Lifebrain

D1.4. Input from Stakeholders – Feedback Incorporated

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Executive Summary

Lifebrain WP1 is dedicated to ensuring stakeholder engagement and input throughout project duration. This deliverable describes how stakeholders have been included in Lifebrain activities and provides examples of how stakeholder input has influenced Lifebrain research and communication. Lifebrain stakeholders are research participants in the cohorts, patient groups and patient organizations, policymakers, clinical and research centers, researchers and research networks, and other relevant stakeholders (e. g. media).

Through WP1, stakeholder involvement has taken place on different levels:

1. Specific activities have been carried out to acquire and register stakeholder perspectives.
2. Stakeholder perspectives have been integrated in Lifebrain to shape research focus and communication activities.
3. Lifebrain has established partnerships with several stakeholder groups, and several Lifebrain events and research activities have been planned and organized in close cooperation with these.

D1.4 outlines in detail which specific stakeholder engagement activities have been conducted in cooperation with which stakeholder groups, what types of input the project has received from stakeholders, and how key stakeholder input has shaped Lifebrain activities.

In sum, ten Lifebrain events, including workshops, lectures, and conferences, have been conducted from the project start in 2017 until spring 2021. WP1 research has also been conducted during this period in collaboration with stakeholders. Six events were organized in collaboration with key stakeholder organizations, and seven stakeholder organizations have been engaged in the WP1 research. In total, Lifebrain reached more than 28,000 stakeholders including researchers and clinicians, brain councils, brain foundations, brain research projects, patient groups and members of the public. More than 800 people attended Lifebrain public events and stakeholder workshops. Five evaluations of stakeholder events and cooperation have been conducted. Furthermore, two scientific papers have been published describing stakeholder perspectives and stakeholders' collaboration in Lifebrain research.

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List of acronyms/ abbreviations

GBHS	Global Brain Health Survey
Lifebrain	Healthy minds from 0-100 years: Optimising the use of European brain imaging cohorts
NIPH	Norwegian Institute of Public Health
PI	Principal Investigator
WP	Work Package

1. Introduction

Deliverable description

D1.4. Input from Stakeholders – Feedback Incorporated

WP1 aims to optimize scientific exchange between Lifebrain researchers and relevant stakeholders, including policy makers, national decision makers, healthcare providers, patient organizations, cohort participants and researchers. Since project start in 2017, the WP has worked systematically to engage key stakeholders and integrate their views and priorities in the project using diverse tools and methods. By engaging stakeholders, the WP aimed to facilitate actual influence by stakeholders on research priorities in the project, thereby securing its relevance to policy makers and public health initiatives. . The project results are hence expected to be of interest to health and public health advisors in terms of stakeholder perspectives on lifestyle choices, motivations for or against making lifestyle changes and/or using tests monitoring brain health, and regulatory initiatives aimed at improving cognition and mental health.

Objectives of the deliverable

The objective of this deliverable is to describe the activities carried out to ensure input from, and cooperation with Lifebrain stakeholders throughout the project. It outlines how and when various stakeholders have contributed to Lifebrain at different stages of the project, reports on specific meeting arenas for involvement and communication and explains how stakeholder perspectives have been systematically collected and integrated in Lifebrain activities.

Collaboration among partners

Activities described in this deliverable have been conducted by the WP1 team in close collaboration with WP5, the WP leaders and cohort PIs, and Lifebrainers in the different partner countries. Importantly, key stakeholder organizations have been involved in connection with activities taking place in their respective countries.

2. Planning of activities to ensure stakeholder engagement and input

The WP1 went through several key steps to enable stakeholder engagement in the project as described below.

2.1 Identifying and targeting stakeholders

First, the WP identified five main groups of stakeholders to engage in the project:

- Research participants in the consortium
- Patient groups and patient organizations
- Policymakers
- Clinical and research centres, researchers and research networks
- Other stakeholders (e.g. national and regional newspapers)

The rationale for selecting these groups has been described previously in Deliverable 1.1 "List of relevant stakeholders for project engagement" submitted in March 2017.

In connection with this deliverable, a stakeholder catalogue was established, which comprised lists of individual and organizational stakeholders to engage. In total, the catalogue listed the consortium's 11 cohorts, 44 patient organizations, 18 policymakers and governmental bodies, 22 research groups, and 31 other stakeholders such as newspapers, television channels and charities. When selecting stakeholders, priority was given to stakeholders interested in brain health, cognition and mental health (e.g. dementia, depression) and located in the countries of the project partners: Norway, Sweden, United Kingdom, Spain, Denmark, the Netherlands and Switzerland. Some international organizations such as the European Brain Council were also considered relevant. The stakeholder list was set up as a living document to be regularly updated as new contacts would be made with diverse stakeholders.

All stakeholder groups were engaged in Lifebrain through various activities. As the project developed, close collaboration was also established with some key stakeholder organizations that are listed in **Annex 1**. The stakeholder organizations include national brain councils, brain foundations, brain research projects, universities, and research registries.

2.2. Developing a stakeholder engagement plan

Second, a detailed 5-year stakeholder engagement plan was established as described previously in D 1.2. "Input to the Dissemination, Exploitation and Communication plan" (submitted in December 2017). The plan was developed in close collaboration with the WP leaders and cohort PIs.

Stakeholder engagement activities were to pivot around three main tasks:

- **Collect data on the views and perspectives of stakeholders** on brain health, using research methodologies. The research was preferably to be conducted in collaboration with key stakeholders.
- **Establish arenas for discussion and exchange with stakeholders**, such as workshops, public lectures, and conferences.

- **Collaborate with stakeholders to disseminate Lifebrain research results**, using for instance social media and audio-visual platforms, with the objective to inform the public and provide guidance to policymakers.

As reported earlier in D1.2, planned engagement activities were plotted according to a tentative timeline, see Table 1.

Table 1. Planned timeline over stakeholder engagement activities

Timeline over WP1 activities	**2017**	**2018**	**2019**	**2020**	**2021**
Data collection/views on brain health					
Stakeholder workshops					
Stakeholder -led or co-led sessions					
Public lectures					
Dissemination					
Evaluation of stakeholder engagement					

2.3 Establishing principles for stakeholder engagement

Some ground principles were established for the conduct of stakeholder engagement in the project:

- Stakeholders events should be conducted preferably in conjunction with project meetings. Preference should be given to inviting local stakeholders to join the events. Local stakeholders should be approached in connection with the planning and conduct of the stakeholder events, depending on the activity's geographical location and the stakeholder's interest, level of expertise and possibility of participating.
- Stakeholders should be free to decide on their level of engagement in the organization of the events and may withdraw from collaborations at any time if they wish so.
- No written contract would be established with stakeholders and no financial compensation provided. Rather, any costs related to the organization of stakeholder events would be covered by Lifebrain.
- When stakeholder activities were to be organized jointly with stakeholders, the stakeholder organizations' logos should be added to any material, like conference programs or web pages. The stakeholders should be given the opportunity to equally contribute to the development of the activities such as event programs and dissemination work.

3. Stakeholder engagement activities

3.1. Collecting data on views and perspectives of stakeholders on brain health – the "WP1 study"

The WP aimed to collect data regarding various stakeholders' views and perspectives on brain health and personalized brain health prevention. There is increasing scientific evidence that healthy lifestyles may be beneficial for the brain [1]. However, we still know very little about how people think about their brain and their brain health. If people are willing to improve their brain health, this would have enormous consequences for individual well-being, for work ability, and for reducing the costs of health care, specifically in light of increased life expectancy and proportion of older persons. Knowing more about people's perceptions brain health can potentially contribute to develop and optimize policy recommendations for brain health.

In 2018, WP1 initiated the WP1 study, which aimed to investigate perceptions on brain health and personalized brain health prevention by the public and various stakeholders.
More specifically, the study aimed to explore:

- Public and stakeholders' perceptions of the brain and brain health,
- Their interest in maintaining a healthy brain,
- Their willingness to know more about their own brain health
- Their willingness to make lifestyle changes, if necessary, to improve or maintain a good brain health and prevent brain disease development

The study was conducted in two phases – a qualitative phase and a quantitative phase.

Phase 1: Individual interviews were conducted with brain research participants at four study sites (Barcelona, Berlin, Oxford, and Oslo). Plans for this qualitative study have been described in D1.2.: "Input to the Dissemination, Exploitation & Communication". This phase was conducted in 2018.

Phase 2: An online survey was launched in June 2019 to collect the views on brain health of a larger group of individuals, including, for instance, members of patient organizations, clinicians, researchers, policymakers in the Lifebrain network, and the general public. Plans for the online survey have been described in D1.3: Online/mobile tools for stakeholder engagement conceptualized and developed. The online survey closed in August 2020.
A more detailed description of the phases, and the types of input received from stakeholders, is provided below.

3.1.1 Interview study with brain research participants

Objectives and background: The interview study aimed to explore in-depth the views of brain research participants within the Lifebrain cohorts on brain health and personalized brain health prevention. Individual interviews were conducted with the participants using an interview guide.

Organizers: The WP1 team in collaboration with the WP leaders, cohort PIs and Lifebrain researchers at the research sites

Participants: Interviewees consisted of 44 individuals participating in brain-health research projects within the Lifebrain consortium, in Spain, Norway, Germany and the United Kingdom.

Key stakeholder input: Results from this study were published in a scientific paper by Friedman and al. in 2020 [2]. The article abstract is provided in **Annex 2.**

In short, the interviews shed light on limited understanding of the brain and what brain health entails by lay participants in brain health research. Most participants associated brain health with memory and cognitive capacities rather than mental health aspects. Although most interviewees knew some of the main factors that affect brain health, most focused on their general health rather than on brain health specifically. Those who did actively seek to strengthen their brain health tended to focus on one activity. The presence of brain health conditions in close family members increased brain health awareness in interviewees.

Several interviewees were positive towards taking brain health tests to learn about their general brain health and potential brain health risks. However, this positive attitude was diminished with respect to non-preventable conditions. Furthermore, their accounts indicated that making any behavioural changes to strengthen brain health would require strong motivation and that awareness of potential risk factors in itself might not be sufficient. The interviewees also requested evidence based and personalized information on brain health maintenance.

3.1.2 Online survey: The Global Brain Health Survey (GBHS)

Objectives and background: The GBHS aimed to investigate public views on brain health and personalized brain health prevention. The survey was made available online on the Lifebrain website to anyone interested and above 18 years of age. The survey was translated into 14 languages including English, Spanish, French and German to reach a large sample of respondents. All languages spoken in the partner Lifebrain countries were represented, such as English, Spanish, German, Italian, Norwegian, Swedish, Dutch and Danish.

Organizers: The WP1 team developed the survey in collaboration with the WP leaders, cohort PIs and Lifebrainers. In addition, WP1 invited national brain councils in Europe to collaborate on the survey and to become official survey co-organizers. National brain councils are independent and multidisciplinary councils that gather scientific organisations of brain specialists, neuroscientists and relevant patient organizations [3].

Survey co-organizers were invited to have their logos added to the survey web page and material, use the aggregate survey results in their own work and disseminate them through their communication channels. Three national brain councils accepted our invitation: The Norwegian Brain Council, The German Brain Council, and the Belgian Brain Council. In addition, several brain foundations and brain projects working for the promotion of brain health expressed interest in the survey and joined as co-organizers. These include the Brain Foundation Netherlands, the Swedish Brain Foundation, and the Women's Brain Project. The National University of Ostroh Academy in Ukraine also joined as a co-organizer. A detailed description of these stakeholder organizations is provided in **Annex 1**.

Participants: In total, 27,590 individuals across 81 countries responded to the survey. Respondents were predominantly from Europe, with the largest response rates from the UK and the Netherlands. The majority of respondents were women, middle-aged or older and with higher education.

Key stakeholder Input: The survey data is currently being analysed, and results will be disseminated in scientific publications and policy briefs. A study protocol paper, published by Budin-Ljøsne et al in August 2020 [4], provides a detailed description of the survey background, development, and design. The article abstract is provided in **Annex 3**.

Some input from stakeholders was collected during the development of the survey. This was done by sharing several draft versions of the survey questionnaire with stakeholders attending the Lifebrain stakeholder workshops, members of the public who participated in Lifebrain stakeholder workshops and public lectures in Spain, Norway and the United Kingdom. Their suggestions for improvement were collected and integrated in later versions of the questionnaire. The questionnaire was also shared with selected national brain councils and brain foundations.

Dissemination by stakeholders: Co-organizers helped disseminate the survey in their networks and urged their members to participate, which is believed to have significantly increased the response rate of the study. Examples of media and stakeholder communication of the GBHS are provided later in this document.

Survey results relating to people's perception of brain health and which factors are important for brain health will be presented in a public lecture at the Oslo Science Festival, and to scientists at the SiNAPSA Neuroscience Conference in Slovenia in September 2021.

We plan to make the results of the GBHS survey easily accessible for policymakers, by providing them with short summaries (policy briefs) and simple statistics on the main topics. We plan to inform the general public, **research participants**, patient organizations of the survey results with short videos and infographics in social media.

3.2 Establish arenas for discussion and exchange with the stakeholders

Between 2017 and spring 2021, WP1 organized four stakeholder workshops. The workshops aimed to gather local and national policymakers, representatives from patient and interest organizations, external scientists, and research groups to engage in discussions regarding the Lifebrain research and ways to collaborate to translate research output into brain health policy of practical use. Two of the arrangements were digital, due to the Covid-19 pandemic. Events were predominantly arranged in connection to the yearly Lifebrain consortium meetings. One workshop was organized in collaboration with the Norwegian Brain Council. A detailed description of each workshop's objectives, target group and key stakeholder inputs collected is provided below.

3.2.1 Stakeholder workshop 1: "LIFEBRAIN Stakeholder workshop", Spain, November 2017

The workshop program and minutes are provided in **Annex 4**.

Objectives and background: This pilot workshop aimed to introduce the Lifebrain project to the stakeholders, review the Lifebrain draft stakeholder engagement plan with the stakeholders and receive their inputs, discuss the design and content of the planned WP1 study, and explore how Lifebrain may interact with stakeholders.

Organizer: Lifebrain

Participants: In total, 24 participants attended the workshop. 13 participants were Lifebrain researchers and 11 were Catalan and national stakeholders such as representatives of patient and interest organizations, brain health researchers, clinicians, brain research participants, and policymakers.

Key input from stakeholders:

Workshop participants provided the following input:

The stakeholders commented on the Lifebrain preliminary plans to conduct an interview study with brain research participants (see 3.1). The draft questions and interview guide were discussed at the workshop. Participants recommended explaining the concept of brain health in more detail to research participants, and to frame interview questions to focus on positive action to take care of the brain rather than individual brain-related disease risk. They also suggested collecting information about the participants' background, as willingness to take care of the brain may vary depending on level of education and experience of brain disease.

The stakeholders also advocated for a greater focus on mental and emotional health in the project. Stressing the need to highlight relevant policy implications of research results, stakeholders also gave advice on how to translate research findings into information of interest for public health policy.

For example, they advised that recommendations to policymakers should be based on reliable and trustworthy evidence that is understandable and concise, reasonable in terms of cost, and lead to tangible benefits.

The stakeholders discussed their level of engagement in the Lifebrain project and explained that they were interested in the project and were happy to help. They however emphasized that it was difficult for them to commit to long-term contribution or cooperation. The stakeholders approved the Lifebrain five-year engagement plan.

Evaluation: An evaluation form was shared with stakeholders at the end of the workshop. 9 out of 24 responded to the evaluation. The majority of these rated the workshop as informative and useful.

3.2.2. Stakeholder workshop 2: "Brain health promotion across the lifespan", Norway, June 2018

The workshop program and minutes are provided in **Annex 5 a**nd the presentations of the event are available here.

Objectives and background: The workshop aimed to investigate opportunities and challenges with respect to promoting brain health across the lifespan. The workshop specifically targeted patient organizations with an interest in cognitive and mental health, clinicians and researchers working in the field of brain health, representatives from medical associations, and policymakers.

Organizers: Lifebrain and the Norwegian Brain Council.

Participants: In total, 44 participants attended the workshop. 27 participants were Norwegian stakeholders with an interest in cognitive and mental health, clinicians and researchers working in the field of brain health, representatives from medical associations, and policymakers. 17 Lifebrain researchers participated.

Key input from stakeholders:

The stakeholders provided several comments and inputs as follows:

The stakeholders stressed the importance of supporting and facilitating family involvement in brain health maintenance and rehabilitation. They furthermore highlighted the need to improve brain health education in relevant public infrastructures such as welfare administration, primary school educators, municipalities, and medical professionals.
The stakeholders recommended to allocate more resources to children with brain disease and apply a low threshold in terms of providing public services to brain patients, in line with the Danish model.
The stakeholders stressed the need to provide evidence-based information on brain health for both health care professionals, government representatives, local authorities, and lay citizens to facilitate better support and integration for patients in everyday life.

Evaluation: An evaluation form was shared with stakeholders at the end of the workshop. 80 % of the respondents to the evaluation (in total 10 out of 44 participants) found the workshop interesting, 100 % gained a good overview over Lifebrain, and 90 % found participation useful.

3.2.3 Stakeholder workshop 3: "Lifebrain Webinar– The Global Brain Health Survey", September 2020

The workshop minutes are provided in **Annex 6**.

Objective: This workshop (held as an online webinar) aimed to discuss with the survey co-organizers the status of the GBHS and initial results as well as plans for analysis process and publications. The co-organizers include the Norwegian Brain Council, The German Brain Council, the Belgian Brain Council, the Brain Foundation Netherlands, the Swedish Brain Foundation, the Women's Brain Project, and the National University of Ostroh Academy in Ukraine.
In addition, two European brain research registries, Join Dementia Research in the United Kingdom and Hersenonderzoek in the Netherlands, contributed without registering as official co-organizers. These two registries, which connect researchers and volunteer brain research participants, contributed by disseminating and collecting responses to the survey.
In addition, three representatives from research groups which showed interest in the GBHS were invited to join the workshop. They included researchers from 1) the Public Health Institute of the United Arab Emirates University, 2) the Institute of Institute of Pathological Physiology at the University of Medicine, Slovenia, and 3) the Department of Psychology at Heriot-Watt University, United Kingdom (see **Annex 2**).

Organizer: Lifebrain

Participants: In total, 10 participants joined the workshop and 5 sent their apologies.

Key input from stakeholders:

The stakeholders provided several comments to the GBHS as follows:

The stakeholders discussed the GBHS in relation to local brain health studies, among else highlighting potentially interesting individual variables among survey respondents and potential cross-study comparisons. They discussed the importance of finding out more about the profiles of respondents and whether gender, participation in brain research, or being a caretaker plays a role in endorsing brain health measures in daily life.

The stakeholders discussed how to translate results from the GBHS into policy recommendations. They emphasized the importance of providing short, compact messages to policymakers. Some participants highlighted the role women take as health ambassadors in the family and in society and suggested to have a closer look at how women can influence behaviour change.

3.2.4 Stakeholder workshop 4: "Global Brain Health Survey" online workshop, April 2021

The workshop minutes are provided in **Annex 7**.

Objectives and background: This workshop (held as an online webinar) aimed to present and discuss first results from the GBHS, potential channels and methods/tools for dissemination of results, and collect some feedback from co-organizers and research registries which helped disseminate the survey regarding their collaboration with Lifebrain.

Organizer: Lifebrain

Participants: In total, the workshop gathered 16 participants, of which 7 were from Lifebrain and 9 were stakeholders and survey co-organizers.

Key input from stakeholders:

The stakeholders provided several comments to the GBHS work progress as follows:

The stakeholders discussed the relevance of the preliminary research results from the GBHS considering their experiences, and suggested strategies for promoting the results to public health officials. For example, the Belgian Brain Council suggested allying with other organizations to direct attention to the silent epidemic of brain disease, whereas the UK organization Join Dementia Research recommended highlighting particular features of some brain conditions that are often under-communicated, such as the relation between Parkinson's and sports injuries.

Several stakeholders volunteered to help disseminate the survey results once the results were published. For example, the Women's Brain Project suggested writing a post on their blog, and the Dutch brain research organization Hersenonderzoek planned to disseminate the findings during an online brain festival for their research participants.

Evaluation: A few days before the workshop, an online, open-ended evaluation questionnaire was shared with the workshop participants (see **Annex 8**). The questionnaire aimed to collect some feedback from survey co-organizers and support organizations regarding their collaboration with Lifebrain on the GBHS.

Six out of the seven respondents reported high levels of satisfaction with cooperating with Lifebrain. Most (5 of 7) respondents highlighted a high level of match between their organizational goals and the research project focus as a central motivation for their involvement. One co-organizer wrote: *"In the future we could do similar activities: raising awareness about the project to increase the number of participants and help with dissemination of the results".*

Most (6 of 7) reported they were going to use the results to improve and target stakeholder communication, for instance policy makers and in public campaigns. In terms of key factors for successful collaborations, several (3 of seven) highlighted good communication with frequent updates and regular seminars/webinars.

Others (2 of 7) stressed the benefits of easily accessible, shareable information and electronic platforms, whereas others again (3 of 7) highlighted budget and time as key constraints for participation. These insights represent valuable input for future research projects in terms of securing successful stakeholder collaboration.

3.3. Collaborating with stakeholders in the dissemination of Lifebrain research results

Between 2017 and spring 2021, WP1 organized five public lectures and one international conference in collaboration with WP5. Lifebrain aimed to invite relevant local stakeholder organizations to be co-organizers in the planning and arrangement of the public events. Stakeholder organizations were invited to include their organizational logos on event material. Four out of five Lifebrain public lectures were organized in collaboration with key stakeholders as well as the first international Lifebrain conference in Berlin.

When the events were organized jointly with stakeholders, they contributed to the development of the event programs, helped select relevant speakers, and informed members in their networks about the events via internal emails, newsletters, and online posts. A description of each event objectives, target group and key stakeholder inputs is provided below. The event programs are also available on the Lifebrain website.

3.3.1 Lifebrain public lectures

The Lifebrain public lectures were open events, accessible to anyone interested and free of charge.

Public lecture 1: "Your brain is your life!", Barcelona, Spain, November 2017.

The public lecture program is provided in **Annex 9** and the presentations are available at the Lifebrain website.

Objectives: This first lecture aimed to present the Lifebrain project to the public and discuss how environmental factors affect the brain throughout life. The program included a mix of presentations in English and Catalan.

Organizer: Lifebrain

Participants: 50 individuals and organizational representatives with an interest in brain health; predominantly researchers and patient organizations.

Public lecture 2: "Take care of the brain! A health brain throughout the life", Oslo, Norway, June 2018

The public lecture program is provided in **Annex 10** and video of the event is available at the Lifebrain youtube channel.

Objectives: This second lecture aimed to present recent brain health research and advice for brain health maintenance. The program included a mix of presentations in English and Norwegian.

Organizers: Lifebrain and the Norwegian Brain Council.

Participants: 200 individuals and organizational representatives with an interest in brain health; predominantly researchers and patient organizations.

Public lecture 3: "Healthy Ageing", Cambridge, United Kingdom, March 2019

The public lecture program is provided in **Annex 11**. The public lecture is available at the Lifebrain youtube channel.

Objectives: This third lecture aimed to discuss what healthy aging is and how a healthy brain can be maintained in older age. Recent Lifebrain findings on brain health were presented, including results from the WP1 interview study on perceptions of brain health. A paper-based draft version of the GBHS questionnaire was also shared with participants to collect their feedback and comments on the readability and relevance of the questionnaire.

Organizers: Lifebrain and the MRC Cognition and Brain Sciences Unit at the University of Cambridge.

Participants: 70 individuals and organizational representatives with an interest in brain health; predominantly researchers and patient organizations.

Key input from stakeholders: 33 questionnaires with comments from the audience were collected. Main comments included clarifying some questions and suggestions for using free text options. The draft questionnaire was also discussed at a separate meeting with volunteers participating in the advisory group of the Cambridge Centre for Ageing and Neuroscience (Cam-CAN) study. All comments were collected, discussed by the research team, and integrated into a revised version of the questionnaire [4].

Public lecture 4: "Good brain health is important", Oslo, Norway, June 2019

The public lecture program is provided in **Annex 12.** The public lectures are available at the Lifebrain youtube channel.

Objective: This fourth lecture aimed to discuss brain health in relation to everyday life. The program focused on the concept of brain health and on how diet, physical activity and stress influence the brain. The GBHS was also officially launched and a paper version of the questionnaire was shared with participants to collect first responses. The talks were in Norwegian.

Organizers: Lifebrain and the Norwegian Brain Council.

Participants: 200 individuals and organizational representatives with an interest in brain health; predominantly researchers and patient organizations.

Public lecture 5: "Lifebrain webinar on brain health", online, June 2020

The webinar program is provided in **Annex 13** and the presentations of the event are available at the Lifebrain youtube channel.

Objective: This fifth lecture was organized as an online webinar due to the covid-19 pandemic. The program focused on presenting the latest Lifebrain research results on the impact of loneliness, depression, and sleep on brain health. The use of blood biomarkers to provide information about brain health was also discussed. The speakers elaborated on how these findings may influence health policymaking and clinical practice, and how they may help citizens maintain a healthy brain. The talks were in English.

Organizers: Lifebrain and the Norwegian Brain Council.

Participants: 95 researchers, clinicians, health professionals, representatives from patient and interest organizations and members of the public.

Evaluation: An evaluation form was shared online with the participants and 36 responses were collected. All participants agreed that they would like to attend a Lifebrain public event in the future. 94% believed that they had learnt something new during the webinar and thought that the duration of the webinar was appropriate. 44% rated the webinar as very interesting and 39% as somewhat interesting.

3.3.2 Lifebrain public conference

In November 2019, WP1 and WP5 organized the first Lifebrain international conference: "Brain health across the lifespan"" in Berlin, Germany, in collaboration with other work packages. The conference program is provided in **Annex 14** and the video presentations are available at the Lifebrain youtube channel.

Objectives: The conference aimed to present the latest experimental approaches and evidence from two major European research consortia, Lifebrain and the Silver Santé Study (also known as the Medit-Ageing Project), with which Lifebrain collaborates closely. Focus was on exploring the impact of socioeconomic factors, physical activity, nutrition, and mental training on cognitive function, mental health, and well-being throughout life. The results were also explored considering prevention and intervention strategies for brain disorders.

Organizers: Lifebrain, the German Brain Council and the Silver Santé Study.

Participants: Approx. 140 participants attended the conference, including researchers and healthcare professionals with an interest in cognitive and mental health, representatives from patient groups and professional societies, patients, and anyone with an interest in brain health.

Evaluation: An evaluation form was shared with the participants. In total, 51 evaluation forms were returned.

All respondents rated their overall experience at the conference as either "good" or "excellent" (43 out of 49 rated it "excellent") and said that the conference had met their expectations. A similar result was achieved for the organisation of the day. The participants rated the scientific content slightly lower (35 rated it as excellent and 14 as good). 100% said the course met their expectations.
Common themes among positive comments included "interesting topics", "good range of topics" and "good speakers," whereas common themes among negative comments included "would have liked more audience interaction," and that the afternoon sessions were of limited relevance.

Most participants expressed that they had a good understanding of Lifebrain following the event; out of a maximum 249 points, Lifebrain scored 196. 47 out of 49 said they would be happy to attend a future event organised by Lifebrain. 32 out of 49 reported that they would like to receive regular updates from Lifebrain.

3.3.2 Dissemination of the WP1 study

Results from the WP1 interview study were published in August 2020. This led to the publication of articles describing results to the public (**Annex 15**).

The co-organizers of the Global Brain Health Survey (GBHS) largely contributed to disseminate the survey in their respective countries. They posted articles on their web sites and social media and regularly reminded their members of the survey using their internal communication channels.
The GBHS received significant public attention. The survey has been presented through several articles in the press and on public websites. Examples of publications are provided in **Annex 15** and also at the Lifebrain website.

4. Summary of inputs and impact of stakeholder engagement

Despite covid-19, WP1 managed to arrange all planned activities and workshops, in addition to a few additional ones. All in all, WP1 arranged four stakeholder workshops, two of which were digital; five public lectures, one was digital, and one international conference. WP1 also conducted the WP1 study to collect information about stakeholder perceptions of brain health. Most activities were organized in collaboration with WP5, the WP leads, Lifebrainers at different locations, and key stakeholder organizations. A summary of stakeholder engagement activities is provided in **Annex 16**.

Through these activities, WP1 collected various inputs from stakeholders related to the WP1 research design. Key inputs, which directly influenced the research were as follows:

- Focus on positive action to take care of the brain rather than individual brain-related disease risk
- Put greater focus on mental and emotional health
- Explain the concept of brain health in more detail to research participants
  Explore gender effects on interest in, and perception of, brain health

In addition, the stakeholders provided numerous inputs concerning organization of stakeholder events (e. g. suggestions to event program, choice of speakers, event format).

The stakeholders also provided recommendations for public brain health promotion and policy interventions such as:

- Provide policymakers and lay citizens with understandable and concise evidence based recommendations on brain health maintenance, that are reasonable in terms of cost, and that lead to tangible benefits. This is important as behavioral changes to strengthen brain health may require strong motivation.
- Acknowledge that people are relatively well-informed and have different priorities.
- Provide data to document the impact of aging and the accumulative interactive effects of environmental factors on brain health.
- Highlight features of under-communicated brain conditions such as the relation between Parkinson's and sports injuries.
- Support and facilitate family involvement in brain health rehabilitation.
- Allocate more resources to children with brain disease, including research to evaluate intervention programs. Follow up children with extra low birth weight in a multidisciplinary manner, i. e. not separating mental health and cognitive health.
- Improve brain health education in relevant public infrastructures such as welfare administration, primary school educators, municipalities, and medical professionals.
- Highlight features of some often under-communicated brain conditions such as the relation between Parkinson's and sports injuries

5. Conclusions and next steps

In total, through the organization of stakeholder engagement activities, Lifebrain reached more than 28,000 stakeholders including researchers and clinicians, brain councils, brain foundations, brain research projects, patient groups and members of the public. More than 800 people attended Lifebrain public events and stakeholder workshops.

Successful collaborations were established with seven key European stakeholder organizations in Europe: the Norwegian Brain Council, the German Brain Council, the Belgian Brain Council, the Brain Foundation Netherlands, the Swedish Brain Foundation, the Women's Brain Project, and the National University of Ostroh Academy in Ukraine. These collaborators provided useful input to the research process, evaluation of results and access to relevant policy networks, and helped to organized events. The co-organizers of the Global Brain Health Survey also took an active role in the dissemination of the survey itself, urging their networks and members to take and promote the survey.

Thus, the GBHS is at present, to our knowledge, the largest survey on public brain health perceptions. As of June 2020, we are aware of at least three research groups willing to launch the survey in their respective countries: The Public Health Institute of the United Arab Emirates, the CARE (Collaboration for Ageing Research Excellence) Centre at the University of Otago, New Zealand, and department of psychology of the Universidad Central "Marta Abreu" de Las Villas in Cuba. WP1 is currently providing support to these groups for survey launch.

Results from the GBHS are expected to provide new insights on public perceptions and attitudes towards brain health, risk factors, motivation for behavioural change and testing. The results from the survey results will be discussed with co-organizers and disseminated within their respective networks and country-specific media, and will provide valuable insights for policy makers, researchers and health care personnel involved in brain health. First survey results relating to concepts and mechanisms for brain health promotion will be described in the upcoming D1.5 Report/policy brief on concepts and mechanisms for uptake of research output.

Results from evaluations of the stakeholder events have been largely positive and stakeholders have expressed interest in participating in future activities.

Finally, recommendations for stakeholder engagement will be developed based on our experiences and described in D 1.6 Reviewing Stakeholders Engagement – Best Practice. Several stakeholder events are also planned for the remaining period of the project, including a workshop with survey co-organizers to discuss survey results, public lectures in Norway and the United Kingdom, and a Lifebrain closing conference in Oxford, in June 2022.

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[3] National brain councils. https://www.braincouncil.eu/about-us/national-brain-councils/

[4] Budin-Ljøsne I, Friedman BB, Suri S, Solé-Padullés C, Düzel S, Drevon CA, Baaré WFC, Mowinckel AM, Zsoldos E, Madsen KS, Carver RB, Ghisletta P, Arnesen MR, Bartrés Faz D, Brandmaier AM, Fjell AM, Kvalbein A, Henson RN, Kievit RA, Nawijn L, Pochet R, Schnitzler A, Walhovd KB, Zasiekina L. The Global Brain Health Survey: Development of a Multi-Language Survey of Public Views on Brain Health. Front Public Health. 2020 Aug 14;8:387. doi: 10.3389/fpubh.2020.00387. PMID: 32923418; PMCID: PMC7456866.

Annex 1-16

Annex 1: Key stakeholder organizations collaborating with Lifebrain

The Norwegian Brain Council (https://www.hjerneradet.no)

The NBC is a non-profit umbrella organization which aims to improve brain health in Norway, representing 61 members comprising user organizations and experts on brain health research, prevention, treatment, and coping mechanisms.

Engagement in Lifebrain: GBHS co-organizer, jointly organized several public lectures and workshops together with Lifebrain, wrote several articles about the Lifebrain GBHS, helped design the GBHS, helped disseminate the GBHS survey.

The German Brain Council (https://www.braincouncil.de)

The GBC is a non-profit umbrella organization that promotes science and research on the human nervous system. It represents patient organizations, scientific associations and other non-profit organizations involved in brain research, prevention, diagnostics, treatment, and rehabilitation in Germany. GBC gathers scientific associations, patient organizations and other non-profit organizations.

Engagement in Lifebrain: GBHS co-organizer, helped disseminate the GBHS survey and jointly organized the Berlin Lifebrain conference in 2019.

The Belgian Brain Council (https://braincouncil.be/)

The BBC is a coordinating association of Belgian agencies and individual partners for the brain and related disorders. The BBC seeks to inform and educate the general public about the brain and related disorders, to lobby for more basic and clinical neuroscience research, and to support member activities and foster networking between them, promoting patient empowerment in brain disorder management and related public policies.

Engagement in Lifebrain: GBHS co-organizer, helped disseminate the GBHS survey.

The Brain Foundation Netherlands (https://www.hersenstichting.nl/)

Hersenstichting is a non-governmental organization working to reduce mortality and disease burden of brain disorders, and to increase the recognition of people with brain disorders. It conducts research, provides public information, seeks to improve patient treatment, rehabilitation, and participation.

Engagement in Lifebrain: GBHS co-organizer, helped disseminate the GBHS survey.

The Swedish Brain Foundation (https://www.hjarnfonden.se/)

Hjärnfonden is a non-profit foundation that collects and distributes funding for brain research and informs the public about the brain and related disorders.

Engagement in Lifebrain: GBHS co-organizer, helped disseminate the GBHS survey.

The Women's Brain Project (www.womensbrainproject.com/)

The WBP is an international non-profit organization based in Switzerland. WBP aims to stimulate a global discussion on sex and gender differences in brain and mental diseases as a gateway to precision medicine.

Engagement in Lifebrain: GBHS co-organizer, helped disseminate the GBHS survey.

The National University of Ostroh Academy, Ukraine (https://www.oa.edu.ua)

Professor in psychology and pedagogy Larysa Zasiekina has been our main contact person.

Engagement in Lifebrain: GBHS co-organizer, helped disseminate the GBHS survey.

The Medical Research Council MRC Cognition and Brain Sciences Unit of the University of Cambridge (www.mrc-cbu.cam.ac.uk)

The unit seeks to "improve human health by understanding and enhancing cognition and behaviour in health, disease, and disorder". The unit researches human cognitive processes and develops new preventative, therapeutic, and educational interventions for clinical disorders of cognition and mental health. The unit hosts regular lectures, seminar series and research meetings.

Engagement in Lifebrain: Helped organize a Lifebrain public lecture, helped disseminate the GBHS survey.

The Silver Santé Study (Medit-Ageing Project www.silversantestudy.eu)

The study is a five-year EC- funded project led by INSERM, France, investigating the determinants of mental health and well-being in the ageing population of Europe. The project conducts clinical trials, focusing on mental health and well-being, including Alzheimer's disease. The project has 11 partners in 6 countries.

Engagement in Lifebrain: Jointly organized the Berlin Lifebrain public lecture

Join Dementia Research (https://www.joindementiaresearch.nihr.ac.uk/)

JDR is a service which allows people to register their interest in participating in dementia research and be matched to suitable studies.

Engagement in Lifebrain: Helped disseminate the GBHS survey.

Hersenonderzoek (https://hersenonderzoek.nl/)
Hersenonderzoek.nl is an online platform where healthy people and patients can register to indicate that they are interested in participating in brain research.

Engagement in Lifebrain: Helped disseminate the GBHS survey.

The Public Health Institute of the United Arab Emirates University (https://www.uaeu.ac.ae/ar/)
Engagement in Lifebrain: In March 2021, a research group launched a new arm of the GHBS in Arabic that will be disseminated in the Arabic countries. The group had regular contact and interaction with WP1 for the development of the Arabic version of the GBHS questionnaire.

CARE (Collaboration for Ageing Research Excellence), University of Otago, New Zealand (https://www.otago.ac.nz/care/index.html)

Engagement in Lifebrain: The centre is collaborating with WP1 on the launching of a new arm of GBHS in New Zealand in 2021-2022.

Department of Psychology, Universidad Central "Marta Abreu" de Las Villas, Cuba
(https://www.uclv.edu.cu/)

Engagement in Lifebrain: The department is collaborating with WP1 on the launching of a new arm of GBHS in Cuba in 2021-2022.

Annex 2 – Scientific paper reporting results from the WP1 interview study - Abstract

Friedman BB, Suri S, Solé-Padullés C, Düzel S, Drevon CA, Baaré WFC, Bartrés-Faz D, Fjell AM, Johansen-Berg H, Madsen KS, Nyberg L, Penninx BWJH, Sexton C, Walhovd KB, Zsoldos E, Budin-Ljøsne I. **Are People Ready for Personalized Brain Health? Perspectives of Research Participants in the Lifebrain Consortium**. *Gerontologist*. 2020 Aug 14;60(6):1050-1059. doi: 10.1093/geront/gnz155. PMID: 31682729; PMCID: PMC7427479.

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 analysed 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.

URL: https://academic.oup.com/gerontologist/article/60/6/1050/5612286

Annex 3 – Survey protocol paper describing the Global Brain Health Survey - Abstract

Budin-Ljøsne I, Friedman BB, Suri S, Solé-Padullés C, Düzel S, Drevon CA, Baaré WFC, Mowinckel AM, Zsoldos E, Madsen KS, Carver RB, Ghisletta P, Arnesen MR, Bartrés Faz D, Brandmaier AM, Fjell AM, Kvalbein A, Henson RN, Kievit RA, Nawijn L, Pochet R, Schnitzler A, Walhovd KB, Zasiekina L. **The Global Brain Health Survey: Development of a Multi-Language Survey of Public Views on Brain Health**. *Front Public Health*. 2020 Aug 14;8:387. doi: 10.3389/fpubh.2020.00387. PMID: 32923418; PMCID: PMC7456866

Abstract

Background: Brain health is a multi-faceted concept used to describe brain physiology, cognitive function, mental health, and well-being. Diseases of the brain account for one third of the global burden of disease and are becoming more prevalent as populations age. Diet, social interaction as well as physical and cognitive activity are lifestyle factors that can potentially influence facets of brain health. Yet, there is limited knowledge about the population's awareness of brain health and willingness to change lifestyle to maintain a healthy brain. This paper introduces the Global Brain Health Survey protocol, designed to assess people's perceptions of brain health and factors influencing brain health.

Methods: The Global Brain Health Survey is an anonymous online questionnaire available in 14 languages to anyone above the age of 18 years. Questions focus on (1) willingness and motivation to maintain or improve brain health, (2) interest in learning more about individual brain health using standardized tests, and (3) interest in receiving individualized support to take care of own brain health. The survey questions were developed based on results from a qualitative interview study investigating brain health perceptions among participants in brain research studies. The survey includes 28 questions and takes 15-20 min to complete. Participants provide electronically informed consent prior to participation. The current survey wave was launched on June 4, 2019 and will close on August 31, 2020. We will provide descriptive statistics of samples distributions including analyses of differences as a function of age, gender, education, country of residence, and we will examine associations between items. The European Union funded Lifebrain project leads the survey in collaboration with national brain councils in Norway, Germany, and Belgium, Brain Foundations in the Netherlands and Sweden, the National University of Ostroh Academy and the Women's Brain Project.

Discussion: Results from this survey will provide new insights in peoples' views on brain health, in particular, the extent to which the adoption of positive behaviors can be encouraged. The results will contribute to the development of policy recommendations for supporting population brain health, including measures tailored to individual needs, knowledge, motivations and life situations.

URL: https://www.frontiersin.org/articles/10.3389/fpubh.2020.00387/full

Annex 4 - Stakeholder workshop 1: "LIFEBRAIN Stakeholder workshop", Spain, November 2017

"Lifebrain: Healthy minds from 0-100 years: Optimising the use of European brain imaging cohorts"

LIFEBRAIN Stakeholder workshop

Hotel H10 Itaca, Av. Roma, 22, E-08015, Barcelona
17 November 2017, 13.00 – 16.30

Brain diseases affect millions of people worldwide. Lifebrain aims to understand how lifestyle, environment, and genes influence our brain. A better understanding of how the brain works may help us prevent brain diseases more efficiently.
We invite you to join this first Lifebrain stakeholder workshop because your views, opinions, and experiences can help us conduct better and more useful research. We would also like to discuss how you want to interact with the scientists in Lifebrain. The workshop participants will be Catalan and national representatives of key patient and interest organizations, brain health researchers and clinicians, research participants, policymakers with an interest in brain health, and Lifebrain researchers.

Moderators: David Bartrés-Faz and Cristina Solé Padullés (University of Barcelona), Barbara Friedman (University of Oslo), Isabelle Budin-Ljøsne (Norwegian Institute of Public Health)

13.00	**Lunch**
14.00 – 14.15	**What is the Lifebrain project?** Kristine B. Walhovd (University of Oslo) / David Bartrés-Faz
14.15 – 14.30	**Why a stakeholder workshop?** Workshop objectives and intended outcomes (Isabelle Budin-Ljøsne) Introduction of workshop participants
14.30 – 14.45	**What can we do together?** Isabelle Budin-Ljøsne
14.45 – 16.00	**Round table discussion**
16.00 – 16.20	**Next steps**
16.20 – 16.30	**Workshop evaluation and wrap-up**

We will send a summary to all participants after the workshop. For questions, please contact Isabelle Budin-Ljøsne, email: Isabelle.budin.ljosne@fhi.no or David Bartrés-Faz, email: dbartres@ub.edu

"Lifebrain: Healthy minds from 0-100 years: Optimising the use of European brain imaging cohorts"

LIFEBRAIN Stakeholder workshop

Barcelona, 17 November 2017 - Summary report

The first Lifebrain stakeholder workshop gathered 13 Lifebrain researchers and 11 Catalan and national stakeholders (representatives of patient and interest organizations, brain health researchers, clinicians, brain research participants, and policymakers). The main objectives of this first workshop were to:

- Introduce the Lifebrain project to the stakeholders
- Discuss questions to be explored in the study conducted by WP1 – Stakeholder engagement
- Explore how Lifebrain may interact with the stakeholders

Feedback from stakeholders

The Lifebrain project

The stakeholders expressed great interest in Lifebrain and wanted to be involved. The specific objectives of the project were, at times, unclear to them (i.e. identifying risk and protective factors at population level vs. developing biomarker analysis tools for diagnostic purposes).

The Lifebrain WP1 study

Lifebrain is planning to investigate people's views on brain health and personalized brain health prevention. The study will be conducted in two steps: 1) individual interviews with brain research participants in Barcelona, Oslo, Oxford, and Berlin; and 2) an online survey to be made broadly available. The stakeholders discussed the research questions to investigate in the study. Their main feedback was that:

- "Personalized risk to develop a brain disease" is a difficult concept. It is problematic to focus on brain health at an individual level. Currently, it is hardly possible to assess an individual's risk for developing brain disease, and it is unsure whether Lifebrain will be able to develop a tool for assessing such risk within 5 years. It is also difficult to evaluate "risk" in a clinical context. The concept of "risk" is abstract and may be frightening for the average person, although studies show that people are interested in knowing about their individual risk of developing a brain disease such as, for instance, Alzheimer's disease, for family planning purposes.

- Rather than risk, it would be useful to focus the questions on what motivates people to take care of their brain health. Motivations for this may vary depending on individual level of education, and experience with brain disease among relatives. Questions concerning lifestyle changes should be based on real evidence (previous papers), and may be useful to guide the

participants when expressing their own opinion about their willingness to change their lifestyle. It may also be useful to use experiences from other domains such as cardio-vascular diseases to develop the questions.

The Dried Blood Spot (DBS) test kit

Lifebrain conducts research to develop a DBS test kit that may provide an indication of how the current health status of an individual influences his/her brain health. The kit is used to collect a blood from nnan individual, and analyze several biomarkers potentially influencing brain health. Many of these biomarkers are also known to provide an indication of cardiovascular health. The stakeholders had many questions regarding the usefulness of the test as a diagnostic tool, and the reliability of the selected biomarkers. They recommended using the kit as a tool for investigation at a population level, rather than for individual diagnostics. They were positive to including a company such as Vitas, the company developing the DBS kit, early in Lifebrain, as it often takes years to place a product on the market based on results from research.

Mental health

Mental health (including emotional health) is often given less priority than, for instance, neurodegenerative diseases, when discussing brain health. The social problems causing mental disorders are often given limited attention. The Lifebrain project should consider early on how to take into account and prevent mental disorders. It is important to understand how to develop practical policies to prevent mental diseases.

Translation of Lifebrain research results into public policy

It is important that Lifebrain maintains regular contact (at least once yearly) with researchers, clinicians, and policy makers to make sure that the results from Lifebrain are translated into information that has a real impact. Researchers should take decisions regarding what to translate into clinical practice. Policies for brain health should take into consideration health care costs.

Role of stakeholders

Several stakeholders said that they are willing to help refine the WP1 study research questions, translate the questions into Catalan, and distribute the online survey among their contacts, including European patient organizations. They were positive to receiving regular updates about Lifebrain. Most of them also expressed interest in helping Lifebrain to translate research results into information of practical utility, and helping disseminate information about Lifebrain. They are also willing to help evaluate the stakeholder engagement in Lifebrain.

Next steps

WP1 of Lifebrain will refine the WP1 study questions based on comments from the stakeholders, and send the questions to those who expressed interest in reviewing them. WP1 will also re-contact the stakeholders to follow up on the development of the Lifebrain online survey in 2018.

Information about Lifebrain will be disseminated yearly, and we will look for ways to include our stakeholders in later phases of the project, for instance, by invitation to attend Lifebrain conferences.

David Bartrès-Faz (dbartres@ub.edu) is the stakeholders' local Lifebrain contact.

THANK YOU FOR YOUR GREAT CONTRIBUTIONS!

Annex 5 - Stakeholder workshop 2: "Brain health promotion across the lifespan", Norway, June 2018

Brain health promotion across the lifespan:
A Lifebrain & Norwegian Brain Council workshop

Hotel Soria Moria, Oslo, 7 June 2018, 09:00 – 13.00

PROGRAM

09.00 – 09.10	**Welcome and workshop objectives** Isabelle Budin-Ljøsne (Lifebrain) and Aud Kvalbein (Norwegian Brain Council)
09.10 – 09.40	**Brain health – A lifespan approach** Professor Kristine B. Walhovd, Lifebrain coordinator, University of Oslo
09.40 – 10.00	**How to promote long-lasting brain health starting early in life?** Professor Jon Skranes, NTNU and Sørlandets sykehus
10.00 – 10.20	**How to adopt a life span perspective in the prevention of cognitive decline and dementia?** Dr. Hege Ihle-Hansen, Oslo University Hospital
10.20 – 10.40	Coffee break
10.40 – 11.00	**What can we do to keep our brain healthy?** Professor Christian A. Drevon, Vitas AS
11.00 – 11.30	**Brain health promotion – opportunities and priorities** Dr. Anne Hege Aamodt, Oslo University Hospital and the Norwegian Brain Council
11.30 – 12.20	**Panel discussion: Brain health promotion across the lifespan** Professor Kristine B. Walhovd, University of Oslo Dr. Hege Ihle-Hansen, Oslo University Hospital Professor Jon Skranes, NTNU Professor Christian A. Drevon, Vitas AS Dr. Anne Hege Aamodt, the Norwegian Brain Council General Secretary Ingeborg Dahl-Hilstad, Personskadeforbundet LTN
12.20 – 12.35	**The Lifebrain study: Are people ready to endorse personalized brain health?** Isabelle Budin-Ljøsne & Barbara B Friedman, Lifebrain
12.35 – 12.50	**Dried Blood Spots (DBS) tests for health assessment – A demonstration** Thomas Gundersen, Vitas AS
12.50 – 13.00	**Summary and workshop evaluation**
13.00	Lunch

Brain health promotion across the lifespan: A Lifebrain & Norwegian Brain Council workshop

SUMMARY REPORT

The workshop aimed to investigate opportunities and challenges with respect to promoting brain health across the lifespan. The workshop specifically targeted patient organizations
The second Lifebrain stakeholder workshop gathered 17 Lifebrain researchers and 27 Norwegian stakeholders with an interest in cognitive and mental health, clinicians and researchers working in the field of brain health, representatives from medical associations, and policymakers, see attached list.

The workshop was jointly organized by Lifebrain and the Norwegian Brain Council (Hjernerådet):

The presentations were followed by a panel discussion with the following highlights:

What could be the most important step towards brain health?

- Investing in families from very early ages and making better conditions for the families.
- Getting more scientific and professional knowledge at all levels of the knowledge chain related to brain health. Some of the topic highlighted during the panel discussion:
    - Headache as one of the most common brain diseases
    - Role of healthy diet
    - Role of early life development: interaction of the various factors
    - Brain injuries: injury can cause problems sometimes much later than an accident occurs. Due to the lack of information patients don't get the help they need: for e.g. special needs at school, job are not taken into account
    - Integration of children with brain diseases to schools
    - Integration of adults back to the job market
    - Education on brain health: in primary schools, medical professionals, municipalities, families, NAV
- Providing enough resources to those with brain injuries so that they can live a healthy life as to the extent possible
- Providing more resources to children with chronic brain disorders: for e.g. to rehabilitation services, and to integrated services after they grow up

How to get research information to the public? Where are the bottlenecks? What should be done to get this information out there?

- We need to acknowledge that people are relatively well-informed and have different priorities *("there are people would simply would not like to live to their 100 years without bacon").* What researchers can do more of is to give detailed information on evidences: *"this is the list of things you can do for your brain".* It is perhaps enough if people start with the easiest things on the list for e.g having a healthier diet.

- When it comes to children with brain diseases perhaps it worthwhile to follow the Danish model with a low threshold service: primary and specialist healthcare should be both available, and parents at risk can make contact and ask for followup when in need for e.g. those effected by drug use, alcohol problems. The primary health care system should help to identify those families in risk.

- Children with extra low birth weight need extended follow-up programs, in a multidisciplinary manner, not separating mental health and cognitive health.

- Evaluation of early and later intervention programmes for children with brain diseases is also crucial, as there has not been enough research done in those fields.

- Although there is a huge amount of information available on brain health, there is still a lot of confusion both in the media and at the professionals, too, *"people rely on the wrong information sources".* What we can do is to help people to learn to understand and select these sources.

How can we create awareness on the brain efficiently? People don't think in a long-term perspective. How do we create awareness on reacting early?

- First of all, dementia should not be treated as a distinct diagnostic category. Most things are not so distinct is life. There is a health span of the brain and there are many-many grey zones: there might be brain decline in periods, when a person is more vulnerable.

- Early life impacts of aging are still not well documented. Lifebrain can fill in this gap: it is a longitudinal study with healthy participants and reflects the dimensional thought that research is to all of us, and all along the lifespan. The various environmental factors have accumulative interactive effects on brain health, and we need to understand them better.

- It is possible to influence society by good quality studies and informing about them.

Responsibility of the individuals vs. state vs. companies

About the responsibility of the individuals there were competing views. The panel members agreed on that people are different, with different priorities in life. This also means that health is not the most important priority to all, as referring to the role of diet *"At lunch everybody makes their choices".* What

is crucial here that people can get access to knowledge to make wise decisions. Companies should also take some responsibility: we could challenge the large companies to include brain health related activities in their daily operation or provide brain health related products. *"If things are happening during your daytime in work it might be effective".*

Importance of acting early: are we starting too late?

- *"Better to start earlier, but never too late".*
- Children's perspective is missing from the brain health strategy of Norway. They are only mentioned as they are family relatives impacted upon.

Some initiatives in the field if brain health

- National brain awareness week; 2018 November by Hjernerådet, week 47
- National programs on math and science: interested in including brain knowledge in their programme
- European Academy of Neurology conference, Oslo, June 2019
- European Brain Council and its white paper
- Stroke plan Canada
- European Stroke Action Plan 2018-2030
- Clinical research centre soon to be appointed by the Norwegian Brain Health Strategy

The Dried Blood Spot (DBS) test kit

Lifebrain conducts research to develop a DBS test kit that may provide an indication of how the current health status of an individual influences his/her brain health. The kit is used to collect a blood from an individual, and analyze several biomarkers potentially influencing brain health. Many of these biomarkers are also known to provide an indication of cardiovascular health. The participants could test the kit and get their analysis done in a weeks time.
The information on the omega 3 analysis is available here:
www.beregndinbioindex.no

Next steps
Lifebrain will contact the stakeholders to follow up on the development of the Lifebrain online survey in the autumn/winter of 2018.
Information about Lifebrain will be disseminated yearly, and we will look for ways to include our stakeholders in later phases of the project, for instance, by invitation to attend Lifebrain conferences.
Isabelle Budin Ljøsne (Isabelle.Budin.Ljosne@fhi.no) is the Lifebrain contact for stakeholder involvement.

THANK YOU FOR YOUR GREAT CONTRIBUTIONS!

Annex 6 - Stakeholder workshop 3: "Lifebrain Webinar– The Global Brain Health Survey", Sept 2020

Lifebrain webinar – The Global Brain Health Survey

MINUTES

22nd September, 2020

Participants

- Maria Teresa Ferretti, Women`s Brain Health project, Austria/Switzerland
- Maria Prigorowsky, Swedish Brain Foundation, Sweden
- Ragnhild Ahlgren, Swedish Brain Foundation, Sweden
- Iffat ElBarazi, United Arab Emirates University, United Arab Emirates
- Javaid Nauman, United Arab Emirates University, United Arab Emirates
- Maja Bresjanac Institute of Institute of Pathological Physiology, University of Medicine, Slovenia
- Alan Gow, Heriot-Watt University, UK
- Isabelle Budin Ljøsne, Norwegian Institute of Public Health, Norway (Lifebrain)
- Athanasia Monika Mowinckel, Center for Lifespan Changes in Brain and Cognition, University of Oslo, Norway
- Barbara B. Friedman, Center for Lifespan Changes in Brain and Cognition University of Oslo, Norway (Lifebrain)

Apologies

- Roland Pochet, Belgian Brain Council, Belgium
- Aud Kvalbein, Norwegian Brain Council, Norway
- Alfons Schnitzler, German Brain Council, Germany
- Solange Cleutjens, Hersenonderzoek.nl, the Netherlands (missed connection)
- James Grassom, Join Dementia Research, UK
- Koko Beers, Hersenstichting, the Netherlands
- Shahnaz Radjy, Women's Brain Project, Austria/Switzerland

Copy to: Yoram Barak, Dunedin School of medicine, New Zealand

Introduction of the participants

- Maria Prigorowsky and Ragnhild Ahlgren: Brain health is a new topic in Sweden, the survey helps to find the right words to talk about it. The foundation contributed to sharing GHBS in Sweden.
- Maria Teresa Ferretti: The Women`s Brain Project is interested in finding out more about the differences of attitudes of women and men to brain health and is focused on gender medicine.
- Maja Bresjanac: A similar survey has been done in Slovenia on the populations' perceptions of brain health. The data are currently being analyzed. The GHBS was distributed in Slovenia, in the last weeks of the data collection process.
- Iffat ElBarazi: The UAE team will conduct the GBHS among the Arabic population.
- Alan Gow: The "What keeps you sharp" study from the UK has very similar questions to that of the GBHS, Lifebrain was unfortunately not aware of this. Interested in discussing opportunities to compare some of their findings with that of GBHS.

Interest in the analysis of the survey

In general, all participants expressed their interest in the planned analysis and are looking forward to the outcomes of the analysis.

Some interesting points from the results of the UK survey by Alan Gow:

- Many are open to change behavior, but do not do anything until something serious happens to them. Brain disease of relatives might not provide enough motivation for change
- Those who think that genetics impact brain health more than lifestyle factors are less likely to do activities for maintaining their brain health

GBHS has unfortunately no data in relation to before Covid-19 and after Covid-19 perceptions to brain health (Maria Teresa Ferretti). The data Lifebrain collected is completely unanimous and cannot be traced back when the survey has been filled out.

Maja Bresjanac plans to compare results of the GHBS with the Slovenian national results. An important message from the Slovenian survey: 38% answered that they are confused about the trustworthiness of information provided on brain health in the various media channels, publications. Gathering reliable information on the maintenance of brain health is a major obstacle for changing health behavior and practices.

GHBS is to be replicated in the United Arab Emirates. The main difference would be that views of immigrants and cultural differences will be explored deeper there. Results will be used to educate the health sector about brain health (Iffaz ElBarazi). Covid-19 questions will also be included.

Participants shared the experience that women are the health ambassadors for their families and for society; they count as change agents when it comes to changing health behavior and practices. The GBHS can provide additional information in relation to this (confirm, provide nuances).

It will be important to find out more about the profiles of respondents and whether gender, participation in brain research, or being a caretaker plays a role in endorsing brain health measures in daily life.

There are no plans yet for the follow-up of GBHS (Maria Prigorowski), but perhaps the EBC could take over this task.

GBHS and policymaking

All expressed their concerns about translating the research results to policy recommendations. This is also an important objective of Lifebrain. It is crucial that the data analysis team and the survey co-organizer provide short, compact messages to policymakers. The timing is good, WHO is dedicating the next decade to healthy ageing.

Maja Bresjanac is interested in shaping proposals for policymakers. Currently, Slovenian public health policies only include traumatic brain injury and stroke among brain conditions which may be somewhat preventable by behavioral changes. Maja is about to launch a website devoted to public engagement in brain health in 2 weeks.

Maria Teresa has good contacts with the European Brain Council.

References from the webinar

- AGE UK: https://www.ageuk.org.uk/information-advice/health-wellbeing/mind-body/staying-sharp/how-well-do-you-know-your-brain/

- What keeps You Sharp?" survey conducted in late 2016/early 2017, which included over 3,000 adults aged 40-98 years old from across the UK. They published 2 papers and a lay summary: http://www1.hw.ac.uk/mediaservices/pageflip/What_keeps_you_sharp/.

- The 2 papers:

    - Niechcial, M. A., Vaportzis, E. & Gow, A. J. (2019). People's views on preserving thinking skills in old age. Educational Gerontology, 45, 341-352. doi: 10.1080/03601277.2019.1627054 OPEN ACCESS
    - Vaportzis, E. & Gow, A. J. (2018). People's beliefs and expectations about how cognitive skills change with age: Evidence from a UK-wide aging survey. American Journal of Geriatric Psychiatry, 26, 797-805. doi: 10.1016/j.jagp.2018.03.016 OPEN ACCESS

- Women`s Brain Health Project: http://www.womensbrainhealth.org

Annex 7 - Stakeholder workshop 4: "Global Brain Health Survey" online workshop, April 2021

Global Brain Health Survey webinar

First results of the survey – Minutes, 22 April 2021

Participants

- Solange Cleutjens, Dutch Brain Research Registry
- Florencia Iulita, Womans Brain Project
- James Grassom, Join Dementia Research UK
- Nicola McMillan, Join Dementia Research UK
- Claire Yates, Joint Dementia Research UK
- Roland Pochet, Belgian Brain Council
- Larysa Zasiekina, Ostroh Academy
- Ragnhild Ahlgren, The Swedish Brain Foundation
- Aud Kvalbein, Norwegian Brain Council
- Isabelle Budin Ljøsne, Norwegian Institute of Public Health
- Nanna Fredheim, Norwegian Institute of Public Health
- Rebecca Bruu Carver, Norwegian Institute of Public Health
- Eniko Zsoldos, University of Oxford
- Athanasia Monika Mowinckel, University of Oslo
- Barbara B. Friedman, University of Oslo
- Christian A. Drevon, Vitas Ltd & University of Oslo

Reminder to all: Please fill in the questionnaire of GBHS co-organisers here. We thank all who have already filled it in.

Isabelle presented the main results of the answers to Q2, Q3, Q4 in the questionnaire relating to perceptions of brain health. The Power Point presentation is not available yet, as results have not been published yet.

Comments on the results

- Women's Brain Project

These are impressive survey results. That hypertension and diabetes scored low at Q2 is striking. It should be stressed that these are important risk factors for brain diseases. Woman volunteer more, they want to know more about health in general, we are not surprised at all. WBP is interested in digging more into the gender differences of the survey responses. Maria Theresa and Florencia would be happy to contribute to the paper writing process. Also, they have a blog targeted to the public on brain health, which can be used later for dissemination.

- Belgian Brain Council

The big number of respondents is impressive. How come small countries scored so high? Were there any special incentives? There are so many questionnaires around to fill in. Dutch Brain Health Registry: there is a large number of volunteers in the Netherlands, half of the answers came from there in the Netherlands.
DG Research in Brussels is increasing its budget: now all talk about Covid, but they should be reminded that brain disease is a silent epidemic. We should ally with other organisations to promote results to public health authorities, Roland will think of some potential organisations. In the current EU calls mental health got an increased budget. Our wording should be adapted to that then. Use "Brain and mental health." "Brain disorder" instead of disease.

Isabelle`s comment: Impact of the survey is crucial: biggest brain health survey ever conducted, although not representative. The respondents are mostly women, white and highly educated, but still gives important insights.

- JDR

Surprisingly underrated diet and lifestyle factors. Mediterranean diet is often discussed in relation to dementia. Genetics scored high, which indicates that people think that there is not so much we can do about it. It's a surprise for us. More women than men sign up to research in the UK as well, we can confirm that. One brain-related disease is often underplayed, Parkinson's disease, it could be highlighted to attract the attention of males, as it is connected with sports and hence, more often with men.

Isabelle, Christian`s comment on diet: One of the key messages we would like to get through is related to diet. There is a lot of indirect evidence about its impact on the brain, especially through the cardiovascular research area. Diabetes stands also strong in research. The Mediterranean diet is highly overrated compared to other healthy diets. The olive oil industry is probably battling with other fat producers, but fatty acids are essential for the brain. One of the major tasks in terms of public health is to disseminate about diet, in addition to prenatal health. The public has not grasped the importance of it yet for e.g. the role of folic acid.

- Dutch Brain Research Registry

There are more women in the registry, but chances of research participants being male is actually higher. They plan to organize a Brain Festival later this year, and are thinking of using the same survey questions as an opening part of the festival. It will be an online festival for their research participants. What can you do yourself for your brain health? Actual scientists can respond to the answers whether they are in line with scientific evidence. That's how they can contribute to actual sharing of results in the Netherlands.

- The Swedish Brain Foundation

There are lot of women in their registries, so they are not surprised by the results. Mental health diseases ranked high, which is also interesting. In Sweden, the importance of diet has not been communicated in a clear way. There is a lot of uncertainty about it. Not surprised that it ranked lower than other factors. PA is more highlighted. Diet is more of an unclear area: diet is being discussed a lot, and how that influences health. Mediterrainian diet is most often discussed. Prenatal findings

are striking, it's good that Scandinavia scores high here, perhaps we talk more about lifestyle during pregnancy and the child's brain development, which is extremely important for brain development in general. Looking forward to using the results in public health communication and give people advice about lifestyle changes.

- Ostroh Academy

Very interesting results. Ukraina had few answers, it is in the "other countries" category, so cannot comment on the country-specific results. It's surprising that demographics factors are underestimated: education, income, they have also an effect on mental health. Prenatal health is crucial.
Would like to join publications and analyze data together. Not surprised at the responses of women: they are usually more reflective and active in health-related topics.

- Norwegian Brain Council

Suggest to establish brain health by applying the concept "brain" together with e. g. "mental disorder" and "neurological condition" in publications.

Isabelle summarized the key messages of the first paper:

- Policymakers should emphasize the importance of diet and prenatal health for brain development

- Hypertension, diabetes scoring low: vascular diseases should be more recognized as important for brain health. Here we need to be more cautious with the interpretation, as the question could have been misunderstood and interpreted as "Are these diseases brain diseases?" and "not associated".

<u>Next steps</u>

Once the results are published, we hope to collaborate with all to write popular science articles. All ideas are welcome, especially on how to reach out to policy makers. We need to publish first the results before we can disseminate at all. Once we have a green light, it would be great to have another chat with all and discuss how to promote the results. We would be happy to share country reports, or any data the co-organisers are interested in. Another webinar is planned after the summer, where we could develop a dissemination strategy together and discuss the next steps. In the meantime, we work on the analysis of the paper on willingness to take tests and motivations to lifestyle changes as well.

Annex 8 – Questionnaire to survey co-organizers, April 2021

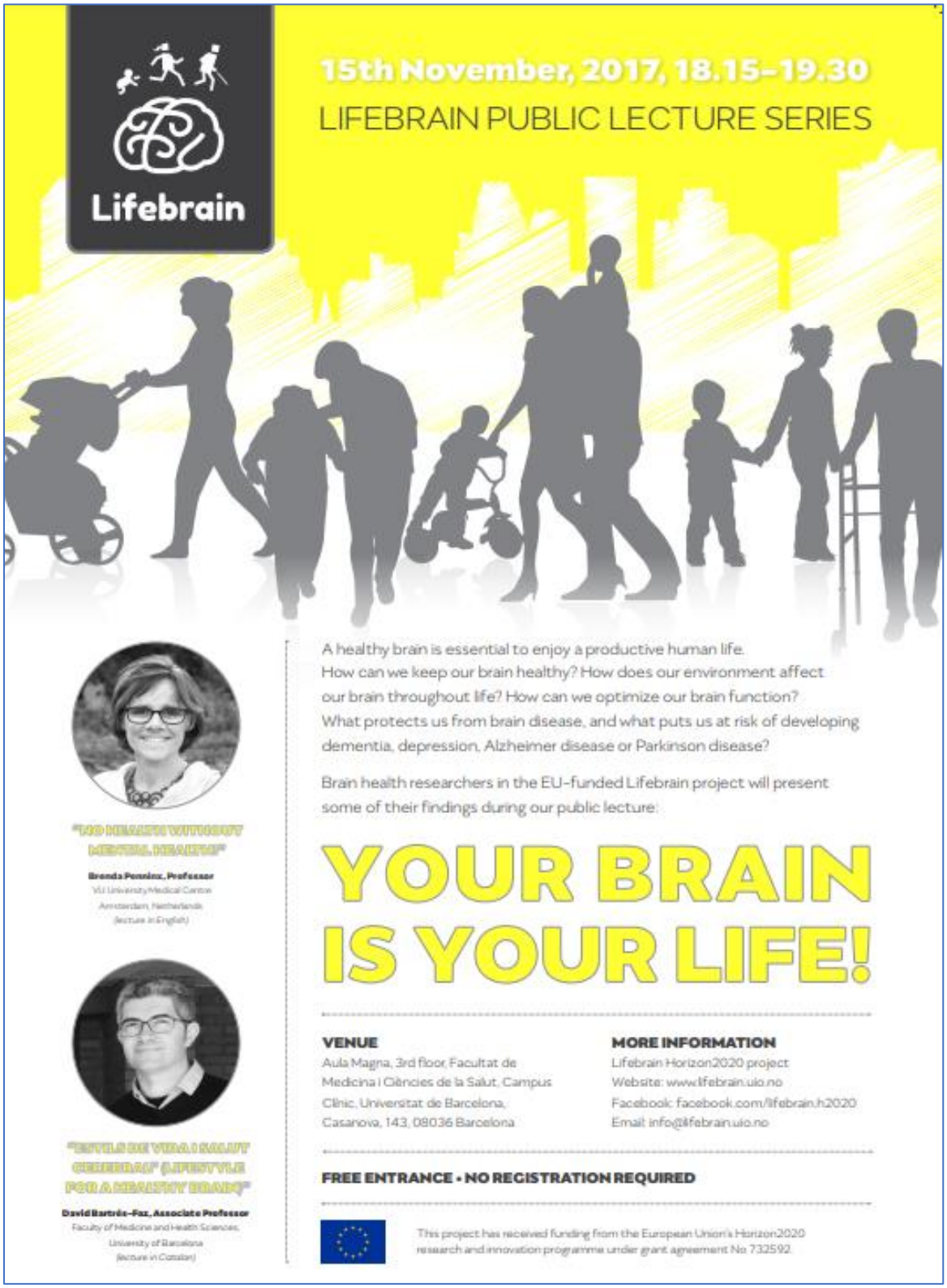
The questionnaire was set up using the services of University of Oslo for online anonymous surveys called Nettskjema: https://www.uio.no/english/services/it/adm-services/nettskjema/

Dear survey co-organizer,

This questionnaire is for you to give us some feedback regarding your collaboration with Lifebrain. The six questions below are open and you are free to provide as much feedback as suits you. The answers will be handled anonymously and will help us evaluate our work. Thank you for your time!

1. Why did your organization agree to be an official co-organizer of the Global Brain Health Survey?
2. How will the results of the survey be useful for your organization?
3. What is your experience with participating as a survey co-organizer in Lifebrain?
4. What activities would you like to conduct with Lifebrain in the remaining timeframe of the project (the project will end in June 2022)?
5. Do you have suggestions for ways to improve collaboration between your organization and research projects like Lifebrain?
6. What types of activities would you like to conduct in the future with research projects like Lifebrain?
7. In your opinion, which factors could hinder your participation in similar projects in the future?
8. In your opinion, which factors could facilitate your participation in similar projects in the future?
9. Any further comments/ suggestions/ experiences you would like to share with us?

Annex 9 - Public lecture 1: "Your brain is your life!", Barcelona, Spain, November 2017



Annex 10 - Public lecture 2: "Take care of the brain! A health brain throughout the life", Oslo, Norway, June 2018

Annex 11 - Public lecture 3: "Healthy Ageing", Cambridge, United Kingdom, March 2019

Annex 12 - Public lecture 4: "Good brain health is important", Oslo, Norway, June 2019

Annex 13 - Public lecture 5: "Lifebrain Webinar on Brain Health", online, June 2020

The Lifebrain researchers will present their latest findings regarding the impact of loneliness, depression and sleep on brain health, and they will discuss the use of blood biomarkers to provide information about brain health. They will elaborate on how their findings may influence policymaking and clinical practice and may help every one of us maintain a healthy brain.

Speakers:
Professor David Bartrés-Faz, Barcelona Brain Stimulation Lab, University of Barcelona
PhD candidate Julia Binnewies, Department of Psychiatry, Amsterdam UMC
Professor Anders M. Fjell, Centre for Lifespan Changes in Brain and Cognition, University of Oslo
Professor Christian A. Drevon, Department of Nutrition, University of Oslo and Vitas Ltd

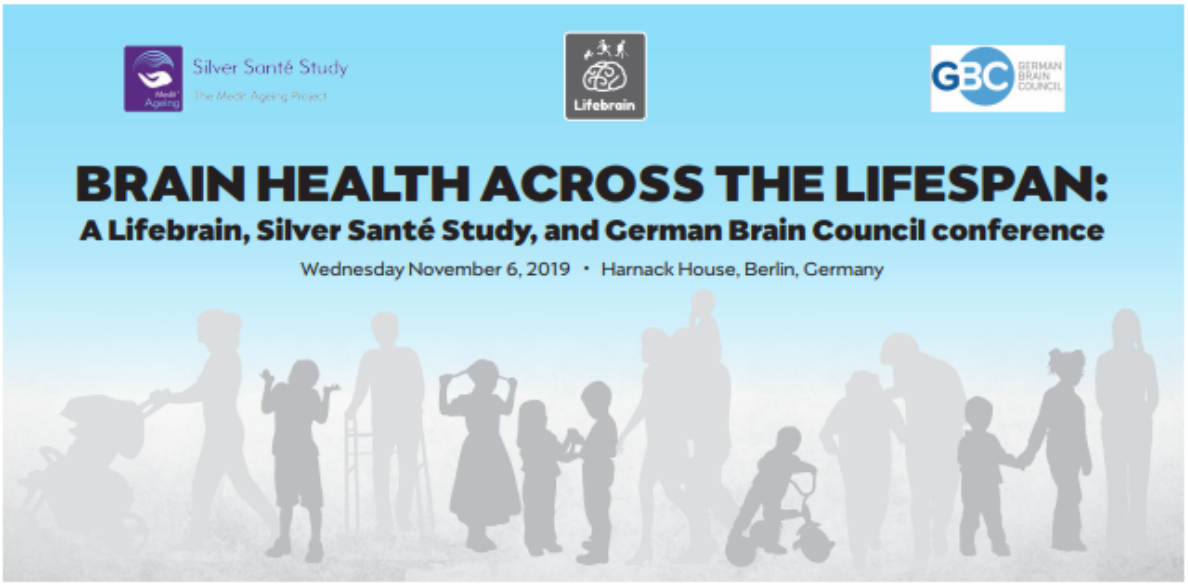
The webinar lasts for one hour.

CLICK HERE TO REGISTER TO THE WEBINAR.

The webinar will be recorded and is free of charge.

This webinar is jointly organised by the Norwegian Brain Council and the EU Horizon2020 project Lifebrain.

Annex 14 – Lifebrain conference "Brain health across the lifespan"" in Berlin, Germany, Nov 2019



PROGRAMME

09.00 – 09.20	**WELCOME BY ORGANISERS:** Welcome by Ulman Lindenberger (Max Planck Institute for Human Development & Max Planck UCL Centre for Computational Psychiatry and Ageing Research) Welcome by Kristine Walhovd (University of Oslo, Lifebrain), Olga Klimecki (University of Geneva, Silver Santé Study), and Alfons Schnitzler (German Brain Council)
SESSION 1:	**HOW TO PROMOTE BRAIN HEALTH ACROSS THE LIFESPAN** **SESSION CHAIR: Klaus Ebmeier (Lifebrain)**
09.20 – 09.50	**KEYNOTE: Cognitive ageing: A lifespan perspective** Ulman Lindenberger
09.50 – 10.20	**KEYNOTE: Promoting healthy brain ageing: What do we know and where are we going? Example from the large European project Silver Santé Study** Gael Chételat, *INSERM, University of Caen, Silver Santé Study*
10.20 – 10.35	Discussion in plenum
10.35 – 11.05	Coffee break
SESSION 2:	**RISK FACTORS AND BRAIN HEALTH** **SESSION CHAIR: Sana Suri and Rogier Kievit (Lifebrain)**
11.05 – 11.25	**What will memory ageing look like for our grandchildren?** Lars Nyberg, *University of Umeå, Lifebrain*
11.25 – 11.45	**How and why our lifestyle shapes the brain in healthy ageing and disease** Gerd Kempermann, *German Center for Neurodegenerative Disease, Dresden*

11.45 – 12.05	**Sticks and stones may break my bones, but can words hurt my brain? How our style of thinking may affect risk for dementia** Natalie Marchant, *University College of London, Silver Santé Study*
12.05 – 12.25	**Depressive illness: Difficult to recognize, but easy to treat** Peter Falkai, *Ludwig-Maximilians-University Munich*
12.25 – 12.40	**Discussion**
12.40 – 13.40	**Lunch**
Session 3:	**PREVENTION AND INTERVENTION STRATEGIES FOR BRAIN HEALTH** **SESSION CHAIR: Miranka Wirth (Silver Santé Study)**
13.40 – 14.00	**Does video gaming affect the brain?** Simone Kühn, *Max Planck Institute for Human Development, Lifebrain/Department of Psychiatry and Psychotherapy, University Clinic, Hamburg-Eppendorf*
14.00 – 14.20	**Episodic memory in pre-clinical Alzheimer's disease** Emrah Düzel, *German Center for Neurogenerative Diseases, Magdeburg*
14.20 – 14.40	**Meditation-based interventions in the elderly** Antoine Lutz, INSERM, *Lyon Neuroscience Research Center, Silver Santé Study*
14.40 – 15.00	**Non-invasive brain stimulation for brain health in the elderly** Agnes Flöel, *University Medicine Greifswald*
15.00 – 15.15	**Discussion in plenum**
15.15 – 15.45	**Coffee break**
Session 4:	**PANEL: Brain health promotion across the lifespan** **SESSION CHAIR: Kristine Walhovd**
15.45 – 15.55	**Are people ready for personalized brain health?** Isabelle Budin-Ljøsne, *Norwegian Institute of Public Health, Lifebrain*
15.55 – 16.05	**Burden and challenges of brain disorders** Alfons Schnitzler, *German Brain Council & University of Düsseldorf*
16.05 – 16.45	**INVITED PANEL MEMBERS:** Ulman Lindenberger, Gael Chételat, Gerd Kempermann, Miranka Wirth, Alfons Schnitzler, Peter Falkai
16.45	**Adjourn**

The Lifebrain and The Medit-Aging project (Silver Santé Study) have received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 732592 and No 667696.

Annex 15 – Examples of public coverage of the WP1 study phase 1 (interview study) and phase 2 (GBHS)

Results from the WP1 interview study were published in August 2020 and presented in the media and on public websites:

"People know little about brain health but want to know more", Norwegian Institute of Public Health, November 2019
https://www.fhi.no/en/news/2019/people-know-little-about-brain-health-but-want-to-know-more/

«Husk å trene hjernen din!», Norwegian public broadcaster NRK, January 2020
https://www.nrk.no/osloogviken/husk-a-trene-hjernen-din_-1.14853211

"Brain researchers want to know how you take care of your brain", March 2020
https://sciencenordic.com/brain-denmark-researchers-zone/brain-researchers-want-to-know-how-you-take-care-of-your-brain/1621966

The GBHS was also promoted by co-organizers and other stakeholder organizations:
"Stor internasjonal studie trenger din stemme!», Norwegian Brain Council, September 2019
https://www.hjerneradet.no/?page_id=27872

"Participa en la Encuesta Global de Salud Cerebral del proyecto europeo Lifebrain", Universidad de Deusto, October 2019
https://www.deusto.es/cs/Satellite/deusto/es/universidad-deusto/vive-deusto/participa-en-la-encuesta-global-de-salud-cerebral-del-proyecto-europeo-lifebrain/noticia

"The Global Brain Health Survey", the Women's Brain Project, January 2020
http://www.womensbrainproject.com/global-brain-health-survey/

«Unik undersøkelse om hjernehelse på 15 språk», Norwegian Brain Council, February 2020
https://www.hjerneradet.no/?page_id=28574&ct=t%28Nyhetsbrev_nr_1_201712_14_2016_COPY_01%29&mc_cid=fae05ab6af&mc_eid=83ffa0b90e

"Global Brain Health Survey", Brain Awareness Week (Dana Foundation), March 2020
https://www.brainawareness.org/event/global-brain-health-survey/

"Wilt u deelnemen aan vragenlijst over hersenen en gezondheid?», Hersenstichting, April 2020
https://www.hersenstichting.nl/nieuws/wilt-u-deelnemen-aan-vragenlijst-over-hersenen-en-gezondheid/

"The Global Brain Health Survey", Sharing Good practices for Brain Education in Europe (Share4Brain), April 2020
https://www.share4brain.org/blog/2020/04/08/the-global-brain-health-survey/

"The Global Brain Health Survey – take part today", Join Dementia Research
https://news.joindementiaresearch.nihr.ac.uk/lifebrain-global-brain-health-survey-uk/

Annex 16 – Overview of WP1 stakeholder activities, and stakeholders reached

Activities	**Co-organizing stakeholder(s)**	**Stakeholders reached**
Stakeholder workshops		
Pilot stakeholder workshop (Spain, 2017)		24
Stakeholder workshop (Norway, 2018)	Norwegian Brain Council	44
Workshop with Global Brain Health survey co-organizers (online, 2020)		10
Workshop with Global Brain Health survey co-organizers (online, 2021)		17
Public lectures/webinars		
"Your brain is your life" (Spain, 2017)		50
"Take care of your brain!" (Norway, 2018)	Norwegian Brain Council	200
"Healthy ageing" (United Kingdom, 2019)	University of Cambridge	70
"Good brain health is important!" (Norway, 2019)	Norwegian Brain Council	200
Webinar on brain health (online, 2020)	Norwegian Brain Council	74
Conference		
"Brain Health across the lifespan" (Germany 2019)	Silver Santé Study, German Brain Council	144
WP1 research		
Interview study (UK, Norway, Spain, Germany, 2018)		44
Global Brain Health Survey (online, 2019-2020)	Norwegian Brain Council, German Brain Council, Belgian Brain Council, Brain Foundation Netherlands, Swedish Brain Foundation, Women's Brain Project, National University of Ostroh Academy	27,590
Total no of stakeholders reached		**28,463**