



Lifebrain

D1.3. Online/mobile tools for stakeholder engagement conceptualised and developed

Project title:	Healthy minds from 0-100 years: Optimising the use of European brain imaging cohorts
Due date of deliverable:	30 th June 2018
Submission date of deliverable:	29 th June 2018
Leader for this deliverable:	Norwegian Institute of Public Health

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Document History				
Version	Date	Reason for Change	Status (Draft/In-review/Submitted)	Distribution
1.0.	6 June 2018	First draft	Draft	E-mail/OneDrive
2.0	13 June 2018	Discussed at the Lifebrain Consortium meeting	In-review	OneDrive, slack
3.0	29 June 2018	Final version	Submitted	Participant portal, OneDrive

Dissemination level		
PU	Public	X

Executive Summary

Lifebrain uses a variety of approaches and methods to engage with its stakeholders. This deliverable describes the development and launching of an online survey to collect data regarding the views of key groups of stakeholders regarding brain health. The online survey is the second phase of the WP1 study previously described in D1.2. Input to the Dissemination, Exploitation & Communication (DEC).

The WP1 study investigates the views of key groups of stakeholders on brain health and personalized brain health prevention.

The WP1 study includes 2 phases:

- Phase 1: Individual interviews with brain research participants at four Lifebrain research sites (Oslo, Oxford, Barcelona, Berlin) - Ongoing
- Phase 2: Online survey to be broadly distributed

The online survey in phase 2 is designed to include similar questions as explored during the interviews with brain research participants in phase 1. However, it will be optimized for use in broader group of stakeholders in the Lifebrain network including e.g. members of patient organizations, clinicians, and researchers.

For a detailed description of the use of social media tools in stakeholder engagement the reader is referred to deliverables D5.1 (Month 6) and D5.2. (Month 18).

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List of acronyms/ abbreviations

Lifebrain	Healthy minds from 0-100 years: Optimising the use of European brain imaging cohorts
MCQ	Multiple Choice Questions
MPIB	Max Planck Institute for Human Development
NIPH	Norwegian Institute of Public Health
PI	Principal Investigator
REGIONH	Region Hovedstaden
UB	University of Barcelona
UiO	University of Oslo
UmU	Umeå University
UNIGE	University of Geneva
UOXF	University of Oxford
Vitas	Vitas Ltd.
VUmc	University Medical Center Amsterdam
WP	Work Package

1. Introduction

1.1. Deliverable description

D1.3: Online/mobile tools for stakeholder engagement conceptualized and developed

Task 1.3: Develop and use innovative approaches for stakeholder engagement. Lead: NIPH;
Participants: All (M4-M18)

From the Lifebrain project proposal: *“Innovative approaches to retrieve stakeholder’s input and feedback will be developed and implemented. Social media, like twitter, will be one area of interest. Also, web-based questionnaires, tests and engagement tools will be considered, and possibly developed. Collaboration with an IT development group at UiO will be initiated in order to develop a web application or an app for a smartphone to be used by stakeholders and possibly utilized as public engagement tools in collaboration with WP5”.*

This deliverable describes the development of an online survey to collect data regarding the views of individuals on brain health. More specifically, the survey will be used to gain insight into how Lifebrain stakeholders such as participants in the Lifebrain cohorts, individual members of patient and interest organizations, researchers, policymakers, and the general public, perceive brain health. The survey constitutes the second phase in the WP1 study which has been described in detail in deliverable D1.2. The WP1 study aims to investigate people’s views on brain health and personalized brain health prevention.

The online survey in phase 2 will explore the same core questions as those explored during the individual interviews with brain research participants in WP1 study phase 1 that involved four Lifebrain sites: Barcelona, Berlin, Oxford, and Oslo. The online survey will be designed as a MCQ in which the respondents can select from multiple answer options.

The survey will be designed and disseminated with support from key groups of stakeholders in the Lifebrain network. For instance, before survey launch, the survey questionnaire will be tested in a pilot gathering Lifebrain researchers and key stakeholders who have agreed to evaluate the questionnaire. The online survey will be developed using the services of an IT development group at UiO.

1.2. Objectives of the deliverable

The objective of D1.3. is to:

- Gain a deeper understanding of what may and may not motivate individuals to take better care of their brain and follow personalized brain health advice
- Reach out to larger groups of stakeholders than those included in phase 1 of the WP1 study, i.e. individual members of patient and interest organizations, researchers, policymakers, and the general public
- Collaborate with key groups of stakeholders on the design and dissemination of the online survey
- Use the results of the survey to formulate potential strategies that may promote brain health and inform public policy
- Disseminate survey results to a broad audience through the Lifebrain communication channels (e.g. website, Facebook)

1.3. Collaboration among partners

Activities described in this deliverable will be conducted by the WP1 core team and in close collaboration with the WP leaders and cohort PIs who will help disseminate the web-based questionnaire through their networks.

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)

2. WP1 study-Online survey

In 2018, WP1 initiated the WP1 study. The study is a qualitative study aiming at investigating the views of key groups of stakeholders on brain health and personalized brain health prevention. The WP1 study has been described in detail in deliverable D1.2.: “Input to the Dissemination, Exploitation & Communication”.

The WP1 study is conducted in two phases:

- Phase 1: individual interviews with brain research participants at four study sites (Barcelona, Berlin, Oxford, and Oslo)
- Phase 2: Online survey

Data collection for phase 1 started during the spring of 2018 and is ongoing. The interviews at the four research sites are expected to be completed in July/August 2018.

The phase 2 online survey will collect data from a larger group of individuals, which includes, for instance, members of patient organizations, clinicians, researchers, policymakers in the Lifebrain network, and the general public.

2.1. Survey questions

The online survey will explore questions similar to those explored in the individual interviews in phase 1. However, the questions will be refined based on the feedback received during the interviews in phase 1 and optimized to the broader and more diverse group of stakeholders that will be targeted in phase 2.

The online survey will consist of approx. 25 multiple-choice questions exploring the respondents’:

- 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.

It should be noted that we already have received some feedback from stakeholders regarding the questions used in this study. More specifically, the questions have been revised following recommendations made by the stakeholders attending the first Lifebrain stakeholder workshop in Barcelona in November 2017. Before the online survey is published and distributed we will conduct a pilot during the fall of 2018, among the Lifebrain researchers and

a selection of stakeholders willing to contribute, to check the pertinence of the questions and evaluate whether the questions are understandable for laypersons.

2.2. Survey languages

The online survey will be made available in at least the following languages: English, Norwegian, Danish, Spanish, Catalan, and German. In addition, if local resources allow the survey will also be translated to Italian, French, Dutch and Swedish, thereby covering all the languages represented in the Lifebrain consortium.

2.3. Technical platform

The online survey complies with the European General Data Protection Regulation. The survey will be provided through a URL link. The online survey questionnaire will be set up using the service of the University of Oslo (UiO) called "Nettskjema". Nettskjema is a tool that is specifically designed to manage data collection using online forms and surveys. The Nettskjema service is available on UiO's web pages and works on all platforms with all popular browsers. The "Nettskjema" will be set up to collect data in a fully anonymized form. Nettskjema only stores information on whether a person has responded to a form or not. The respondent cannot be linked to the submitted form.

In principle, ethics approval will not be necessary to collect data through Nettskjema, although local ethics approvals may be required for some Lifebrain cohorts to be able to re-contact their participants and invite them to respond to the survey.

To investigate possible variations in responses between brain research participants (who may have increased interest in brain health compared with the general population), and other respondents we will distribute two identical "Nettskjema":

- Nettskjema 1 will be distributed among participants in the Lifebrain cohorts
- Nettskjema 2 will be distributed among stakeholders in the Lifebrain network e.g. clinicians, researchers, patient organizations as well as the general public through, e.g. Facebook or the Lifebrain website.

The survey data will be stored on the Lifebrain dedicated partitions on the secure and dedicated "services for sensitive data (TSD)" server at the University of Oslo. Results from the survey may be provided in different formats (e.g. SPSS, STATA or R) for analysis purposes.

Below is an example of a survey using Nettskjema¹:



Figure 1 Nettskjema

2.4. Dissemination of the survey and timeline

The survey will be launched during the fall 2018/spring 2019 using the following channels:

The link to the Nettskjema 1 online survey will be distributed to participants in the Lifebrain cohorts according to local procedures (e.g. link to the survey provided by email, or information about the survey in the cohort newsletter or web site). In principle, all Lifebrain cohorts that include adult participants can inform their participants about the survey. Local ethics approvals for re-contacting the participants will be collected if necessary.

¹ For more information about Nettskjema <http://www.uio.no/english/services/it/adm-services/nettskjema/>

The link to the Nettskjema 2 online survey will be distributed to patient groups, clinicians, researchers, and policymakers in the Lifebrain network who will be invited to forward the survey link to their contacts nationally and in Europe, as well as to the general public. Some stakeholders in Barcelona and Oslo already agreed to distribute the survey through their own channels. To reach the general public the link to the online survey will be made available also on the Lifebrain web site and Facebook page.

It is expected that responses from a minimum of 300 respondents will be collected. Results from the survey will be analysed and presented at international conferences and workshops, and published in international scientific journals. The results will also be made available to the general public in a lay language and using online platforms such as, for instance, the Lifebrain web page and social media as well as traditional media platforms.

2.5. Survey interface

Nettskjema is a simple and user-friendly interface that does not require any particular IT-competence to use. The users of the online survey will be able to respond to the survey using their personal computer, tablet or cell phone.

When starting the survey, respondents will be asked to consent to the use of their data for research. The survey will also collect information about the respondent's gender, age range, marital and employment status, educational level, and country of residence (in an anonymous form). The survey may also include questions to ask whether the respondents have previously participated in brain research or are individual members of a patient organization.

Responding to the survey is expected to take approx. 10-15 minutes.