



Lifebrain

D1.5 Report/policy brief on concepts and mechanisms for uptake of research output (R)

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Document history

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1.0	10.08.2021	First draft	Draft	E-mail
2.0	31.08.2021	Final version	Revised based on comments	Submitted to the Participant portal

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Executive Summary

D1.5 concerns the identification of mechanisms that will enable uptake of research outputs. Based on an early request made by stakeholders during a Lifebrain stakeholder workshop in 2017, WP1 investigated avenues for the communication of brain health promotion strategies considered valuable by members of the public. This was done through the inclusion of specific questions pertinent to brain health promotion in the questionnaire of the Global Brain Health Survey, a Lifebrain online initiative that collected data across 81 countries on people's perceptions of, and attitudes towards, brain health.

This deliverable describes steps taken to collect survey data and develop a public report, which provides recommendations relevant for policymakers and related initiatives such as civil society organizations seeking to improve public brain health. The public report will be made broadly available using diverse dissemination strategies.

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List of acronyms/ abbreviations

Lifebrain	Lifebrain Horizon 2020 consortium (2017-2022). Healthy minds from 0-100 years: Optimising the use of European brain imaging cohorts
NIPH	Norwegian Institute of Public Health
PI	Principal Investigator
UiO	University of Oslo
WP	Work Package

1. Introduction

1.1. Deliverable description

D1.5 Report/policy brief on concepts and mechanisms for uptake of research output (R)

Background

In the Lifebrain project proposal (Task 1.4), WP1 aimed to identify concepts and mechanisms that will enable uptake of research outputs. A core objective of the Lifebrain project is to provide an evidence base on modifiable and life-style related factors that likely interact and affect brain, cognitive, and mental health through the lifespan. Such an evidence-base may inform brain health promotion in populations and should be made easily available to key stakeholders including policymakers, health care professionals and civil society organizations with an interest in brain health. Importantly, it must also be available and accessible to citizens.

In our early interactions with policymakers and key stakeholders during the initial phase of the Lifebrain project, notably during a pilot workshop in Spain in 2017, stakeholders identified communication of brain health information as a significant challenge. They explained the importance of providing policymakers and lay citizens with reliable and trustworthy evidence on brain health maintenance that is understandable and concise, reasonable in terms of cost, and leads to real benefit (See D1.4 Input from Stakeholders – Feedback Incorporated). This is important as behavioural change to strengthen brain health may require strong motivation. They also supported WP1's ambition to collect new knowledge regarding which mechanisms one should use to disseminate policy-relevant research results and promote citizen brain health.

Based on discussions with stakeholders and researchers in Lifebrain, the WP1 developed the Global Brain Health Survey (GBHS) to collect data on people's perceptions of brain health and willingness to take care of their brain by adopting new lifestyles (See D1.3 for online/mobile tools for stakeholder engagement). In accordance with stakeholders, policy-relevant questions related to government interventions to maintain and improve public brain health were added to the survey (GBHS).

Deliverable

This deliverable presents survey results relevant for policy making and related initiatives seeking to improve public brain health. The report consists of two sections. The first is a public report, describing survey results relevant for public brain health interventions and communication.

The report hence primarily addresses policymakers and other stakeholders such as health care professionals and civil society organizations with an interest in communicating evidence-based brain health information to the public.

The second part of the deliverable contextualizes the public report and describes how relevant insights in the report will be disseminated to relevant public authorities within the EU and specific member countries.

1.2. Objectives of the deliverable:

The objective of D1.5 is to facilitate the application of WP1 research results in public brain health promotion. The deliverable investigates:

- i) Mechanisms to support citizens willing to alter their lifestyles to improve or maintain brain health
- ii) Measures that public health authorities may adopt to promote brain health, as seen from the perspective of members of the public
- iii) Communication channels to inform citizens about brain health

1.3. Collaboration among partners

Activities described in this deliverable are conducted by the WP1 core team, in close collaboration with various country-specific and European brain councils, the WP leaders and cohort PIs.

WP1 core team

- Isabelle Budin Ljøsne, WP1 leader (NIPH)
- Barbara Bodorkos Friedman, Lifebrain administrative coordinator (UiO)
- Nanna Fredheim, Researcher (NIPH)
- Rebecca Bruu Carver, Communication Officer, WP5 member (NIPH)

GBHS Co-Organizers

- 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
- The National University of Ostroh Academy in Ukraine

In addition, the following organizations have collaborated closely with Lifebrain in the development and dissemination of the GBHS: Join Dementia Research (UK); Herzenonderzoek (The Netherlands). (See Annex 2 for more information on co-organizers).

2. Description of activities

2.1. The Global Brain Health Survey (GBHS)

As previously described in D1.2 (Input to the Dissemination, Exploitation and Communication(DEC) plan (T5.1), D1.3 (Online/mobile tools for stakeholder engagement conceptualized and developed), the WP1 developed the Global Brain Health Survey to investigate people's:

- Perceptions of the brain and brain health,
- Interest in maintaining a healthy brain,
- Willingness to know more about one's own brain health,
- Willingness to act to maintain good brain health and prevent brain disease development
- Perceptions of support needed to improve brain health

A scientific paper published in 2020 provides a full description of the survey's design, background, and dissemination (Budin-Ljøsne and al., 2020).

The GBHS was developed together with key stakeholder representatives. An interview study preceded the GBHS, where questions were based on previous surveys on brain health and developed in collaboration with stakeholders in the Lifebrain consortium's network such as patient organizations, brain health researchers, clinicians and cohort participants. Findings from the interview study were then used to develop the Global Brain Health Survey questionnaire. Lifebrain investigators, colleagues in the Lifebrain network, representatives of patient organizations, clinicians and lay people were furthermore invited to comment on the survey questionnaire. A pilot of the questionnaire was tested at a Lifebrain public lecture in 2019, and furthermore discussed in a meeting with the advisory group of the Cambridge Centre for Ageing and Neuroscience (CamCAN) study.

The questionnaire was digitally available in 14 languages on the Lifebrain website (www.lifebrain.uio.no) for 14 months between June 2019 and August 2020. The survey was promoted and disseminated in close cooperation with the stakeholder co-organizers listed above (see D1.4 for a more detailed overview).

In total, 27,590 people from 81 countries worldwide responded to the survey. Respondents were predominantly from Europe, notably from the UK and the Netherlands. Most respondents were women (71 %), middle aged or older (66 % are between 41-70), and highly educated (70 % attended graduate school).

The survey asked about respondent's interest in and knowledge about brain health, their interest in taking brain health tests to uncover brain disease risk, respondent's motivation for lifestyle changes to improve brain health, and assistance needed to do so.

Finally, a few questions addressed what public health authorities could do to promote brain health, and brain health information sources. The questions were multiple choice and questioned:

- i) Assistance needed to succeed with life-style changes,
- ii) Interventions by public authorities to improve public brain health, and
- iii) Sources people trust for brain health information.

(see Annex 1 for the survey questions concerning D1.5).

For the second question about assistance there was a free text option. In total, 810 respondents volunteered additional suggestions for assistance needed to succeed with lifestyle changes. Most of the free text responses were from UK respondents (348), mirroring the relatively large proportion of UK respondents in general.

2.2. Public report, findings and dissemination

To speed up the dissemination of results from the Global Brain Health Survey and ensure that all results are made publicly available within Lifebrain's timeframe, WP1 developed a public report that present survey results pertaining to the promotion of brain health.

The public report present results relevant for policy makers and public health authorities. It should be noted that as the report targets non-experts rather than academic readers, accessibility and readability has been prioritized in communication of the results.

Overall, the results show that to implement and sustain lifestyle changes for brain health maintenance and improvement, respondents believe they would need:

- Professional support (86 %)
- Regular monitoring (80 %)

Suggestions from the free text on additional supportive measures were largely recurrent across countries. Common topics included the need for:

- Accessible, scientific, and easily understandable information on brain health and lifestyle
- Personalized plans and follow-ups to improve brain health
- Online resources, such as courses, activities, tests, communities, training
- Peer support by others with the same condition
- Practical and/or financial aid to enable lifestyle changes

Respondents think activities by public authorities to promote brain health should include:

- Reliable information (95 %)
- Provide free brain health tests to discover the risk of developing a brain disease (81 %). Note that such tests were not specified, and largely hypothetical, as such tests do not currently exist.
- Introduce relaxation activities and sports into schools and workplaces (76 %)
- Subsidize healthy food and activities (72 %)

In terms of trusted sources for brain health information, respondents rated the following as the most trusted sources:

- Brain health specialists (95 %)
- Scientific journals (65 %)

Social media were the least trusted sources. However, demographic groups differed somewhat in terms of which sources they trusted. The high level of trust in Scientific journals is likely a reflection of the large number of highly educated respondents.

A draft of the report was shared in June with the survey co-organizers (see Annex 2) to secure readability and broad public dissemination. The public report has been published 31st August 2021 and can be [downloaded from the Lifebrain website](#).

The report will be disseminated as follows:

- The Lifebrain website
- Lifebrain cohort partner websites and social media accounts, such as the Norwegian Institute of Public Health.
- Social media: Lifebrain Twitter and Facebook accounts
- Within stakeholder co-organizer's networks, such as EU and European national policy makers
- On stakeholder co-organizers communication platforms (websites, social media)

References

[Budin-Ljønsne 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, Zasiakina 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.](#)

Annex 1 – GBHS questions applied in this report

14. Imagine you decide to change your lifestyle to maintain or improve your brain health. What kind of assistance would you need?

Select all those that apply.

- Advice from my GP or from a specialist, e.g. a nutritionist or a personal trainer
- Support from family members and/or friends
- Group support, e.g. a walking group
- A mobile app to help with brain and physical training
- Regular monitoring to review the effect of lifestyle changes

Other kind of help (please specify):

15. The public health authorities should:

	Yes	No	Do not know
Inform the public about brain health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Raise taxes on products that are unhealthy for the brain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Subsidize food and activities that are beneficial for the brain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Offer brain health tests free of charge to citizens	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Introduce relaxation activities and sports in schools and work places	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prevent insurance companies from accessing the results of brain health tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. To what extent do you trust the following sources of information on brain health?

	<u>To a great extent</u>	<u>Moderately</u>	<u>Not at all</u>
My general practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A brain health specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online medical forums	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Official websites of public health authorities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Newspapers, magazines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social media (Facebook, Twitter, Instagram)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
TV/radio (including pod-casts)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Public researchers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Scientific journals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Annex 2- Stakeholder co-organizers of the GBHS

Co-organizers listed below helped design and disseminate the GBHS:

- **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.
- **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.
- **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.
- **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.
- **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.
- **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.
- **The National University of Ostroh Academy, Ukraine (<https://www.ou.edu.ua>)**

Other organizations that helped disseminate the GBHS survey.

- **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.
- **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.