



Lifebrain

D1.2. Input to the Dissemination, Exploitation & Communication (DEC) Plan (T5.1)

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Executive summary

D1.2. Input to the Dissemination, Exploitation & Communication (DEC) plan of Lifebrain consists of a stakeholder engagement (SE) plan describing the activities to be conducted in WP1 throughout the project. The plan also provides a preliminary time line for these activities. The SE plan is fully integrated in the DEC plan of Lifebrain (D 5.1), which was submitted in June 2017.

Some of the SE activities that are described herein will be conducted in partnership with WP5, and will require practical support and collaboration from the project partners.

The SE plan includes the following activities:

- A study (hereafter “the WP1 study”) to investigate people’s views on brain health and personalized brain health prevention
- Annual stakeholder workshops held in conjunction with the Lifebrain annual consortium meetings
- Stakeholder-led or co-led sessions in conjunction with Lifebrain conferences
- Public lectures in conjunction with Lifebrain annual consortium meetings and conferences (organized in partnership with WP5)
- Dissemination (e.g. e-newsletter, website, Facebook/Twitter) – in partnership with WP5
- Evaluation of stakeholder engagement in Lifebrain

The SE plan targets five main groups of stakeholders as defined in the D1.1 List of relevant stakeholders:

- Research participants in the consortium cohorts
- Patient groups and patient organizations
- Policymakers
- Clinical and research centres, research networks, research societies
- Other stakeholders (e.g. general public, media)



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List of acronyms/ abbreviations

Lifebrain	Healthy minds from 0-100 years: Optimising the use of European brain imaging cohorts
AC	Administrative Coordinator
CA	Consortium Agreement
CO	Coordinator Project Office
EB	Executive Board
EC	European Commission
GA	Grant Agreement
LB	Lifebrain
M	Month
MPIB	Max Planck Institute for Human Development
NIPH	Norwegian Institute of Public Health
NGO	Non-governmental organizations
PI	Principal Investigator
PM	Person month
PO	Patient organizations
SE	Stakeholder engagement
UB	University of Barcelona
UCAM	University of Cambridge
UiO	University of Oslo
UNIGE	University of Geneva
UmU	Umeå University
UOXF	University of Oxford
VUmc	University Medical Center Amsterdam
WP	Work Package
WPL	Work Package Leader



1. Introduction

Deliverable description

Lifebrain is committed to engage with its stakeholders throughout the project. Stakeholders include participants in the Lifebrain cohorts, patient groups and patient organizations, policymakers, clinical and research centers, research networks, research societies, researchers and clinicians, and the public. Engagement will start early in the project period and continue throughout the project lifetime. It will provide stakeholders the opportunity to influence development of the project, and secure efficient implementation of the project results in healthcare and public health policies.

WP1 includes several activities to engage stakeholders in the Lifebrain research. We will collect data about the views and perspectives of key groups of stakeholders regarding brain health, and regularly organize meetings with the stakeholders. Experiences from conducting these activities, as well as the regular feedback from stakeholders, will serve as a basis for developing recommendations for stakeholder engagement in EU-projects. Our stakeholder activities will be documented thoroughly, and the results of our work disseminated through the communication platforms developed in WP5.

Objectives of the deliverable

This deliverable provides a detailed description of the activities planned to take place in WP1 to engage stakeholders. An important feature of WP1 is that it will use feedback from stakeholders to inform Lifebrain activities. This means that our SE plan may be modified if the feedback from the stakeholders indicates that other activities are more relevant, or that other topics than those proposed, may be interesting to explore.

Collaboration among partners

Activities described in this deliverable will be conducted by the WP1 core team and in close collaboration with WP5. All WP leaders and cohort PIs will be regularly involved in our work. They will also provide practical support for the realization of our goals and activities.

WP1 core team:

- Isabelle Budin Ljøsne, WP1 leader (NIPH)
- Barbara Bodorkos Friedman, Lifebrain administrative coordinator (UiO)
- Sana Suri, researcher (UOXF)
- Cristina Solé-Padullés, researcher (UB)
- Sandra Düzel, researcher (MPIB)

With support from the LB PIs.

2. Description of activities/discussion

Several activities are planned to take place in WP1:

- The WP1 study on people’s perspectives on personalized brain health
- Stakeholder workshops held in conjunction with the LB consortium meetings
- Stakeholder-led or co-led sessions in conjunction with the LB conferences
- Public lectures in conjunction with LB consortium meetings and conferences (in partnership with WP5)
- Dissemination – in partnership with WP5
- Evaluation of stakeholder engagement in LB

These activities will serve as a basis to fulfil our deliverables in WP1.

WP1 has the following deliverables:

- D1.1 List of relevant stakeholders for project engagement across a number of WPs **(delivered)**
- D1.2 Input to the Dissemination, Exploitation and Communication (DEC) plan (T5.1) **(delivered)**
- D1.3. Online/mobile tools for stakeholder engagement conceptualized and developed (due M18)
- D1.4 Input from stakeholders – feedback incorporated (due M54)
- D1.5 Report/policy brief on concepts and mechanisms for uptake of research output (due M56)
- D1.6 Reviewing stakeholders engagement – best practice (Due M58)

Table 1. below describes how each activity will inform our deliverables.

WP1 activities	Input to deliverables
The LB WP1 study	D1.3, D1.4, D1.6
Annual stakeholder workshops	D1.4, D1.5, D1.6
Stakeholder-led or co-led sessions	D1.4, D1.5, D1.6
Public lectures	D1.6
Dissemination	D1.6
Evaluation of stakeholder engagement	D1.6

Table 1. Input to WP1 deliverables

A detailed description of each activity in the SE plan is provided below.

2.1. The WP1 study

WP1 will conduct a study to investigate the views of key groups of stakeholders on brain health and personalized brain health prevention. More specifically, it will explore:

- Perceptions of the brain and brain health,
- Interest in maintaining a healthy brain,
- Willingness to know more about own brain health, and,
- Willingness to act to maintain a good brain health and prevent brain disease development.

The key groups of stakeholders targeted in this study are:

- Participants in brain health research
- Individual members of patient and interest organizations
- The general public

Expected study outcomes:

- Increased understanding regarding what may and may not motivate individuals to act to maintain a healthy brain and prevent brain disease
- Formulation of potential strategies that may motivate individuals to take better care of their brain; strategies that may inform public policy.

The study is planned to be conducted in two steps:

- Step 1: individual interviews with brain research participants (in 2018).
- Step 2: An online survey (fall 2018/spring 2019). We will ask patient groups, clinicians, researchers, and policymakers in the LB network, to distribute the survey among their contacts at national and international level.

The same core research questions will be explored in the interviews and the online survey.

In order to ensure that the questions explored in this study are pertinent, WP1 consulted representatives from patient organizations, policymakers, clinicians and researchers collaborating with LB during the first LB stakeholder workshop in Barcelona, 17 November 2017. During the workshop, the stakeholders discussed the core questions, and provided some recommendations regarding how to improve the questions.



Step 1: Individual interviews

Individual interviews will be conducted with randomly selected brain research participants at four study sites: Barcelona, Berlin, Oxford, and Oslo. The plan is to interview 10-12 participants per site (in total approx. 40-48 participants).

The same inclusion criteria will be used across research sites to recruit participants:

- Healthy individuals participating in brain research studies
- Individuals in 3 age groups:
 - (Y) Young adult (18-35);
 - (M) Middle age (36-64);
 - (O) Older adults (65+).

We will aim for a balanced representation of each age group and gender whenever possible.

Exclusion criteria:

- Minors
- Individuals diagnosed with a brain condition
- Individuals not participating in brain research
- Individuals who do not want their interview to be audio recorded

The participants will be invited to sign an informed consent form of which they will receive a copy. Each study site will apply for local ethics approval. In addition, ethics approval will be sought in Norway for the whole project. The researchers conducting the interviews will use an interview guide. The interviews will be audio recorded for data analysis.

Step 2: Online survey

An online survey will be developed in 2018 with the objective to explore the same core questions as those explored during the interviews within a broader sample of stakeholders. The questions may however be refined depending on the feedback we receive during the interviews in Step 1.

The survey will be distributed broadly using the following channels:

- The Lifebrain PIs will inform their cohort participants about the survey, either by sending them the link to the survey by email (if re-contact is possible), or by informing about the survey in the cohort newsletter or web site. In principle, all the LB cohorts that include adult participants can inform their participants about the survey.



- Patient groups, clinicians and researchers, and policymakers in the Lifebrain network will be invited to forward the survey link to their contacts nationally and internationally about the survey. Some stakeholders in Barcelona already agreed to help distribute the survey.
- Other channels such as the LB Facebook page may be considered.

The online survey will be set up using the services of the University of Oslo called "Nettskjema", or any similar tool with an equivalent security level. It will be designed to collect data in an anonymous way. Ethics approval will be sought in Norway if necessary. This work will provide data to inform deliverable D1.3 - Online/mobile tools for stakeholder engagement conceptualized and developed (due M18).

When starting the survey, respondents will be asked to consent to the use of their data for research, and confirm that they are over 18 years old. The survey will be translated into Norwegian, French, Spanish, Catalan, German, Dutch and Danish.

All data collected for the WP1 study, including audio data, transcription files, and survey data, will be stored on the dedicated services for sensitive data server at the University of Oslo.

Results from this study will be presented at national and international conferences and policy workshops, and in several international journals. In addition, we may consider writing "national" papers in Spanish, German, and Norwegian whenever possible.

2.2. Annual stakeholder workshops

Annual stakeholder workshops will be organized in 2017, 2018, and 2020, gathering local and national policymakers, representatives from patient and interest organizations, external scientists, and research groups. The objective of these workshops will be to engage in discussions with stakeholders regarding the LB research and ways to collaborate to translate research output into brain health policy of practical use.

The first LB stakeholder workshop was organized as a pilot in conjunction with the LB annual meeting in Barcelona, Spain, 15-17 November 2017.

The main objectives of this first workshop were to:

- Introduce the LB project to the stakeholders



- Discuss questions to be explored in the study conducted by WP1 – Stakeholder engagement of LB
- Explore how LB may interact with the stakeholders.

The workshop gathered 13 LB researchers and 11 Catalan and national stakeholders (representatives of patient and interest organizations, brain health researchers, clinicians, brain research participants, and policymakers). The stakeholders expressed great interest in LB and wanted to be involved. A summary workshop report was drafted after the workshop and sent out to the workshop participants. Information about the workshop is also available on the Lifebrain website and Facebook page.

The 2018 stakeholder workshop is planned to take place in conjunction with the next LB annual meeting 5-7 June 2018 in Oslo. The focus of this next workshop is currently under discussion.

It is important for Lifebrain to maintain good contact with the stakeholders participating in our workshops throughout the duration of the project. The local PIs will be responsible for regularly re-contacting the stakeholders to inform them about new developments in the project, and invite them to Lifebrain events that may take place in their country or any other location. Updates on the latest project news, ongoing and future project activities, and current research results, will be provided by email to the stakeholders on a regular basis. The stakeholders will be provided with the opportunity to comment on developments in Lifebrain and telephone meetings or webinars may be organized if the stakeholders specifically ask for an opportunity to discuss various aspects of Lifebrain in more detail.

2.3. Stakeholder-led or co-led sessions

LB will organize two scientific conferences to share results with the scientific community. The conferences will be open to researchers from LB-related research fields. The following LB conferences will be organized:

- November, 2019 in Berlin, Germany
- Closing conference in December 2021 in Oxford, UK

Stakeholders will be invited to lead or co-lead sessions in conjunction with these conferences. This may be particularly relevant for patient organizations, which will have an opportunity to bring forward their views and concerns regarding brain health.



2.4. Public lectures

In conjunction with the LB yearly consortium meetings, public lectures will be organized in collaboration with WP5. These lectures will inform about research conducted in LB to a large audience. The lectures will be free of charge and open to anybody interested. Local organizers of the LB yearly consortium meetings are expected to contribute to the practical organization of the public lectures.

The first Lifebrain public lecture was held in Barcelona, 15 November 2017, at the University of Barcelona, in conjunction with the Lifebrain annual meeting. The lecture lasted from 18.15 to 19.30 and gathered approximately 50 participants, including students and professors from the University of Barcelona, research volunteers, representatives of patient organisations and 15 Lifebrain researchers. The public lecture was advertised at the University of Barcelona and on the Facebook page of the Barcelona Brain Health Initiative.

The next Lifebrain public lecture is planned to take place in conjunction with the planned Lifebrain annual meeting 5-7 June 2018 in Oslo, Norway, in a coffee shop environment (e.g. "Litteraturhuset") to make it more accessible.

2.5. Dissemination

WP1 will use the Lifebrain dissemination channels developed by WP5 (through e.g. Newsletter, website, Facebook/Twitter) to come in contact with the stakeholders, inform them about developments in the project, and spread invitations to WP1 events. The dissemination channels will also be used to inform the stakeholders about results from the work conducted in WP1. Results will also be presented at international conferences and through publications in scientific journals.

2.6. Evaluation of stakeholder engagement in Lifebrain

Toward the end of the project, an evaluation of all stakeholder engagement activities in Lifebrain will be conducted. This evaluation will be based on the feedback received from stakeholders during the stakeholder workshops (including evaluation questionnaires distributed at each workshop), observations from the Lifebrain researchers, and ongoing discussions with stakeholders. A report/paper will be written summarizing the stakeholder engagement activities conducted in the project, and lessons learned from conducting such activities. The stakeholders will be invited to comment on the report/paper.

3. Timeline for stakeholder activities

Table 2. provides the timeline for the stakeholder activities in Lifebrain.

WP1 activities	2017	2018	2019	2020	2021
Data collection for WP1 study					
Annual stakeholder workshops					
Stakeholder-led or co-led sessions					
Public lectures					
Dissemination					
Evaluation of stakeholder engagement					

Table 2. Timeline for stakeholder activities

4. Conclusion

The Stakeholder Engagement plan is fully integrated in the DEC plan of Lifebrain (D 5.1), which was submitted in June 2017.

Many of the SE activities will be conducted in partnership with WP5:

- the formulation of WP1 study questions
- the stakeholder workshops/stakeholder led or co-led sessions, and public lectures held in conjunction with the LB consortium meetings and conferences and
- dissemination activities