



Lifebrain

D1.1. List of relevant stakeholders for project engagement

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Contributors to deliverable:	Name	Organisation	Role / Title
Deliverable Leader	Gun Peggy Knudsen/ Isabelle Budin Ljøsne	NIPH	WP1 leader
Contributing Author(s)	William Baarè	REGIONH	
	Lars Bertram	UzL	
	Sandra Düzel	MPIB	
	Brenda Penninx	VUmc	
	Ole Jørgen Røgeberg	Frisch	
	Christian Drevon	Vitas	
	Anders Martin Fjell	UiO	
	René Westerhausen	UiO	
	Barbara B. Friedman	UiO	
	David Bartrès-Faz	UB	
	Mikael Stiernstedt	UmU	
	Paolo Ghisletta	UNIGE	
	Sezen Cekic	UNIGE	
	Klaus Ebmeier	UOXF	
	Rik Henson	UCAM	
	Lorraine Tyler	UCAM	
	Rogier Kievit	UCAM	
Reviewer(s)	Kristine B. Walhovd	UiO	Coordinator
	Christian Drevon	UiO	WP5 leader
Final review and approval	Barbara B. Friedman	UiO	Administrative coordinator

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Executive Summary

A list of relevant stakeholders for project engagement has been identified in 5 stakeholder groups in all participating countries:

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

4 potential levels of engagement identified in the literature were discussed:

- Inform – Regular information about the project is provided to stakeholders (e.g. website, newsletter, social media, webinars, public talks)
- Consult – Stakeholders are consulted on different matters throughout the project (e.g. interviews, questionnaires, surveys, focus groups)
- Involve – Stakeholders might be fully engaged in the project and provide resources and data (e.g. stakeholder fora, workshops)
- Collaborate – Stakeholders might be effective partners in the research team and influence research directions (e.g. steering groups)

Stakeholder engagement strategies, activities and methods will be described in D 1.2. Input to the Dissemination, Exploitation and Communication plan (Month 12). To the extent possible, activities will be coordinated with WP5.



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List of acronyms/ abbreviations used in this document

Lifebrain	Healthy minds from 0-100 years: Optimising the use of European brain imaging cohorts
WP	Work Package
UiO	University of Oslo
UmU	Umeå Universitet
UOXF	University of Oxford
MPIB	Max Plank Institute for Human Development
UB	Universitat de Barcelona
REGIONH	Region Hovedstaden
MRC	Medical Research Council
VUmc	University Medical Center Amsterdam
UCAM	University of Cambridge
NIPH	Norwegian Institute of Public Health
UNIGE	University of Geneva
Frisch	Frisch Centre
Vitas	Vitas Ltd.
UzL	University of Lübeck

1. Introduction

Description of Task 1.1

Identify and invite research participant groups, patient groups, clinicians and policy makers that will have an interest in the project and that should be taken into consideration.

Lead: NIPH; Participants: All (M1-2)

NIPH will work with all project partners to invite relevant stakeholder groups who have to be considered as part of a stakeholder engagement strategy for the project. The establishment of a number of 'web-based' workshops (M1-2) will determine stakeholders across nations, institutions, cohorts and patient groups and also include the role of patient groups, clinicians, policy makers, research institutions, SME/Industry etc. With a comprehensive list determined a second focus will be on determining the 'different levels' of engagement required from identified stakeholder groups. The collection, management and sharing of data in the project requires an ethical framework and handling of data privacy issues. Themes of particular importance to discuss with stakeholders to ensure trust and implementation of results into policies and health behavior recommendations are participant/patient consents, data security measures, handling of incidental findings, feedback of results to research participants and patients.

Collaboration among partners

Each partner contributed to draft the list of stakeholders. Two teleconference sessions were organized (24th January, 2017 and 31st January, 2017) to discuss which stakeholders are important to LIFE BRAIN and for which stakeholders LIFE BRAIN may be important. The draft list of stakeholders was distributed several times by email among partners involved in the work package, and made available on OneDrive for inputs.

2. Discussion

5 categories of main stakeholders were identified:

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

The method used to identify specific stakeholders was to ask the partners in WP1 to recommend stakeholders they already collaborated with, or thought would be of interest to engage. Stakeholders should be working within (or have an interest in) areas such as brain health, cognition, mental health (e.g. Alzheimer, dementia, depression). The partners were asked to identify specific stakeholders nationally and internationally. Some of the stakeholders listed already are collaborating with the LIFE BRAIN partners, whereas others will have to be contacted.

The partners in WP1 also discussed potential ways to engage stakeholders. 4 potential levels of engagement, and corresponding methods identified in the literature were discussed:

- INFORM – Regular information is provided about the project to stakeholders (e.g. website, newsletter, social media, webinars, public talks)
- CONSULT – Stakeholders are consulted on specific matters throughout the project (e.g. Interviews, questionnaires, surveys, focus groups)
- INVOLVE – Stakeholders might be fully engaged in the project and provide resources and data (e.g. stakeholder fora, workshops)
- COLLABORATE – Stakeholders might be effective partners in the research team and drive research directions (e.g. steering groups)

3. Conclusion

How the different stakeholders will be engaged in LIFE BRAIN, and which methods to use for engagement, depends on several factors:

- Feasibility - communicating with specific stakeholders (e.g. some cohorts) requires taking into consideration the existence and use (or lack of) current communication channels.
- Specific objectives for each engagement activity
- Resources available in the different countries
- The level of interest and availability of the stakeholders

Some of the stakeholders identified already have regular contact with researchers in the LIFE BRAIN team. Others may be contacted by means of telephone, email or invitation to join LIFE BRAIN events. A specific strategy will be developed to contact research participants in the cohorts depending on local circumstances.

Stakeholder engagement strategies, activities and methods will be described in D 1.2. Input to the Dissemination, Exploitation and Communication plan (Month 12). To the extent possible, activities will be coordinated with WP5.

4. Appendix-List of stakeholders

5 main categories of LIFE BRAIN stakeholders

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

4 potential levels of engagement

- INFORM – Regular information about the project is provided to stakeholders (e.g. website, newsletter, social media, webinars, public talks)
- CONSULT – Stakeholders are consulted on different matters throughout the project (e.g. interviews, questionnaires, surveys, focus groups)
- INVOLVE – Stakeholders might be fully engaged in the project and provide resources and data (e.g. stakeholder fora, workshops)
- COLLABORATE – Stakeholders might be effective partners in the research team and influence research directions (e.g. steering groups)

Source: BiodivERSA Stakeholder Engagement Handbook

OBS! This list is a living document and will be regularly updated depending on the needs of the project and the types of activities conducted.

Research participants in the cohorts (INFORM/CONSULT)			
Stakeholder	Contact person	Country	Comments
Barcelona Spain UB	David Bartrès-Faz	Spain	<p>Current tools for communication/engagement:</p> <ul style="list-style-type: none"> Cohorts involved in Lifebrain in Barcelona are in general not being followed-up, but we are actually following a small number of participants (i.e. 30-50) that we could try to engage in focus groups. These are people mostly interested in prevention and lifestyles engagement. <p>Potential engagement methods: Focus groups</p>
BASE II	Sandra Düzel	Germany	<p>Current tools for communication/engagement:</p> <ul style="list-style-type: none"> BASE-II newsletter biannually summarizing very broadly results from the different projects to avoid intervention effect Website BASE-II (https://www.base2.mpg.de/en) including all news and links to published papers and media coverage related to all projects We have an internal Call-Center for direct contact with participants We send out Christmas Cards to all BASE-II participants since 5 years <p>Potential engagement methods:</p> <ul style="list-style-type: none"> Socio-Economic-Panel Germany (annual survey of the German Institute of Economic Research) Assessments & short surveys are possible as well as contact-updates via phone (call-center) Within a new intervention-study that is running now (ENERGI), around 80 BASE-II participants are included and evenly distributed in 4 different intervention groups (language, exercise, combined and active control), a comprehensive MR-protocol, cognitive tests, blood samples are assessed at 3 timepoints – Additionally, all participants are equipped with a tablet on which we regularly push small surveys. Additionally, we will plan a colloquium including all participants of this intervention study (n=160) A subsample of 400 participants are part of the MR- longitudinal study (2 timepoints are assessed)

BASE-I MPIB, Uzi	Sandra Düzel	Germany	<p>Current tools for communication/engagement:</p> <ul style="list-style-type: none"> Website BASE: https://www.base-berlin.mpg.de/en including links to Book releases, media coverages, contact details etc. <p>Potential engagement methods:</p> <ul style="list-style-type: none"> All BASE participants are deceased within the past years
Betula	Mikael Stiernstedt	Sweden	<p>Current tools for communication/engagement:</p> <ul style="list-style-type: none"> The main Betula-project is finished, so there is no general communications with the participants at this time. For the ongoing data-collection for the MR-sample, the main communications has been done through mail and telephone.
Cobra	Mikael Stiernstedt	Sweden	<p>Current tools for communication/engagement:</p> <p>Communication with participants has been done through mail and telephone.</p>
LCBC	Barbara B. Friedman	Norway	<p>Current tools for communication/engagement:</p> <ul style="list-style-type: none"> Our participants are distributed across four different sub-project, with partly their own lives. We have previously sent out newsletter informing about some results from the project, but not often, or at very regular intervals We have a website where we post news and all published papers (www.oslobrains.no), and also link to some media coverage related to our group and the various projects Most participants are part of longitudinal studies, so we have regular contact regarding their participation In one of the projects which is a memory training intervention study, participants meet at our lab once a week for 8 weeks X 2 periods for quite close interaction The projects have facebook pages which are used for recruiting mostly <p>Potential engagement methods:</p> <ul style="list-style-type: none"> It will be possible to conduct brief surveys when the participants are coming in for new tests (maybe 300 a year). Most interesting would maybe be questions related to their motivation for participation, how they feel about their participation, whether they think that contributing to research is useful for them and/ or for the society, and what is their perception on the relation between the choices of lifestyle and its impact on their cognitive/ mental functions. Some for e.g. do fitness exercises, because they perceive that it can help to prevent aging disorders. Generally participants are highly motivated to contribute and learn

			<p>more about research results, research tools (for e.g. what is a blood test good for) and various prevention tools.</p> <ul style="list-style-type: none"> • In the neurocognitive plasticity (NCP) project the research participants are interested in memory training. As soon as new research results are available, a group discussion is planned on explaining research results to the participants in an understandable way. • In another project (not part of cohort, just interesting for stakeholder engagement) related to research on cognitive function changes in stroke patients, the experience was that participants wanted to learn more about cognitive function changes and what they could do to counteract changes. • We have email addresses of participants. Usually participants are asked if they would allow to be contacted in the future. Such a re-contacting would be best done together with "data enrichment" when the participants are re-contacted anyway, or together with ongoing data collection. Otherwise one might overload the goodwill of the participants.
Whitehall II UOXF	Klaus Ebmeier	UK	<p>Current tools for communication/engagement:</p> <ul style="list-style-type: none"> • Nothing apart from group website • Whitehall newsletter (30th anniversary meeting on November 2016)
Cam-CAN	Rik Henson/Lorraine Tyler	UK	<p>Current tools for communication/engagement:</p> <ul style="list-style-type: none"> • We used to send regular newsletters, which can be found here: http://www.cam-can.org/index.php?content=newsletter <p>Potential engagement methods (e.g.: survey, newsletter, focus groups, open meetings):</p> <ul style="list-style-type: none"> • The last newsletter was in 2015, when our major funding finished. We hope that Lifebrain will provide an opportunity to send more newsletters. • We should conduct new engagements, but would need REC amendment (which we plan to do anyway for Lifebrain "enrichment").
CALM	Rik Henson/Lorraine Tyler	UK	<p>Current tools for communication/engagement:</p> <ul style="list-style-type: none"> • Annual CALM workshop for all involved referrers/practitioners (e.g. speech and language therapists) • The schools are only tangentially involved if the referrer happens to include them on the report, but not consistently <p>Potential engagement methods:</p> <ul style="list-style-type: none"> • Working on first newsletter. Current CALM ethics don't (yet) include anything about interactive recontacting, but it could be incorporated perhaps

			<ul style="list-style-type: none"> For CALM, we organize an annual CALM workshop for all involved referrers/practitioners (e.g. speech and language therapists)
HUBU	William Baarè	Denmark	<p>Current tools for communication/engagement:</p> <ul style="list-style-type: none"> Info meeting (at study start), Newsletters, Email <p>Potential engagement methods:</p> <ul style="list-style-type: none"> Participants are not planned to be reassessed, except for Lifebrain online enrichment
LISA	William Baarè	Denmark	<p>Current tools for communication/engagement:</p> <ul style="list-style-type: none"> Email and newsletter <p>LISA is an randomized clinical trial (RCT) intervention study: The 2 training groups have their 3 times training a week, whereas the control group participate in many non-exercise activities and thus meet for lectures, playing cards, and book reading in smaller groups.</p> <p>Potential engagement methods: Given it is a RCT intervention study, additional engagement is not deemed feasible.</p>
NESDA	Laura Nawijn	Netherlands	<p>Current tools for communication/engagement:</p> <ul style="list-style-type: none"> NESDA website (http://www.nesda.nl) for researchers and participants. Annual NESDA newsletter to participants, and also 1 for researchers. Link to depression patient society (Brenda Penninx is member of scientific advisory board), outreach activities (e.g. presentations at scientific and community/patient group meetings), annual meeting for all NESDA researchers. <p>Potential engagement methods:</p> <ul style="list-style-type: none"> Newsletter/website

Patient groups/organizations (INFORM/CONSULT/INVOLVE)	
Stakeholder	Country
Hjernerådet http://www.hjerneradet.no/	Norway
Folkehelseforeningen Norwegian Public Health Organisation http://folkehelseforeningen.no/	Norway
Prematurforeningen http://www.Prematurforeningen.no	Norway
Norges Parkinsonforbund http://www.parkinson.no/	Norway
Nasjonalforeningen for folkehelsen- The National Health Association (for dementia) http://nasjonalforeningen.no/	Norway
Stiftelsen Bergensklinikkene (Helping addicts) http://bergensklinikkene.no/	Norway
Rådet for psykisk helse http://www.psykiskhelse.no/	Norway
Alzheimer's UK http://www.alzheimers.org.uk	UK
University of the Third Age (U3A) http://www.u3a.org.uk	UK
Alzheimer Research UK (ARUK) http://www.alzheimersresearchuk.org/	UK
Dementia Platform UK (DPUK) http://www.dementiasplatform.uk/	UK
Parkinsons' UK https://www.parkinsons.org.uk/	UK
ATB - Association of people with bipolar disorder or depression http://www.association-atb.org	Switzerland
Pro Mente Sana - Association of people with psychic disorders http://www.promentesana.org	Switzerland
Alliance contre la depression – Association of patients with depression http://www.alliancedepression.ch	Switzerland
Association Alzheimer Suisse Genève – Association of people with Alzheimer disease http://www.alz-ge.ch/	Switzerland
Svenska hjärnfonden http://www.hjarnfonden.se	Sweden
Alzheimersfonden http://www.alzheimerfonden.se/	Sweden
Parkinsonsfonden http://www.parkinsonfonden.se/	Sweden
Alzheimerforeningen http://www.alzheimer.dk/	Denmark
Depressionsforeningen http://depressionsforeningen.dk/	Denmark
Parkinsonforeningen http://www.parkinson.dk/	Denmark
Depressievereniging http://www.depressievereniging.nl/	Netherlands
Hersenstichting https://www.hersenstichting.nl/	Netherlands
Angst- dwang en fobie stichting http://adfstichting.nl/	Netherlands

Fonds psychische gezondheid http://www.psychischegezondheid.nl/	Netherlands
AFAB – Associació de Familiars de malalts d'Alzheimer de Barcelona http://www.afab-bcn.org/	Spain
Fundació Alzheimer Catalunya http://alzheimercatalunya.org/	Spain
Confereracion española de Alzheimer http://www.ceafa.es/	Spain
Mesclerosis Multiple España http://www.esclerosismultiple.com	Spain
Fundació Salut i Envelliment UAB (Fundación Salud y Envejecimiento de la Universidad Autónoma de Barcelona) http://salut-envelliment.uab.cat/en/	Spain
Federación Española de Párkinson http://www.fedesparkinson.org/	Spain
Freno al Ictus http://www.frenoalictus.org	Spain
European Headache Alliance http://www.europeanheadachealliance.org/	Europe
ENUSP - European Network of (ex)Users and Survivors of Psychiatry http://enusp.org/	Europe
EPDA - European Parkinson's Disease Association http://www.epda.eu.com/en/#	Europe
EUFAMI - European Federation of Associations of Families of People with Mental Illness http://www.eufami.org/	Europe
GAMIAN Europe - Global Alliance of Mental Illness Advocacy Networks http://www.gamian.eu/	Europe
MHE-SME - Mental Health Europe http://www.mhe-sme.org/	Europe
Alzheimer Europe http://www.alzheimer-europe.org/	Europe
AHDH Europe http://www.adhdeurope.eu/home.html	Europe
The European Depression Association http://eddas.eu/	Europe
European Federation of Neurological Associations (EFNA) http://efna.net/	Europe
International Psychogeriatric Association (IPA) https://www.ipa-online.org/	International

National organizations can also be identified by using the members' lists of European umbrella organizations. These lists are available on their web pages.

Policymakers (INFORM/CONSULT/INVOLVE)	
Stakeholder	Country
Helsedirektoratet (Ministry of Health) https://helsedirektoratet.no/English	Norway
Norwegian Academy of Science and Letters (Det Norske Videnskaps-Akademiet) http://english.dnva.no/	Norway
Medical Research Council http://www.mrc.ac.uk	UK
Local MP	UK
UK government Dept of Health https://www.gov.uk/government/policies/dementia	UK
UK BBSRC and MRC research councils	UK
Future of Ageing taskforce https://www.gov.uk/government/collections/future-of-ageing	UK
Catalan Government Department of Health	Spain
Generalitat de Catalunya Canal Salut http://canalsalut.gencat.cat/ca/inici/index.html	Spain
Catalan Agency for the Quality and Sanitary Assessment http://aquas.gencat.cat/en/inici/index.html	Spain
DGS (Direction Générale de la Santé)	Switzerland
Federal Office of Public Health FOPH	Switzerland
The County council in general, - County council (geriatrics) - County council (psychiatry) http://www.vll.se/startside/om-landstinget/organisation-och-verksamheter/tjanstemannaledning http://www.vll.se/startside/om-landstinget/organisation-och-verksamheter/ledning-och-staber	Sweden
Ministry of Health and Social Affairs http://www.government.se/government-of-sweden/ministry-of-health-and-social-affairs/	Sweden
Capital Region of Denmark https://www.regionh.dk/english/Pages/default.aspx	Denmark
Danish Health Authority https://www.sst.dk/en	Denmark
Trimbos institute https://www.trimbos.org/	Netherlands
Federal Ministry of Health https://www.bundesgesundheitsministerium.de/en/en.html	Germany

Clinical and research centers, research networks, research societies (INFORM/CONSULT/INVOLVE)	
Stakeholder	Country
Barne og ungdomspsykiatrisk poliklinikk (BUP, Clinic for children and young with psychiatric problems) http://www.bupbarn.no	Norway
The Guttmann Institute Catalan National Reference Research Hospital for acquired brain damage	Spain
Hospital de la Santa Creu i Sant Pau Neurology service	Spain
Hospital Clinic de Barcelona, Neurology Service	Spain
Barcelona Alzheimer Treatment and Research Centre (ACE) http://www.fundacioace.com/en/	Spain
CELLEX foundation http://cellex-mpq.icfo.eu/about_2/	Spain
La Caixa Foundation https://obrasociallacaixa.org/en/	Spain
Fundació Catalunya-La Pedrera http://www.fundaciocatalunya-lapedrera.com/es/content/proyecto-rems-0	Spain
Sociedad Española de Neurología (SEN) http://www.sen.es/	Spain
Neuroscience of Emotion and Affective Dynamic Lab from University of Geneva http://cms.unige.ch/fapse/neuroemo/ https://medweb4.unige.ch/labnic/	Switzerland
Laboratory for Behavioral Neurology and Imaging of Cognition from University of Geneva	Switzerland
Laboratory for the study of Emotion Elicitation and Expression from University of Geneva http://cms.unige.ch/fapse/EmotionLab/Members/david-sander/index.php	Switzerland
Cognitive Neuroscience Lab from University of Geneva http://cms.unige.ch/fapse/people/bavelier/	Switzerland
Cognitive Aging Laboratory from University of Geneva http://cigev.unige.ch/fr/actu/	Switzerland
Danish Society for Neuroscience http://www.dsfn.dk/	Denmark
Amsterdam Neuroscience https://www.amsterdamresearch.org/web/neuroscience/home.htm	Netherlands
Amsterdam Mental Health https://www.amsterdamresearch.org/web/public-health/research-1/mental-health.htm	Netherlands
Swedish brain power http://www.swedishbrainpower.se	Sweden
British Neuroscience Association (BNA) https://www.bna.org.uk/	UK
Deutsche Gesellschaft für Neurologie http://www.dgn.org/	Germany
European Brain Council https://www.braincouncil.eu/	Europe
Federation of European Neuroscience societies http://www.fens.org/	International

Other stakeholders (INFORM)	
Stakeholder	Country
Kunnskaps og moderniseringsdepartementet	Norway
Bryn Rotary Club (Citizen organization)	Norway
Arbeids- og sosialdepartementet	Norway
Academy of Music/Norsk musikkhøyskole (Citizen organization)	Norway
Society for Psychology/Norsk Psykolog Forening (Citizen organization)	Norway
Blå Kors (Association for helping drug users) http://www.blakors.no	Norway
NAV Neuropsychology Section (Citizen organization)	Norway
NRK Radio, Newslunch, Kveldsåpent	Norway
Tidsskrift for den norske legeforening	Norway
Lifescience Lunch, UiO	Norway
A-magasinet	Norway
DN Magasinet	Norway
Dagbladet, Morgenbladet, Aftenposten, VG.no, Dagsavisen, forskning.no, Apollon	Norway
Virkebladet, Telemarksavisa, Vest Telemarkblad, Avis Nordland	Norway
TV2 God morgen/Det sterkeste kjønn	Norway
Nordre Aker skole	Norway
UK GPs in Cambridge	UK
Speech & Language therapists, referring schools	UK
Tribune de Genève (Newspaper)	Switzerland
Scientific TV show "36.9" broadcasted by a local television station	Switzerland
Forskning och framsteg http://www.fof.se	Sweden
Svenska dagbladet http://www.svd.se	Sweden
Dagens Nyheter http://www.dn.se	Sweden
Queen Sofia Office	Spain
Neuroalianza http://neuroalianza.org/	Spain
Grifols https://www.grifols.com/en/web/international/home	Spain
Esteve https://www.esteve.es/	Spain
NedKAD (Nederlands kenniscentrum angst en depressie) http://nedkad.nl/	The Netherlands
Videnskab.dk	Denmark
Ældresagen http://www.aeldresagen.dk	Denmark
Helse http://www.magasinetilse.dk/	Denmark

All other major newspapers/scientific journals in partner countries also to be considered