them? In many ways, I think that it is OK not knowing what the future may bring. Live well, use the days and enjoy it while you are there. I am unsure whether I would like to know everything that may happen to me in the future.

We asked the participants to imagine how they would react if they learned that they had a 25% increased risk of developing a brain disease compared with the general

population. Most participants expected that they would not know how to interpret the statistics, and would seek information and advice regarding potential measures to reduce the risk. Some participants foresaw an emotional reaction such as worry or fear.

I think I would want the statistics explained to me a bit more because 25% risk (...), it looks very clear but quite often when you look at statistics they are not quite as clear as that, so I would want to know a bit more about how the statistics were gathered. I would also want to know what the response was (...) I mean if it is genetic and you do nothing about it, well I guess you just try and enjoy life while you can, but if there are significant things that I could do, then I would want to be told whether it is taking a tablet or I don't know, eating more fruit or something.

Most participants did not expect to react more strongly if there was a 50% increase in the risk compared to the general population. Finally, the participants often attached specific conditions to being tested, for instance, the test should be easily administered and reasonably priced. Most participants also expected professional follow-up and counseling to understand the results and take optimal action.

### Measures to Maintain Brain Health

The participants primarily recommended being intellectually active, eating healthy, and being physically and socially active to maintain a healthy brain. Some participants mentioned getting enough sleep and fewer recommended avoiding smoking and alcohol consumption although they were unsure about the impact on the brain. When specifically referring to mental health, participants suggested stress-reducing strategies such as avoiding noise and overstimulation, finding the right balance between professional and private life, and being out in nature.

Many participants said they would be willing to change their lifestyle, for instance, by adopting a healthier diet, or increasing their level of physical activity, if they knew that they were at risk of developing a brain disease. However, they would need evidence, for instance, from research, that the lifestyle change has a positive impact and can truly prevent disease. Such actions should also be enjoyable and easily accommodated in their daily routine. Interestingly, some participants explained that, based on their personal experience, adopting and implementing new behaviors "from scratch" was more challenging than changing current behaviors, for instance reducing alcohol consumption. The participants also suspected that they would need professional guidance, for instance from nutritionists or mentors to implement lifestyle changes, or support from family members or an organized group. As one participant stated: "I would not want just to be given a leaflet and off I go."

Finally, most participants believed that it was important to take care of the brain in early life, that is, childhood and adolescence, while the brain is impressionable and developing, although some also emphasized the importance of taking care of the brain throughout the life span. Still, others felt that taking care of the brain in older age is important because that is when the brain starts deteriorating.

### Promoting Brain Health

As laid out in [Table 3](#), participants suggested that public health authorities could do more to promote brain health in the general population. The most commonly referenced measures included making scientifically reliable information more accessible to the wider public, encouraging healthy behaviors by subsidies, and de-incentivizing unhealthy behaviors.

National and local health authorities as well as academic institutions were considered the most trusted sources of information about brain health. The participants also appeared confused and distrustful of some contradicting scientific findings and the lack of transparency of scientific studies.

The trouble is that the papers and news are full of one day "you must eat more carbohydrates", next day "you must eat more protein." And the trouble is that even among medical professionals, there is no consensus about what is right.

**Table 3.** Public Health Measures Proposed by the Participants to Promote Brain Health

Dissemination	Run national brain health campaigns with evidence-based, demystifying and consistent messages, tailored to specific age and/or target groups, (e.g., risk, risk prevention, maintenance, improvement)
	Run targeted campaigns to inform about brain health—focusing on lifestyle changes necessary for improved brain health (e.g., in primary care centers, senior centers)
Incentives and disincentives	Subsidize healthy food and increase taxes on unhealthy food, alcohol, and tobacco
	Enable affordable access to sports and social and cultural activities
	Establish reward systems to encourage physical activity
	Encourage employers to offer work-out time to employees during working hours and flexible working hours
Other possible measures	Offer citizens periodic brain checks such as blood tests or brain scans free of charge
	Introduce meditation and mindfulness classes in schools
	Put more resources into mental health research and prevention
	Train seniors to use new technologies
	Reduce mental stress by improving access to proper living conditions (e.g., housing and education)

## Discussion and Implications

To our knowledge, this is the first multi-site European study investigating research volunteers' perceptions of brain health. Due to the sample size, and because results were largely similar across age groups, sex, or educational level, we purposefully did not compare results between countries.

Most of our participants were not familiar with the concept of brain health, did not consciously think about their brain health, and did not purposefully adopt lifestyles to take care of their brain health. Rather, in their daily life, they focused on maintaining general body health and well-being. However, they had some knowledge of major factors influencing brain health, were willing to change their lifestyle to maintain good brain health, and were interested in learning more about brain health promotion. These results are in line with results from other studies showing that people may have some knowledge about behaviors promoting brain health but would benefit from more detailed guidance regarding how to maintain a healthy brain (Friedman et al., 2015; Hosking, Sargent-Cox, & Anstey, 2015; Wilcox et al., 2009).

In our ageing society, people over 60 years will soon outnumber those under 14 years, making age-related diseases and mental health disorders an increasingly important consideration for future generations. It is estimated that more than 115 million individuals worldwide will live with dementia by 2050 (Alzheimer's Disease International & The World Health Organization, 2012). Not only has the brain received limited attention, biomedical research thus far has focused on increasing the *quantity* of life with limited appreciation of how this may affect *quality* of life. This is remarkable, and a situation that must be mended, in light of recent estimates—albeit preliminary—that about one third of dementia cases may in theory be prevented, by applying a life course model (Livingston et al., 2017). Efforts are currently made to introduce the concept of brain health in the public domain and promote brain health. Based on our findings, we suggest some steps that may support these efforts.

### Promoting Public Awareness and Knowledge

Our participants showed a limited understanding and knowledge of the brain as an organ. One may speculate that this is because they perceived the brain more as an abstract entity linked to intellectual reflection rather than an organ with physiological functions like regulation of breathing and circulation. Thus, when communicating about brain health, it may be useful to clarify the role of the brain in body functions and highlight the impact of lifestyle on *brain* health specifically, explaining that what affects the body affects the brain. Our participants suggested that the scientific community and public health authorities take an active role in disseminating established

scientific knowledge about brain health in a balanced and accessible way. Other researchers have shown the importance of providing specific information about brain health in a transparent, consistent, and reliable manner, acknowledging the limitations and even the contradictions in brain research (Friedman et al., 2009). An illustration of such approach is the recently conducted evaluation of the impact of software-based “brain games” on cognitive performance (Max Planck Institute for Human Development and Stanford Center on Longevity, 2014).

### Motivating Individual Action

Participants were mostly positive to undergoing brain health tests and believed that such tests would be useful to motivate them to prevent diseases or plan for the future. These results are similar to other studies investigating people's willingness to undergo medical or genetic testing, and to learn about their risk of developing cognitive disorders in the future (Caselli et al., 2014; Wikler, Blendon, & Benson, 2013). Many lifestyle factors influencing brain health are modifiable on an individual level. It has been argued that up to a third of cases with Alzheimer's disease and other types of dementia might be prevented by addressing factors contributing to brain health decline that can be mended by societal policy, health care or lifestyle improvement (Livingston et al., 2017). However, our results show that providing information about individual risk of developing brain disease in the form of a statistical percentage may be insufficient to support health-related decisions, as reported by others (Hollands et al., 2016). This suggests that health care professionals should be adequately trained to communicate risks in a way that is informative (what is the risk and how to reduce it) and encourages long-term lifestyle changes.

Furthermore, our results suggest that increasing awareness of risk and protective factors is hardly enough to promote healthy behaviors; it is also necessary to create an environment that supports people in making good lifestyle decisions (Kelly & Barker, 2016). Our participants suggested specific steps like subsidizing healthy food and initiating work-place exercise programs (Table 3).

Changing behavior is a complex process, as lifestyle choices such as smoking, diet, alcohol consumption, as well as social and physical activities are embedded in everyday routines and habits (Michie, van Stralen, & West, 2011). These activities are often socially motivated and help people define themselves within the context of their social environment. Our participants suspected that they would need strong motivation to initiate changes in their daily life to promote brain health. Other research has also shown that awareness of individual risk (Vernarelli, 2013) and knowledge of the benefits of lifestyle changes often do not translate into real intentions to undertake lifestyle changes (Hollands et al., 2016).

## Maintaining Lifestyle Changes

Participants argued that personalized follow-up and counseling to tailor lifestyle activities would be the most efficient approach to motivate them to maintain their brain health (Kelly & Barker, 2016). Personalization may for instance include regular individual support, either in-person, by phone, or via the Internet, by a general practitioner or nutritionist, as preferred by our participants. *People-centered* approaches supporting individuals to plan their own lifestyle changes may have positive outcomes such as increased self-efficacy and sense of control (Lawrence et al., 2016). However, it is unlikely that our health care systems will have the resources to provide people-centered support for personalized treatments on a wide-scale. Use of digital tools may offer new opportunities for health promotion and brain disease prevention (Wesselman et al., 2019). For instance, some of our participants were positive about using brain health apps, although they were unsure whether they would continue to use them over time. Digitized tools may play an important role in initiating, tracking, and supporting personalized lifestyle changes. Investigating and documenting further the benefits and drawbacks of such tools may be useful as well as exploring their impact on health and suitability across all age and socioeconomic groups (Gordon & Hornbrook, 2018).

The Lifebrain project and similar initiatives (Weiner et al., 2018) collect new scientific evidence concerning risk and protective factors and prepare the ground for personalized brain health promotion. In line with work conducted to investigate the public's view on dementia (Alzheimer's Disease International, 2019), more research should be conducted to learn more about public perceptions of brain health and its variation across the life span and between different sociodemographic settings. For this purpose, a global online brain health survey (The Lifebrain Consortium, 2018) investigating views on brain health has been launched in June 2019 and is available in several languages (The Lifebrain Consortium, 2018). The survey is coordinated by the Lifebrain consortium in collaboration with the Norwegian Brain Council (Hjernerådet, 2019), the German Brain Council (German Brain Council, 2019), the Belgian Brain Council (The Belgian Brain Council, 2019), and the National University of Ostroh Academy (The National University of Ostroh Academy, 2019). Results from this survey will be discussed in a forthcoming paper from the Lifebrain Consortium.

## Study Limitations

Our study has several limitations. It was conducted on a limited and non-representative sample. We invited healthy participants in ongoing brain health projects to partake in this study. All participants had previous experience with either cognitive, genetic, and/or brain scan-based testing. Thus, our sample likely had more access to brain research results and resources, and was more up-to-date with, and

interested in, brain health strategies than the average individual. This might also influence their willingness to undergo tests to receive information on brain health. Healthy adults may also have different views on brain health than adults diagnosed with a brain illness. Thus, our results cannot be generalized to the wider public. Second, due to the nature of the cohorts, each of the samples from the four sites differed in characteristics with respect to age and education. The Norwegian sample was mainly well educated, whereas the German participants primarily included lower educated participants, and the Spanish sample mainly included older adults. Due to the sample size, we did not explore potential site-specific differences and these may be interesting to explore in a larger survey. Nevertheless, we observed that participants' responses were similar across sites and age groups, and agreed on initiatives to stimulate brain health. Similarly, we did not investigate whether perceptions varied by race and ethnicity.

Our forthcoming global brain health survey will address most of these limitations and is expected to provide further insights into the possibility of country-specific differences in the public perception of personalized brain health strategies.

## Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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## Conflict of Interest

The authors declare no conflict of interest except for Christian A. Drevon, who is a cofounder, stock-owner, board member, and consultant in the contract laboratory Vitas AS, performing personalized analyses of blood biomarkers.

## References

- Academy of Medical Sciences. (2015). Stratified, personalised or P4 medicine: a new direction for placing the patient at the centre of healthcare and health education. Retrieved from <https://acmedsci.ac.uk/download?f=file&i=32644>
- Alzheimer's Disease International. (2019). Survey on attitudes around dementia. Retrieved from <https://www.alz.co.uk/news/survey-on-attitudes-around-dementia-now-open>
- Alzheimer's Disease International & The World Health Organization. (2012). Dementia: a public health priority. Retrieved from [https://apps.who.int/iris/bitstream/handle/10665/75263/9789241564458\\_eng.pdf;jsessionid=4837501796221D09C6446D0927DBF771?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/75263/9789241564458_eng.pdf;jsessionid=4837501796221D09C6446D0927DBF771?sequence=1)
- Bierman, E. J., Comijs, H. C., Jonker, C., & Beekman, A. T. (2005). Effects of anxiety versus depression on cognition in later life. *The American Journal of Geriatric Psychiatry*, *13*, 686–693. doi:10.1176/appi.ajgp.13.8.686
- Cahill, S. (2019). WHO's global action plan on the public health response to dementia: Some challenges and opportunities. *Aging & Mental Health*, *1*–3. doi:10.1080/13607863.2018.1544213
- Caselli, R. J., Langbaum, J., Marchant, G. E., Lindor, R. A., Hunt, K. S., Henslin, B. R., ... Robert, J. S. (2014). Public perceptions of presymptomatic testing for Alzheimer disease. *Mayo Clinic proceedings*, *89*, 1389–1396. doi:10.1016/j.mayocp.2014.05.016
- Choudhry, F. R., Mani, V., Ming, L. C., & Khan, T. M. (2016). Beliefs and perception about mental health issues: A meta-synthesis. *Neuropsychiatric Disease and Treatment*, *12*, 2807–2818. doi:10.2147/NDT.S111543
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*, 107–115. doi:10.1111/j.1365-2648.2007.04569.x
- Fiocco, A. J., Krieger, L., D'Amico, D., Parrott, M. D., Laurin, D., Gaudreau, P., ... Ferland, G. (2019). A systematic review of existing peripheral biomarkers of cognitive aging: Is there enough evidence for biomarker proxies in behavioral modification interventions? An initiative in association with the nutrition, exercise and lifestyle team of the Canadian Consortium on Neurodegeneration in Aging. *Ageing Research Reviews*, *52*, 72–119. doi:10.1016/j.arr.2019.04.008
- Friedman, D. B., Becofsky, K., Anderson, L. A., Bryant, L. L., Hunter, R. H., Ivey, S. L., ... Lin, S. Y. (2015). Public perceptions about risk and protective factors for cognitive health and impairment: A review of the literature. *International Psychogeriatrics*, *27*, 1263–1275. doi:10.1017/S1041610214002877
- Friedman, D. B., Laditka, J. N., Hunter, R., Ivey, S. L., Wu, B., Laditka, S. B., ... Mathews, A. E. (2009). Getting the message out about cognitive health: A cross-cultural comparison of older adults' media awareness and communication needs on how to maintain a healthy brain. *Gerontologist*, *49* (Suppl. 1), S50–S60. doi:10.1093/geront/gnp080
- Fuhrmann, D., Nesbitt, D., Shafto, M., Rowe, J. B., Price, D., Gadie, A., ... Kievit, R. A.; Cam-CAN. (2019). Strong and specific associations between cardiovascular risk factors and white matter micro- and macrostructure in healthy aging. *Neurobiology of Aging*, *74*, 46–55. doi:10.1016/j.neurobiolaging.2018.10.005
- German Brain Council. (2019). German Brain Council. Retrieved from <https://www.braincouncil.de/>
- Global Council on Brain Health. (2017). Engage your brain: GCBH recommendations on cognitively stimulating activities. Retrieved from <https://www.aarp.org/health/brain-health/global-council-on-brain-health/cognitively-stimulating-activities/>
- Gordon, N. P., & Hornbrook, M. C. (2018). Older adults' readiness to engage with eHealth patient education and self-care resources: A cross-sectional survey. *BMC Health Services Research*, *18*, 220. doi:10.1186/s12913-018-2986-0
- Gorelick, P. B., Furie, K. L., Iadecola, C., Smith, E. E., Waddy, S. P., Lloyd-Jones, D. M., ... Zerna, C.; American Heart Association/American Stroke Association. (2017). Defining optimal brain health in adults: A presidential advisory from the American Heart Association/American Stroke Association. *Stroke*, *48*, e284–e303. doi:10.1161/STR.0000000000000148
- Helse-og Omsorgsdepartementet, N. (2017). Nasjonal hjernehelsetrategi (2018–2024). Retrieved from [https://www.regjeringen.no/contentassets/8eba3248e9e843f6b09e97a84a97a153/hjernehelsetrategi\\_2018-24\\_121217.pdf](https://www.regjeringen.no/contentassets/8eba3248e9e843f6b09e97a84a97a153/hjernehelsetrategi_2018-24_121217.pdf)
- Hjernerådet. (2019). Hjernerådet (The Norwegian Brain Council) website. Retrieved from <http://www.hjerneradet.no/>
- Hollands, G. J., French, D. P., Griffin, S. J., Prevost, A. T., Sutton, S., King, S., & Marteau, T. M. (2016). The impact of communicating genetic risks of disease on risk-reducing health behaviour: Systematic review with meta-analysis. *British Medical Journal (Clinical Research ed.)*, *352*, i1102. doi:10.1136/bmj.i1102
- Horton, R., Sartorius, N., Herrman, H., Swartz, L., Dhanda, A., Narayan, T., ... Miller, G. (2017). Global Mental Health 2007—series from the *Lancet* journals. *Global Mental Health 2007*. Retrieved from <https://www.thelancet.com/series/global-mental-health>
- Hosking, D. E., Sargent-Cox, K. A., & Anstey, K. J. (2015). An Australian survey of cognitive health beliefs, intentions, and behaviours through the adult life course. *Preventive Medicine Reports*, *2*, 498–504. doi:10.1016/j.pmedr.2015.06.008
- Kelly, M. P., & Barker, M. (2016). Why is changing health-related behaviour so difficult? *Public Health*, *136*, 109–116. doi:10.1016/j.puhe.2016.03.030
- Lawrence, W., Black, C., Tinati, T., Craddock, S., Begum, R., Jarman, M., ... Barker, M. (2016). 'Making every contact count': Evaluation of the impact of an intervention to train health and social care practitioners in skills to support health behaviour change. *Journal of Health Psychology*, *21*, 138–151. doi:10.1177/1359105314523304
- Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., ... Mukadam, N. (2017). Dementia prevention, intervention, and care. *Lancet*, *390*, 2673–2734. doi:10.1016/S0140-6736(17)31363-6
- Max Planck Institute for Human Development and Stanford Center on Longevity. (2014). A consensus on the brain training industry from the scientific community. Retrieved from <http://longevity.stanford.edu/a-consensus-on-the-brain-training-industry-from-the-scientific-community-2/>
- McDermott, L. M., & Ebmeier, K. P. (2009). A meta-analysis of depression severity and cognitive function. *Journal of Affective Disorders*, *119*, 1–8. doi:10.1016/j.jad.2009.04.022

- Mehegan, L., & Rainville, C. (2018). 2018 AARP Brain Health and Mental Well-Being Survey. Retrieved from <https://www.aarp.org/research/topics/health/info-2018/brain-health-mental-well-being.html>
- Mehegan, L., Rainville, C., & Skufca, L. (2016). 2016 AARP Social Engagement and Brain Health Survey. Retrieved from <https://www.aarp.org/research/topics/health/info-2017/2016-social-engagement-brain-health-survey.html>
- Mehegan, L., Rainville, C., & Skufca, L. (2017). 2017 AARP Cognitive Activity and Brain Health Survey. Retrieved from <https://www.aarp.org/research/topics/health/info-2017/2017-cognitive-activity-brain-health-survey.html>
- Michie, S., van Stralen, M. M., & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, *6*, 42. doi:10.1186/1748-5908-6-42
- Milne, R., Bunnik, E., Diaz, A., Richard, E., Badger, S., Gove, D., ... Brayne, C. (2018). Perspectives on communicating biomarker-based assessments of Alzheimer's disease to cognitively healthy individuals. *Journal of Alzheimer's Disease*, *62*, 487–498. doi:10.3233/JAD-170813
- National Institute on Aging. (2019). What is brain health? Retrieved from <https://brainhealth.nia.nih.gov/>
- Nyberg, L., Lövdén, M., Riklund, K., Lindenberg, U., & Bäckman, L. (2012). Memory aging and brain maintenance. *Trends in Cognitive Sciences*, *16*, 292–305. doi:10.1016/j.tics.2012.04.005
- Olesen, J., Gustavsson, A., Svensson, M., Wittchen, H. U., & Jönsson, B.; CDBE2010 Study Group; European Brain Council. (2012). The economic cost of brain disorders in Europe. *European Journal of Neurology*, *19*, 155–162. doi:10.1111/j.1468-1331.2011.03590.x
- Price, A. E., Corwin, S. J., Friedman, D. B., Laditka, S. B., Colabianchi, N., & Montgomery, K. M. (2011). Older adults' perceptions of physical activity and cognitive health: Implications for health communication. *Health Education & Behavior*, *38*, 15–24. doi:10.1177/1090198110369764
- Skufca, L. (October 2015). 2015 Survey on Brain Health. Retrieved from <https://www.aarp.org/research/topics/health/info-2015/2015-brain-health-survey.html>
- Smith, B. J., Ali, S., & Quach, H. (2014). Public knowledge and beliefs about dementia risk reduction: A national survey of Australians. *BMC Public Health*, *14*, 661. doi:10.1186/1471-2458-14-661
- Tang, E. Y., Harrison, S. L., Errington, L., Gordon, M. F., Visser, P. J., Novak, G., ... Stephan, B. C. (2015). Current developments in dementia risk prediction modelling: An updated systematic review. *PLoS ONE*, *10*, e0136181. doi:10.1371/journal.pone.0136181
- The Belgian Brain Council. (2019). The Belgian Brain Council. Retrieved from <https://braincouncil.be/>
- The European Brain Council. (2019). European Brain Council. Retrieved from <https://www.braincouncil.eu/>
- The Lifebrain Consortium. (2018). Lifebrain. Retrieved from <http://www.lifebrain.uio.no/>
- The National University of Ostroh Academy. (2019). The National University of Ostroh Academy. Retrieved from <https://www.oua.edu.ua/en/>
- Vernarelli, J. A. (2013). Impact of genetic risk assessment on nutrition-related lifestyle behaviours. *The Proceedings of the Nutrition Society*, *72*, 153–159. doi:10.1017/S0029665112002741
- Walhovd, K. B., Fjell, A. M., Westerhausen, R., Nyberg, L., Ebmeier, K. P., Lindenberg, U., ... Bertram, L.; for Lifebrain Consortium. (2018). Healthy minds from 0-100 years: Optimising the use of European brain imaging cohorts ("Lifebrain"). *European Psychiatry*, *47*, 76–87. doi:10.1016/j.eurpsy.2017.10.005
- Walhovd, K. B., Tamnes, C. K., & Fjell, A. M. (2014). Brain structural maturation and the foundations of cognitive behavioral development. *Current Opinion in Neurology*, *27*, 176–184. doi:10.1097/WCO.0000000000000074
- Weiner, M. W., Nosheny, R., Camacho, M., Truran-Sacrey, D., Mackin, R. S., Flenniken, D., ... Veitch, D. (2018). The Brain Health Registry: An internet-based platform for recruitment, assessment, and longitudinal monitoring of participants for neuroscience studies. *Alzheimer's & Dementia*, *14*, 1063–1076. doi:10.1016/j.jalz.2018.02.021
- Wesselman, L. M., Hooghiemstra, A. M., Schoonmade, L. J., de Wit, M. C., van der Flier, W. M., & Sikkes, S. A. (2019). Web-based multidomain lifestyle programs for brain health: Comprehensive overview and meta-analysis. *JMIR Mental Health*, *6*, e12104. doi:10.2196/12104
- Wikler, E. M., Blendon, R. J., & Benson, J. M. (2013). Would you want to know? Public attitudes on early diagnostic testing for Alzheimer's disease. *Alzheimer's Research & Therapy*, *5*, 43. doi:10.1186/alzrt206
- Wilcox, S., Sharkey, J. R., Mathews, A. E., Laditka, J. N., Laditka, S. B., Logsdon, R. G., ... Liu, R. (2009). Perceptions and beliefs about the role of physical activity and nutrition on brain health in older adults. *The Gerontologist*, *49* (Suppl. 1), S61–S71. doi:10.1093/geront/gnp078
- Wilson, R. S., Barnes, L. L., Mendes de Leon, C. F., Aggarwal, N. T., Schneider, J. S., Bach, J., ... Bennett, D. A. (2002). Depressive symptoms, cognitive decline, and risk of AD in older persons. *Neurology*, *59*, 364–370. doi:10.1212/wnl.59.3.364
- World Health Organization. (2004). Promoting mental health: concepts, emerging evidence, practice: summary report. Retrieved from [https://www.who.int/mental\\_health/evidence/en/promoting\\_mhh.pdf](https://www.who.int/mental_health/evidence/en/promoting_mhh.pdf)
- World Health Organization. (2010). Global strategy on diet, physical activity and health. Retrieved from [https://www.who.int/dietphysicalactivity/factsheet\\_adults/en/](https://www.who.int/dietphysicalactivity/factsheet_adults/en/)
- World Health Organization. (2016). Disease burden and mortality estimates 2000–2016. Retrieved from [https://www.who.int/healthinfo/global\\_burden\\_disease/estimates/en/index1.html](https://www.who.int/healthinfo/global_burden_disease/estimates/en/index1.html)
- World Health Organization. (2017). Global action plan on the public health response to dementia 2017–2025. Retrieved from <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=D29BBE4ABE91564AC714D2D3BF2E6093?sequence=1>
- World Health Organization. (2019). Risk reduction of cognitive decline and dementia: WHO guidelines. Retrieved from <https://apps.who.int/iris/bitstream/handle/10665/312180/9789241550543-eng.pdf?ua=1>