



Lifebrain

D1.6 Reviewing Stakeholders Engagement – Best Practice (R)

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

Due date of deliverable: 31st October 2021

Submission date of deliverable: 25th October, 2021

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Document history

Version	Release Date	Reason for change	Status (draft/ in review/ submitted)	Distribution
1.0	14.09.201		First draft	
2.0	08.10.2021		Revised draft	
3.0	11.10.2021		Revised draft for evaluation	

Dissemination Level

P	Public	
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Executive Summary

This deliverable is related to Task 1.5 (Review and evaluate effect of stakeholder engagement) and provides an evaluation of stakeholder engagement activities during the period January 2017 until September 2021 (first four and a half years of the project, for more details, see D1.4 Input from stakeholders – Feedback incorporated).

The evaluation is based on two main feedback components:

- Results from external evaluations conducted among selected stakeholders
- Results from internal evaluations conducted among Lifebrain researchers

Several methods were used to evaluate activities including paper-based and online questionnaires, and group discussions.

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List of acronyms/ abbreviations

Lifebrain	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
GBHS	Global Brain Health Survey

1. Introduction

As outlined in the Lifebrain project description, WP1 aimed to optimize scientific exchange between stakeholders and support the uptake of project outputs to stakeholders, including relevant policy makers, national decision makers, healthcare providers, patient organizations, cohort participants and researchers. To do so, the WP developed tools and platforms to engage the different stakeholders and bring the stakeholder's views and priorities in the project. Engagement was to start early in the project period and continue throughout the project lifetime, providing stakeholders opportunity of real influence on priorities early in the project and securing efficient implementation of the project results in healthcare and public health policies.

After project start, the WP1 identified five groups of Lifebrain stakeholders:

- participants in the research cohorts
- patient groups and patient organizations
- policymakers
- clinical and research centers, researchers and research networks
- other relevant stakeholders (e. g. media) (for more details, see D1.1 List of stakeholders).

A detailed 5-year stakeholder engagement plan was established as described previously in *D1.2. 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 in WP1 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.

Different innovative tools were used in the WP to engage stakeholders. In 2018, a qualitative interview study was conducted at four Lifebrain sites to investigate the views of cohort participants on brain health [1]. In 2019, an online survey (the Global Brain Health Survey [2]) was launched to collect the views on brain health of a larger group of individuals, including 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*.

In addition, several types of activities were conducted including stakeholder workshops, stakeholder-led or co-led sessions at conferences, public lectures, and dissemination (for details, see *D1.4. Input from Stakeholders – Feedback Incorporated*).

In *D1.5 Report/policy brief on concepts and mechanisms for uptake of research output*, first results pertaining to the online survey were presented in 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 was made broadly available using diverse dissemination strategies.

1.1 Objectives of the deliverable

This deliverable summarizes our experiences from stakeholder engagement in Lifebrain after four and a half year of activity. It covers all activities described in D1.1. to D1.5 and describes the tools and methods used to evaluate our work. It summarizes the feedback received from stakeholders and researchers, including suggestions for best practice.

1.2 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 provided feedback on activities they have been involved in.

2. Activities to evaluate effect of stakeholder engagement

From project start in 2017 until September 2021, 11 Lifebrain events, including workshops, lectures, and conferences, have been conducted. Through organization of these engagement activities, and research conducted in WP1, 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 1,100 people attended Lifebrain public events and stakeholder workshops. An overview of the activities conducted is provided in **Annex 1**.

To evaluate our dissemination activities, we used paper-based and online tools and collected feedback from external stakeholders as well as Lifebrain researchers. Group discussions were also conducted. The different evaluation approaches and summary of the results are described below.

2.1. External evaluation by stakeholders

Stakeholders attending stakeholder events were invited to fill in evaluation forms either on paper forms when the meetings were organized face-to-face, or online in the case of digital events.

In total, we collected stakeholder feedback in connection with four stakeholder events (two workshops, one conference, one webinar). In addition, an anonymous survey was conducted among selected stakeholders collaborating with Lifebrain on the organization of the Global Brain Health Survey. To secure the anonymity of the respondents, we simply provided aggregate information about feedback.

2.1.1 Workshop evaluations

Evaluation forms were shared with participants at two stakeholder workshops.

Stakeholder workshop 1: “LIFEBRAIN Stakeholder workshop”, Barcelona, Spain, November 2017

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

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.

A paper-based evaluation form was shared with stakeholders at the end of the workshop. Nine out of 11 stakeholders responded to the evaluation. The form included four questions (**Annex 2**).

1. How would you like to interact with Lifebrain?

- All the respondents (9 out of 9) stated that they would like to discuss with Lifebrain how to use the research results in an optimal way from Lifebrain. Six out of nine would like to collaborate with Lifebrain to outline research questions for the Lifebrain study.
- Regarding dissemination activities, the respondents all stated that they were willing to inform about Lifebrain in their networks (friends and colleagues, via web sites, talks at conferences, etc). One respondent, however, stated that informing about Lifebrain would be useful for people with mental health issues.
- Four out of nine participants agreed to help recruit participants in the Lifebrain WP 1 study and help identify organizations Lifebrain should collaborate with.
- Seven out of nine were positive to collaborate with Lifebrain on organizing stakeholder workshops/webinars, and eight out of nine would help disseminate information about Lifebrain progression and results.
- Seven out of nine participants were positive to discussing with Lifebrain brain health policies in their country and six out of nine would like help to evaluate the stakeholder engagement in Lifebrain.

2. What do you see as potential benefits to interacting with Lifebrain?

The most often selected benefits were:

- Achieve a better understanding of Lifebrain research (7 out of 9)
- Possibility to influence how Lifebrain results are used and disseminated (7 out of 9)

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- Possibility to learn from each other (7 out of 9)
- Possibility to influence research directions (6 out of 9)
- Develop my personal and my institution's network (5 out of 9)

3. How do you evaluate this workshop? Rate from 1 (strongly agree) to 5 (strongly disagree)

	1 - strongly agree	2	3	4	5 - strongly disagree
The duration of the workshop was appropriate	6	1	1		1
The workshop was informative	5	2	1	1	
The handout was informative	5	2	1	1	
The discussion and questions were interesting	3	2	4		
I gained a good overview of the LB project	4	2	2	1	
It was useful to participate	6		1	2	

It seems that two participants filled in the Likert scale upside down (wrong order). This is corrected for in the table above.

4. Suggestions for improvement and future activities:

Other suggestions included:

- Discuss early dissemination of information
- Focus on the optimal goals of stakeholder engagement and not try to discuss everything in two hours

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

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. In total, 48 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. The workshop was jointly organized by Lifebrain and the Norwegian Brain Council.

Evaluation forms were handed out (**Annex 3**), and 10 stakeholders completed the forms.

- Nine out of 10 found the duration of the workshop appropriate
- Eight out of 10 agreed/strongly agreed that the discussions and questions were interesting
- Eight out of 10 agreed/strongly agreed that they gained a good overview of current challenges and opportunities in the field of brain health
- All agreed/strongly agreed that they gained a good overview of the Lifebrain project
- Nine out of 10 agreed/strongly agreed that it was useful to participate in the workshop
- Nine out of 10 reported to be interested in participating in Lifebrain activities in the future

- Seven out of 10 reported that they would like to know more about the Norwegian Brain Council

2.1.2 Conference evaluation

Lifebbrain organized a large scientific conference, "Brain health across the lifespan" in Berlin, Germany, in November 2019. The conference was jointly organized by the Lifebbrain consortium, the [Silver Santé Study](#) (also an EU Horizon 2020 project), and the [German Brain Council](#). The conference programme, information about speakers, and the abstracts of the presentations is accessible [on the Lifebbrain website](#).

The conference was well received; a total of 144 participants attended the conference. Evaluation forms were handed out, and we collected 49 completed forms (**Annex 4 for the Evaluation form**).

- 100% of respondents to the evaluation rated their overall experience of the conference as either "good" or "excellent" (1 = poor, 5 = excellent)
- 98% rated the scientific content in the conference as either "good" or "excellent"
- All respondents reported that the conference had met their expectations

Thirty-two people would you like to receive regular news from Lifebbrain via e-newsletter and were added to our list of subscribers.

2.1.3 Public lectures/webinar evaluation

Lifebbrain organized 6 public lectures between project start and September 2021. In general, evaluation forms were not distributed at the lectures as it may be difficult to ensure that people take the time to respond. However, one public lecture was organized as a webinar in 2020 due to the Covid-19 pandemic. The online tool enabled the organizing team to set up a rapid evaluation at the end of the event.

In total, 140 participants attended the webinar and 36 completed the online evaluation.

Would you join a Lifebbrain/Norwegian Brain Council webinar again?	Yes	36	100 %
	No	0	0 %
Did you learn something new during the webinar?	Yes	34	94 %
	No	2	6 %
What do you think of the duration of the webinar?	Appropriate	34	94 %
	Too short	2	6 %
	Too long	0	0 %
How interesting was the webinar?	Very interesting	16	44 %
	Somewhat interesting	14	39 %
	Not so interesting	0	0 %

2.1.4 Survey among co-organizers of the Global Brain Health Survey and contributors

As described in *D1.4. Input from Stakeholders – Feedback Incorporated*, the WP1 team worked closely with several stakeholder organizations that helped develop the Global Brain Health Survey (GBHS) and disseminate it in their networks. The survey aimed to collect the views on brain health of a large group of individuals, including members of patient organizations, clinicians, researchers, policymakers in the Lifebrain network, and the general public [1].

Seven stakeholders agreed to become co-organizers of the GBHS:

- [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 addition, two research registries prominently contributed to disseminate the survey among their members:

- [Join Dementia Research in the UK](#)
- [Hersenonderzoek in the Netherlands](#)

Collaboration with the survey co-organizers and research registries was continuous throughout project duration and two workshops were organized in September 2020 and April 2021 to present and discuss preliminary results from the GBHS (for more information, see *D1.4. - Input from Stakeholders – Feedback Incorporated*).

In connection with the second workshop in April 2021, an online questionnaire was shared with the survey co-organizers and the research registries to ask them for some feedback regarding their collaboration with Lifebrain. The questionnaire was anonymous and included nine questions and space for free text. The questionnaire took 5-10 minutes to complete (**Annex 5**). Seven completed questionnaires were collected. Answers provided by the respondents are summarized/synthesized to ensure anonymity and extract main points.

1. Why did your organization agree to be an official co-organizer of the Global Brain Health Survey?

Reasons provided included:

- This is an interesting and important survey, and its scope is within our field of interest
- The survey has theoretical and practical implications, and could have a positive effect on wellbeing and quality of life
- The survey provided a way to involve our volunteers in a multinational study

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- The outcomes of the survey are very relevant for our activities, especially regarding education about brain health. Together we can reach more participants for the survey.

2. How will the results of the survey be useful for your organization?

- The results will be used in our communication and in planning information campaigns about brain health towards the public and in lobbying towards politicians and policymakers
- The results will be shared with the respondents in our network to thank them for their time and effort, to give them interesting new information on brain health and to give them extra motivation to participate in future research
- The outcomes of the survey will help us to understand better the views of our target audience regarding brain health and (if necessary) adjust our message accordingly

3. What is your experience with participating as a survey co-organiser in Lifebrain?

- Good/very good experience and good communication, easy to collaborate
- Great to have participated in a follow-up meeting about the results
- Perfect collaboration and good contacts, prompt response if we had any questions

4. What activities would you like to conduct with Lifebrain in the remaining timeframe of the project (the project will end in June 2022)?

- Participate in the final discussion of the survey results and share results in our networks
- Co-organize meetings for the public about the survey results
- Contact with professionals in neuroscience and brain research
- Joint publications reporting on survey results
- Conduct further research to explore the impact of the pandemic has on attitudes to research

5. Do you have suggestions for ways to improve collaboration between your organization and research projects like Lifebrain?

- Make scientific papers available on the Lifebrain website
- Involve stakeholders in future projects like Lifebrain
- Ensure that research projects receive national ethical approvals as it may be a requirement for the stakeholders to join the research

6. What types of activities would you like to conduct in the future with research projects like Lifebrain?

- Be a partner in a European project meaning with a budget
- Use survey results in our communication
- Joint research, presentations, conferences, joint publications
- Raise awareness about the project to increase the number of participants and help with dissemination of the results

7. In your opinion, which factors could hinder your participation in similar projects in the future?

- Lack of budget/limited resources in our organization/time constraints
- Difficulties to find partner universities
- The need for the project to have a study site nationally due to research regulation
- Not sharing updates; bad communication
- The project themes need to be relevant for our strategy (for instance, future focus on specific brain diseases vs more general brain health)

8. In your opinion, which factors could facilitate your participation in similar projects in the future?

- Available budgets
- Information or surveys that are easy to share in newsletter, on our website, in social media etc.
- Having one person to contact
- Interesting topic for research
- Our desire and willingness to be flexible to help with similar projects
- Enthusiastic researchers that are willing to communicate with participants before, during and after participation besides their actual research
- The most important factor is whether it's beneficial for all parties. If the project fits very well with our strategy and we benefit from the results, and if it's not a big investment in terms of time, we are most likely to join the project

9. Any further comments/ suggestions/ experiences you would like to share with us?

- If you are going to apply for any project, please inform us, and we would be happy to contribute to the application and research activities
- This has been a useful project for us, and we are pleased so many of our contacts were able to take part
- Compliments for making this interesting project a success!

2.2 Internal evaluation by Lifebrain researchers

2.2.1 Internal workshop

In November 2019, a workshop was organized by WP1 to discuss and map first experiences from stakeholder engagement in the project. The workshop was organized in connection with the Lifebrain conference in Berlin and gathered WP1 members from all project partners.

A preliminary mapping of stakeholder activities and experiences was conducted using the structure of a publicly available conceptual framework developed by Ray and Miller that provides researchers with a structure to plan, evaluate and report stakeholder engagement [3]. Discussions at the workshop









served as a basis for drafting a scientific paper reporting on the project’s experiences of stakeholder engagement, and recommendations for future projects.

2.2.2 Survey with Lifebrain researchers

In July 2021, an anonymous online questionnaire was sent to the Lifebrainers to ask them about their views and experiences on stakeholder engagement in Lifebrain. The questionnaire included eight questions (**Annex 6**) and took 5-10 minutes to complete. The responses would/will be used to inform the development of recommendations for stakeholder engagement in future research projects to be provided in a scientific paper. The survey closed in August 2021. In total, responses from 18 Lifebrainers were collected.

1. Which Lifebrain stakeholder engagement activities have you participated in?

The survey had an introductory question, asking the respondents to report on which Lifebrain stakeholder engagement activities they had participated in. The answers were as follows:

Activities	No	%
Setting up a list of stakeholders	8	44,4 % 
Planning and implementation of the interview study (See paper in The Gerontologist)	4	22,2 % 
Development and dissemination of the Global Brain Health Survey	13	72,2 % 
Stakeholder workshops	10	55,6 % 
Public lectures/webinars	8	44,4 % 
Conference in Berlin	7	38,9 % 
Other stakeholder engagement activities (for e.g. local Science Festivals)	6	33,3 % 
None	2	11,1 % 

Most respondents (72.2%) had contributed to developing and disseminating the GBHS. 55.6% participated in the stakeholder workshops and 44.4% participated in the public lectures/webinars and helped identify relevant stakeholders for the project. Answers provided by the respondents are summarized/synthesized to ensure anonymity and extract main points.

2. What was your initial expectation of stakeholder engagement in Lifebrain, if any?

Expectations of Lifebrain regarding SE.

Initially, the Lifebrain researchers did not have many expectations to stakeholder engagement activities and were in most cases indifferent to the potential value of engagement. This was partly because, as mentioned by one respondent, *“Lifebrain is very much a basic science endeavour.”* Another explained that stakeholder engagement is *“something most projects find difficult to implement in practice.”*

Most common points of initial expectations for engagement were linked to more passive, one-way activities such as promoting research results, increasing visibility of the project, and getting insights in

views and priorities of policymakers, patient organisations and the general public. Only very few researchers discussed the *“possibility of taking these into account”/learning about what we could focus more on in research/research communication.*”

If the researchers had expectations, these were related to:

- Engagement contributing to promote brain research (foster interest in research on lifespan cognitive development)
- Making Lifebrain known to other institutions and help us disseminate results and the Global Brain Health Survey
- Hoping that it would be a positive experience, that the researcher can learn and benefit from in his/her future career
- A mean to get insight in views from policymaking and patient perspective
- One respondent stated that stakeholder engagement *“turned out to be much better than expected due to good teamwork”*

3. What is your actual experience with stakeholder engagement in Lifebrain? What do you think about stakeholder engagement in Lifebrain?

Overall, the respondents reported that their experience was positive, *“surprisingly good,” “exciting and energizing”* and that engagement seems to have been done *“very professionally.”* The researchers` commitment to meaningfully engage with stakeholders has grown as the research process was unfolding and as researchers experienced the benefits of such a process when *“establishing a new, strong collaborative network”, “data acquisition” and “production of papers.”* The actual experience with engagement activities seems to have broadened the initial horizon of basic scientists regarding engagement.

Most researchers were engaged in activities related to the design, dissemination, and analysis of the Global Brain Health Survey. It seems that this engaged most researchers, because it delivered the best promise of new scientific knowledge production and at the same time opened for actual engagement in the project (*“timely initiative that opened a window to more directly engage stakeholders/policymakers”*). However, some respondents reported limited participation in the stakeholder engagement or limited activity.

Opinions about stakeholder engagement in Lifebrain include:

- Useful to hear people's views on what matters
- Useful when making specific demands; like asking for the stakeholders` opinion on research questions

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- Engagement is relevant (Engagement activities matched the basic science nature of Lifebrain, the GBHS was a timely initiative that opened a window to engage stakeholders/ policymakers more directly, valuable addition to the consortium activities)
- Challenging to maintain relationship with stakeholders in the long run (stakeholders change position, difficult to get continuity in some cases)
- Difficult to pursue engagement if no constant feedback is provided

One researcher reported having limited awareness of engagement activities in the project.

4. In your opinion, are there any benefits of engaging stakeholders in Lifebrain?

11 out of 14 respondents identified benefits of engaging stakeholders. Major benefits are related to gaining field relevance for research: understanding the value of the research beyond the academic setting and the *“context of research on human development.”* Beyond the production of papers, establishing new networks and spreading the word about research results were considered as important benefits as well. Gaining insights into stakeholder views and the possibility of taking these into account in research were of concern to several researchers.

Benefits identified include:

- Useful tool to disseminate our research (*“It spreads the word of what we do and find; it is a field-relevant flavor that researchers often lack”, “it helps for information/ education”, “dissemination of knowledge to a broader public”*)
- Provides the project with increased visibility and awareness (*“it can enhance publicity of the project to the public and decision-makers”*).
- Provides increased awareness of research processes
- Provides insights into stakeholder views and possibility to take these into account (*“We as scientists get a feeling for what is important to people”; “we get interesting views from people on what matters for brain health, with some discrepancies regarding my own/ what our research tells us”*)
- Provides inputs from stakeholders/inputs on specific questions (*“good suggestions for important questions in daily life”; “what we could focus more on in research and research communication”*).
- Helps building network (by establishing a new/strong(collaborative) network)
- Useful to think about the larger context of research on human development

One respondent acknowledged that there are, in principle, benefits of engagement but stated that *“translation of research activity outcomes to stakeholder advice seems premature.”* Another respondent noted that benefits are *“difficult to measure”* and that *“a more intense stakeholder strategy would have allowed to better assess the impact”*.

5. In your opinion, what are the barriers/limitations of engaging stakeholders in Lifebrain?

The basic science nature of Lifebrain was considered initially one of the main hindrances for engagement activities, namely the prematurity of any engagement possibilities. Especially the

translation of research outcomes to stakeholder advice in the form of *“valuable recommendations”* and *“tangible and helpful feedback to clinicians”* has been found *“premature”* by many. Many Lifebrain cohorts include healthy subjects, and the core research activities in Lifebrain are not related to specific brain diseases. Some of the respondents felt that this has created a major barrier for selecting and targeting specific stakeholders.

Another challenge lies apparently in the difficulty of communication between scientists and lay people/society, more specifically the lack of common language: some researchers expressed their concerns that the questions we discussed required a certain scientific background. Establishing a common ground for the most important notions has been a key, such as in our case the common understanding of *“brain health,” “risk”* or *“personalized medicine.”*

Barriers identified included:

- The Covid-19 pandemic, that made science and outreach more difficult
- Language and concepts
- Expectations and priorities of researchers/stakeholders
- Lack of time (*“If stakeholder engagement leaves little time for conducting research, it is a threat”; “participating in activities that are time-consuming is probably difficult”*)
- Difficulty to translate research findings into lay language for dissemination (*“making our work understandable and relevant”; “to convey to them specific messages that have a clear impact”*)
- Distance between science and society and lack of scientific background to understand questions we are asking
- Difficulty to select relevant stakeholders (*“target stakeholder group could be potentially many”; “broad scope of the project is a challenge”*)
- Nature of project as a basic science project
- Difficulty to maintain relationships over time (motivation, time, and person availability; *“stakeholders are not always institutions, but people representing these institutions, and people change”*)

6. Do you have ideas/suggestions for improving stakeholder engagement in Lifebrain?

Suggestions included:

- Establish several stakeholder contacts with one institution
- Dedicate project staff to maintain regular contact with stakeholders
- Be clear about what stakeholder engagement entails
- Dissemination (*“forcing each publication to go through the press release process”*)
- Target specific groups of stakeholders (e.g. developmental research and research with children)
- Allocate budget for stakeholder engagement (i.e., the Lifebrain application budgeted for personnel with 57,5 person months in total dedicated to this aspect)
- Engage stakeholders from an early start and throughout project duration
- Ally with stakeholders to collect data

7. Do you have any new ideas for specific stakeholder engagement activities in Lifebrain?

Ideas included:

- Organize stakeholder events (e.g., seminars, workshops, flyer distribution etc)
- Invite stakeholders to open meetings and provide summary reports
- Use new dissemination channels (e.g. Lifebrain in natural science museums, TV, and newspapers)
- Target specific groups of stakeholders (e.g., groups that are under-represented in research)

8. What would motivate you to engage in future stakeholder engagement activities in other research projects?

Suggestions included:

- Having results that are worth communicating
- Conduct research clearly focused on e.g. a specific disease
- Greater ability to interact with locally relevant stakeholders (e.g. clinicians, policymakers)
- Funding
- Organization of conferences
- Relevance of engagement for the project (“scope must be meaningful with respect to the aims and objectives and nature of the research project”)
- Engaging with “hard to reach” groups i.e., the people that need it the most (“outside the standard highly motivated and educated people that always find their way into research, and already can find the information and help they need”), or talking to people who have practice-based experience with these groups
- Training in engagement (e.g. support to participate in engagement)
- Clarity regarding what involvement implies/expected and real impact and more details provided about what this involves/benefits (e.g., “understandable information about what my efforts - and the other participants - had contributed”)

One respondent reported that nothing would motivate him/her to engage with stakeholders.

3. Next steps

The Lifebrain experiences with stakeholder engagement are currently being summarized in a scientific paper that will be submitted to PLOS ONE in November/December 2021. Main recommendations made by Lifebrain for the conduct of stakeholder engagement in future research projects will be provided in the paper and are therefore not described here.

4. References

- [1] 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.
- [2] 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, Zasiokina 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
- [3] Ray KN, Miller E. Strengthening stakeholder-engaged research and research on stakeholder engagement. *J Comp Eff Res*. 2017;6(4):375-89. doi:10.2217/cer-2016-0096.

Annex 1. Overview of WP1 stakeholder activities, stakeholders reached, and evaluation forms collected (also in D1.4)

Activities	Co-organizing stakeholder(s)	Stakeholders reached	No evaluation forms collected
<i>Stakeholder workshops</i>			
Pilot stakeholder workshop (Spain, 2017)		24	9
Stakeholder workshop (Norway, 2018)	Norwegian Brain Council	44	10
Workshop with Global Brain Health survey co-organizers (online, 2020)		10	N/A
Workshop with Global Brain Health survey co-organizers (online, 2021)		17	N/A
<i>Public lectures/webinars</i>			
“Your brain is your life” (Spain, 2017)		50	N/A
“Take care of your brain!” (Norway, 2018)	Norwegian Brain Council	200	N/A
“Healthy ageing” (United Kingdom, 2019)	University of Cambridge	70	N/A
“Good brain health is important!” (Norway, 2019)	Norwegian Brain Council	200	N/A
Webinar on brain health (online, 2020)	Norwegian Brain Council	74	36
“How are brain health and lifestyle related? (Oslo, September 2021)	Norwegian Brain Council	250	N/A
<i>Conference</i>			
“Brain Health across the lifespan” (Germany 2019)	Silver Santé Study, German Brain Council	144	49
<i>WP1 research</i>			
Interview study (UK, Norway, Spain, Germany, 2018)		44	N/A
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	N/A
Total no of stakeholders reached		28,713	104

In addition, it is estimated that about 80,500 individual stakeholders were reached through the Lifebrain website, social media, and presence in the news.

Annex 2. Evaluation form Barcelona workshop (2017)



"Life Brain: Healthy minds from 0-100 years: Optimizing the use of European brain imaging cohorts"

LIFEBRAIN Stakeholder workshop

Evaluation form

Name: _____

Institution: _____

1. How would you like to interact with Lifebrain?

(1) Research - I/my institution may:

- Collaborate with Lifebrain to outline the research questions for the Lifebrain study
- Discuss with Lifebrain how to best use the research results from Lifebrain

Other: _____

(2) Dissemination - I/my institution may:

- Inform about Lifebrain in my network (friends and colleagues, via web site, talks at conferences, etc)
- Help recruit participants in the Lifebrain study
- Help identify organizations Lifebrain should collaborate with
- Collaborate with Lifebrain on the organization of stakeholder workshops/webinars
- Collaborate with Lifebrain to disseminate information about Lifebrain progress and results

Other: _____

(3) Advisory role - I/my institution may:

- Discuss with Lifebrain brain health policies in my country
- Help evaluate the stakeholder engagement in Lifebrain

Other: _____



WEBSITE: www.lifebrain.uio.no
FACEBOOK: facebook.com/lifebrain.h2020



Annex 3. Evaluation form Oslo workshop (2018)



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

Name:

Institution:

How strongly do you agree with the following statements?

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
The duration of the workshop was appropriate					
The discussions and questions were interesting					
I gained a good overview of challenges and opportunities in the field of brain health					
I gained a good overview of the Lifebrain project					
It was useful for me to participate at the workshop					
I am interesting in participating in Lifebrain activities in the future					
I would like to know more about the Norwegian Brain Council (Hjernerådet)					

Annex 4. Evaluation form Berlin conference (2019)

Name:

Job title/occupation:

Company/institution:

Address:

Email address:

You may remain anonymous if preferred.

1. How would you rate the organisation of today's free public conference, e.g. attendee information, catering, facilities, etc.? 1-5

Would you like to comment on your rating:

2. How would you rate your own overall experience at today's free public conference? 1-5

Would you like to comment on your rating:

3. Did the conference meet your expectations?

YES/NO. If yes, how? If no, why not?

4. Did you attend the whole day?

YES/NO. If NO which sessions did you attend – please tick list below

5. Which session did you find most useful for you? Why?

6. Which session did you find least useful for you? Why?

7. As a result of attending today's conference, how would you rate your understanding of :

- a. The Silver Santé Study – 1-5
- b. Lifebrain – 1-5
- c. German Brain Council – 1-5

8. Do you have any suggestions on how the event or content could have been improved?

9. Would you be interested in attending a future event on brain health organised by these projects/organisations?

10. Would you like to receive regular news via e-newsletter from?...

- a. The Silver Santé Study – Yes/No
- b. Lifebrain – Yes/No
- c. German Brain Council – Yes/No

Annex 5. Global Brain Health Survey - Feedback from co-organisers

Dear Lifebrain survey co-organizer,

This questionnaire is for you to give us some feedback regarding your collaboration with Lifebrain. It includes nine questions, and you are free to provide as much feedback as suits you. It should not take more than 5-10 minutes to complete. The answers will be handled anonymously to evaluate our work. All questions marked with a * require text answer.

Thank you for your time and thank you for your cooperation so far!

- 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-organiser 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 6. Survey among Lifebrain researchers on stakeholder engagement

1. Which Lifebrain stakeholder engagement activities have you participated in? Select any from the following list. You must select at least one option.

- Setting up a list of stakeholders
- Planning and implementation of the interview study (See paper in The Gerontologist)
- Development and dissemination of the Global Brain Health Survey
- Stakeholder workshops
- Public lectures/webinars
- Conference in Berlin
- Other stakeholder engagement activities (for e.g. local Science Festivals)
- None

2. What was your initial expectation of stakeholder engagement in Lifebrain, if any?

3. What is your actual experience with stakeholder engagement in Lifebrain? What do you think about stakeholder engagement in Lifebrain?

4. In your opinion, are there any benefits of engaging stakeholders in Lifebrain?

5. In your opinion, what are the barriers/limitations of engaging stakeholders in Lifebrain?

6. Do you have ideas/suggestions for improving stakeholder engagement in Lifebrain?

7. Do you have any new ideas for specific stakeholder engagement activities in Lifebrain?

8. What would motivate you to engage in future stakeholder engagement activities in other research projects?