

## **ERA-NET NEURON Cofund**

# 'European Research Projects on Ethical, Legal, and Social Aspects (ELSA) of Neuroscience'

# **Joint Transnational Call 2017**

## **Impact Report**

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### **ABBREVIATIONS**

AKA Academy of Finland, Finland

BMBF Federal Ministry of Education and Research, Germany CIHR-INMHA Canadian Institutes of Health Research, Canada

ELSA Ethical, legal and social aspects
ERA-NET European Research Area Network

FNRS Fonds de la Recherche Scientifique, Belgium FRQS Fonds de Recherche du Quebec – Sante

FWF Austrian Science Fund

ISCIII Institute of Health Carlos III, Spain

JTC Joint Transnational Call KPI Key Performance Indicator

NEURON Network of European Funding for Neuroscience Research

M Million

MD Medical Doctor
PhD Doctor of Philosophy
Pl Principle investigator

VIAA State Education Development Agency



### **Executive Summary**

Neuroscientific research has a high societal impact, as the brain in its complexity determines our humanity, our thinking and decisions. To ensure that new developments in neuroscientific research truly serve society, it is important to reflect on and shed light onto ethical, legal and societal aspects (ELSA) of scientific results.

NEURON had realized early that this international and interdisciplinary funding scheme is exceptional in providing regular funding opportunities for ELSA research. Accordingly, NEURON aims at a regular cycle for ELSA calls. This second ELSA call under the umbrella of ERA-NET NEURON delivered important answers within three consortia working in international collaborations.

Using key performance indicators, this report shows that this call successfully contributed in enhancing interdisciplinary cooperation between excellent scientists of various fields of research: The funded consortia were established based on previous, mostly partial, collaborations and showed a high interdisciplinarity of researchers in humanities, social sciences and life sciences. They encompassed more than 47 persons as personnel in only three consortia.

The projects in this call were conducted during the COVID19 pandemic and with that faced unprecedented challenges related to this exceptional situation. Yet, the projects adapted to the situation and were able to reach their aims. The call resulted in numerous publications of results to the scientific community <u>and</u> the general public as well as other relevant stakeholders using a broad range for outreach activities including discursive formats, as highlighted below (see p. 13).

Monitoring of the projects' progress and results is of high importance for NEURON. As part of the final report for each project, researchers were asked to fill out a questionnaire to measure the key performance indicators set by NEURON (table 4). This tool allows to assess and further improve the funding activities to accomplish NEURON's principal aim: to pave the way for translation of research results for the benefit of patients and those around them. The reported analyses provide support for short- and long-term strategic planning for further NEURON's funding activities.

### Introduction

### **ERA-NET NEURON**

Public health is a central priority for individuals and governments globally. Diseases of the brain and nervous system decrease the quality of life of those affected by them, their families and caregivers. Worldwide, the World Health Organisation estimates one billion people suffering from neurological disorders, with disorders of the brain accounting for 1 in 10 deaths. Neuroscientific research yields constant progress regarding our basic understanding of the structure and function of the human brain under healthy and pathological conditions, giving rise to development of diagnostics and treatments.

As the brain in its complexity determines our humanity, our thinking, decisions and (motor) actions, we feel deeply affected by developments that involve its manipulation. Accordingly, it



is of utmost importance to make sure that developments in neuroscientific research are utilized in ways which are of the best possible benefit for our society and the individual. Research on ethical, legal, and social aspects (ELSA) is an interdisciplinary field that addresses various questions related to risks and benefits of life sciences – and in this case neuroscientific methods and findings.

Such developments and societal challenges go beyond borders and cannot be confronted on a national level alone. To join forces and help to use pooled resources in the most meaningful way, the European Commission has initiated European Research Area Networks (ERA-NETs) in several areas of research. ERA-NETs support research that is conducted across countries, allowing research groups to jointly work on specific scientific questions, exchange ideas, and benefit from transnational expertise and resources.

The overarching aim of ERA-NET NEURON is to coordinate research efforts and pan-European funding programmes in the field of disease-related neuroscience, and to support the translation of results from fundamental research into improved prevention, diagnosis, therapy and rehabilitation for the patients, their family and carers. Joint Transnational Calls (JTC) for research proposals are the centrepiece of NEURON's transnational activities. These funding calls aim to push forward research in strategically identified areas by encouraging transnational and cross-disciplinary projects. To this day, NEURON has launched overall 17 annual biomedical calls, covering a variety of topics (see https://www.neuron-eranet.eu/joint-calls/bio-medical/).

Importantly, to address the high societal relevance of neuroscientific research, and the continuously high public interest and ongoing public discourse in this area, a dedicated call scheme for research on ethical, philosophical, legal and socio-cultural aspects related to neuroscientific research was embedded in the ERA-NET NEURON. Since 2015 four calls on "Ethical, Legal, and Social Aspects (ELSA) of Neuroscience" (

Table 1) were launched (see <a href="https://www.neuron-eranet.eu/joint-calls/elsa/">https://www.neuron-eranet.eu/joint-calls/elsa/</a> ).

Year of the call	Topic	Impact Report
2015	ELSA of Neuroscience	<u>completed</u>
2017	ELSA of Neuroscience	current
2020	ELSA of Neuroscience	projects ongoing
2023	ELSA of Neuroscience	projects ongoing

Table 1: Status of ELSA calls implemented within NEURON

# **Joint Transnational Call in 2017** "Research Projects on Ethical, Legal, and Social Aspects (ELSA) of Neuroscience"

Neuroscientific research yields constant progress regarding our basic understanding of the structure and function of the human brain under healthy and pathological conditions. This knowledge is fundamental for the development of new diagnostics and treatments for patients suffering from neurological or psychiatric diseases. At the same time, the neurosciences have implications for the understanding, and thus potentially also the control, of human decision-



making, behaviour, emotions, and social interactions. Therefore, it is of major importance to investigate the ethical, legal, and social aspects (ELSA) of the neurosciences and their recent advances in regular calls on "ELSA of Neuroscience" under the NEURON framework. This funding scheme aims to help ensuring that neuroscientific methods and findings are utilized in ways which are of the best possible benefit for our society.

This call was intended to provide opportunity for a breadth of research topics (see Annex I). Exemplary scientific topics invited under this call concerned ELSA- issues arising from novel diagnostic methods, neuroenhancement and intelligent technologies like brain-computer interfaces, changes in traditional philosophical questions and concepts, or societal and cultural changes in induced by neuroscientific knowledge and its application, to name a few.

For this ELSA-JTC2017 eight research funding organisations from seven countries (Table 2) joined forces and funding, mobilizing overall 3.5 M€ earmarked budget to support international ELSA research. In this second ELSA call, mandatory consortia size was increased from 2 to 3 to 5 partners from at least three different countries.

Ten eligible proposals were submitted by consortia composed of overall 39 principle investigators (Pl's) leading independent research groups, which were eligible for the participating funding bodies. This number has been considerably lower compared to the first ELSA-JTC 2015.

Countries	Funding agencies
Austria	Austrian Science Fund (FWF)
Belgium	Fonds de la Recherche Scientifique (FNRS)
Canada	Canadian Institutes of Health Research – Institute of Neurosciences, Mental Health and Addiction (CIHR-INMHA)
Canada	Fonds de Recherche du Quebec – Sante (FRQS)
Finland	Academy of Finland (AKA)
Germany	Federal Ministry of Education and Research (BMBF)
Latvia	State Education Development Agency (VIAA)
Spain	National Institute of Health Carlos III (ISCIII)

Table 2: Funding agencies participating in ELSA- JTC2017

### Peer-Review process

The ten proposals addressed a wide variety of subjects for research e.g. neuroenhancement, criminal law, gambling and addiction, incidental findings in neurological disorders, neurotechnologies and brain-computer interfaces. This variety met the intention of the broad call topic, only limiting ELSA approaches to the neuroscientific context.

The research proposals were evaluated in a single-step procedure by five international peer reviewers from various disciplines. Each proposal was reviewed by a multi-disciplinary set of three expert reviewers with scientific backgrounds concordant with the composition of the given consortium.

Projects were evaluated using the following criteria:

- Relevance of the research question to the aim(s) of the call
- Scientific quality of the proposal (originality, methodology)



- Feasibility of the project (adequacy of project work plan and related risk analysis, budgetary and other resources, time schedule)
- Qualification and expertise of participating institutions and research groups in the field(s) of the proposal
- Quality of collaborative interaction between participating groups, and added value of the network, from both scientific and transnational perspectives, of the research consortium.
- Impact of the expected results on society and future scientific applications.

After detailed discussion in a peer review panel meeting a ranking list determined the best proposals.

### Funded projects

Finally, three proposals including 11 eligible PI's from four countries were selected for funding (Table 3). Two consortia were coordinated in Finland and one in Germany. Topics of research tackled questions surrounding addiction, neurotechnology and bodily augmentations, and autonomy in the context of neuroenhancement. Numerous methods were employed, among others, conceptual ethical and philosophical studies, legal analyses, as well as interview and questionnaire studies of different affected parties and stakeholders.

The funded projects conducted and completed their research between February 2018 and December 2022. While all projects set out with a project duration of 36 months, two consortia extended their runtimes by 1 and 1.5 years, respectively, due to COVID19 restrictions.

Acronym	Project Title	Principal Investigators (Coordinator bold)	Country, Agency
A-BRAIN	Addiction in the Brain: Ethically Sound Im-	Matilda Hellman	Finland, AKA
	plementation in Governance	Patricia Conrod	Canada, FRQS
		Christian Hendershot	Canada, INMHA
		Sarah Forberger	Germany, BMBF
FUTUREBODY	The Future of the Body in the Light of	Christopher Coenen	Germany, BMBF
	Neurotechnology	Gregor Wolbring	Finland, AKA
		Oliver Müller	Germany, BMBF
		Markus Schmidt	Austria, FWF
THERENIA	Therapeutic and Enhancement Uses of	Juha Räikkä	Finland, AKA
	Neuroscientific Knowledge: A Question of Individual Autonomy?	Jennifer Chandler	Canada, INMHA
	,	Kai Vogeley	Germany, BMBF

Table 3: ELSA-JTC2017 funded consortia

### Midterm Symposium

For each call NEURON organises a midterm symposium after about half of their run time where funded projects are presented and discussed. The assessment of the projects' progress is supported by a previous member of the respective peer review panel. These assessments are fed back to the coordinators of each consortium and their funders. With this, NEURON aims to support the funded consortia on the development of the projects.



A second aim of the midterm format is the chance for networking among the funded groups of a particular call. In 2019 an exceptional joint midterm symposium took place in Lisbon, Portugal. As in 2017 two parallel JTC's were launched, one on "ELSA of Neuroscience" and a biomedical call on "Synaptic Dysfunctions", the networking aspect was emphasized and several actions were taken to increase exchange between and among the groups in the two calls. This symposium was held in conjunction with the International Conference on Neuroethics (ICONE5) to increase the networking of the communities in biomedical science and ELSA research including humanities, legal and social sciences. A variety of workshops, a Young Investigators Satellite Meeting and a joint poster session for early-career researchers of all disciplines, two practical workshops on ethics self-assessments and embedded ethicists were offered.

As general feedback of the midterm symposium researchers acknowledged the opportunity to meet other consortia, scientists and possible future collaboration partners. It was noted as helpful to get insight on different project approaches and organization structures in other consortia. Yet, participants asked for longer breaks for informal networking. Especially the early career researchers appreciated the chance to meet and discuss among other early career and experienced scientists. The workshops specifically targeted at early career researchers were perceived particularly well.

A mixed feedback was given on the integration of ELSA and biomedical projects into a joint symposium. While many appreciated the interdisciplinarity and the opportunity to interact with "foreign" disciplines, others experienced the ethical projects as "disconnected" from other biomedical NEURON projects.

### **Key Performance Indicators**

In 2013 NEURON developed a series of key performance indicators (KPIs) to evaluate different aspects of the impact of the finalised projects. KPIs were adjusted in 2020 and tailored for the ELSA call (Table 4). As part of the final reporting researchers filled out a questionnaire to assess these KPIs (see Annex II). A summary of the different aspects evaluated by this questionnaire is described below and organised according to the overarching objectives of NEURON. A summary of the major achievements can be found in Table 5.

In addition to the indicators used for this final analysis, NEURON constantly monitors the progress of the funded research projects through annual reports summarizing the most important scientific results and consortia achievements. Furthermore, coordinators of the funded projects present interim results at the midterm symposium (page 5), subjected to evaluation. This continuous interaction between the consortia's coordinators and the call secretariat was established from the beginning, ensuring the appropriate development and completion of the planned work and a dedicated use of funding.



Objective of the	Key performance indicators	Measures
Funding Programme		(i.e. items in the questionnaire)
Enhance excellent co- operation between scien- tists working in the field of ELSA of neuroscience	NEURON JTC as starter of new collaborations	Have the partners participating in the NEURON project collaborated before applying for the NEURON JTC2017? (Question 1.2)
	New research groups from other countries joining the consortium	Has the development of the project funded by ELSA-NEURON motivated the establish- ment of new collaboration(s) with other team(s)? (Question 1.3)
	Sustainability of the collaboration (obtaining further funding for the same consortium)	Has the consortium collaboration led to new applications/grants in other funding programmes? (Question 1.4)
	Intensity of collaboration, early researcher participation (mobility)	List of meetings, young researchers involved in the project, lab visits/exchange of researchers, and training within the consortium (Question 1.5)
	Scientific communication of re- sults	List of publications and communications - level of joint publications. ( <b>Question 2.1</b> )
	Sharing of resources and technol- ogies	Have the consortium partners exchanged resources (Question 5.2)
		Has the consortium created/developed transnational database /registry, media (e.g. blog, newsletter), educational tools or similar (Question 5.1)
2. Promote multi-discipli- nary consortia and to en-	Consortium Composition	List of research groups, expertise represented in consortium (Question 1.1)
courage translational re- search proposals with so- cietal impact	Patient Involvement	patients/patient representatives involved in planning and/or conducting the research project? (Question 2.3.1)
	Public involvement	Was the public involved in any stages of the research project? (Question 2.3.2)
3. Support exploitable outputs with impact for society or health	Non-scientific communication of results	List of (non-scientific) publications and communications (Question 2.2.)
,	Output and achievements with impact for society or health	List of outputs with impact for society or health (Question 4.1)
		Potential impact / achievements, e.g. New methods, Development of decision making tools, Information for general population, Information for policy and de- cision makers, Added value for education, New guidelines (Question 6)
	Patents and licenses	Patents and other outcomes with impact to health (Question 4.2)

Table 4: Key performance indicators<sup>1</sup> in relation to the objectives of the funding programme.



Objective of the	Key performance indicators	Results
Funding Programme  1. Enhance excellent cooperation between scientists working in the field of	NEURON JTC as starter of new collaborations	→ all consortia were partially pre-existing with at least 2 PIs collaborating before
ELSA of neuroscience	New collaborations formed by consortia in the runtime	→ all acquired new collaborations
	Sustainability of the collaboration (obtaining further funding for the same consortium)	$\rightarrow$ 2 of 3 had at least 2 PI's applying jointly for further funding
	Intensity of collaboration, early researcher participation (mobility)	<ul> <li>→ all consortia attended the midterm symposium</li> <li>→ each consortium held at least 2 in person meetings with all partners [range 2-4]</li> <li>→ all consortia reported online meeting formats for additional exchange</li> <li>→ all consortia had at least one joint publication (at least 2 Pl's) either published or submitted by the end of the time of the reporting</li> </ul>
	Scientific communication of results	→ overall 43 peer reviewed publications were reported (average of 14.3, range 10-22)  → each consortium published books or book chapters (total 14, average 4.7, range 2-7)  → 131 presentations at scientific meeting were given, e.g. talks, posters [ average 43.7, range 13-91]
	Sharing of resources and technologies among the consortium	→ 2 of 3 consortia shared resources
Promote multi-discipli- nary consortia and to en- courage translational re- search proposals with soci- etal impact	Consortium Composition	3 consortia  → average size of consortia: 3.6 [3 or 4 partners]  - 11 partners (Pls) from 3 countries each  - 36 non-permanent personnel  → 4 Pl held dual expertise [range 1-2/consortium]  → nine disciplines were represented  → average of 4.3 disciplines / consortia [3-7]  → all included at least one philosopher  → 2 included a neuroscientist  → 2 included a social scientist
	Patient Involvement	<ul> <li>→ patients were actively involved in one project</li> </ul>
	Public Involvement	→ public was actively involved in one project
3. Support exploitable outputs with impact for society or health	Non-scientific communication of results	<ul> <li>→ each consortium communicated results to the broader public</li> <li>→ overall 28 non-scientific publications were reported:</li> <li>7 articles in newspapers and magazines</li> <li>6 interviews, 6 active roles in panel discussions, 5 public lectures and 3 blog entries</li> </ul>
	Output and achievements with impact for society or health	→each consortium reported potential impact / achievements for society/health, New methods (1), Information for general population (3), Information for policy and decision makers (3), Added value for education (2), New concepts (1)
	Patents and licenses	No patents or licenses were reported

Table 5: Summary of major achievements



### **Objectives of the Funding Programme**

# **Aim 1.** Enhance Excellent Cooperation between Scientists Working in ELSA of Neuroscience

One of the main goals of NEURON is to boost scientific cooperation beyond countries borders. This section evaluates the outcomes related to the consortium composition in terms of history and sustainability of collaboration, the interactions with other research teams, their mobility between partner groups, and the communication and dissemination of project results in joint scientific publications.

#### NEURON JTC as a starter of new collaborations

Each consortium included partners from three countries. The three consortia encompass overall 11 funded partners, i.e. PI's and their research groups. In average 3.7 partners collaborate per funded consortium.

Previous history of collaboration between the members of a consortium before applying to ELSA-JTC2017 is used to distinguish established collaborations from newly formed ones. The objective is understanding to which extent NEURON encourages formation of new collaboration in ELSA neuroscience research.

All consortia reported at least a partial collaboration in their history as basic foundation, none were fully new established. Two PIs had previously collaborated in each consortium, two consortia reported a collaboration between all partners involved, at least bilaterally.

During the lifetime of the projects, all three consortia acquired additional collaborations with other researchers, teams and institutes in Austria, Australia, Germany, Turkey, and UK.

### Intensity of Collaboration

Consortia are encouraged to organise regular meetings and staff exchanges to take full advantage of the range of expertise of project partners and to develop the skillsets of individual group members. Sharing of resources among the consortia and beyond is crucial not only as indicator of successful active exchange but also a foundation for further research in the field. In general, the funding scheme invites for active exchange among the partners, also in the form of mobility periods.

Over their lifetime, each consortium organised at least two in-person meetings with all partners, and all attended the NEURON midterm symposium (see p. 6 for details). Towards the end of the projects' runtime, in-person meetings were not possible due to the pandemic situation. This was compensated by more virtual exchange.

Additional exchange was organised mostly as online or hybrid meetings in heterogenous ways, e.g. one consortium reported to have used weekly meetings over a half year for an intensive exchange in preparing a joint publication. One consortium used the mobility option to visit their partner group for one week and one month, each, e.g. for data collection. Another consortium relied on bilateral short-time visits.

Further, two consortia were able to share resources, thereby allowing common studies and harmonisation, i.e. by sharing video material, but also table and figure designs. Honouring the



open science policy of NEURON, about 30% on the scientific publications were published in open access journals (Table 6).

#### Scientific Communication of Funded Research Results

The project results were communicated in scientific journals, dissertations, books, communication to non-scientific audience, at scientific meetings, and other formats (summary depicted in Table ). Publications including at least two partners (i.e. multi-partner publications) were considered to partially account for the intensity of cooperation within the consortium.

Type of publication	# overall
Peer Reviewed Research Articles (plus submitted or in preparation)	43 (20)
Thereof joint publications	2 (5)
Thereof published in open access journals	13
Peer Reviewed Review Articles	1
Books or Book Chapters	14
Presentations in Scientific Meetings (e.g. talks, posters)	131
Doctoral or master's thesis, etc.	2
Others (letters to the editor, comments, responses, etc.)	2

Table 6: Total scientific publications/communications resulting from projects funded through JTC 2017

A total of 43 published peer reviewed articles [range 10-22] and one review were reported by the ELSA consortia at the time of the final reports, six months after finalization, with ~30% being published open access. 20 additional articles were yet pending as submitted or in preparation at that time.

Publications including at least two partners (i.e. multi-partner publications) were considered to partially account for the intensity of cooperation within the consortium. All consortia prepared joint papers by the end of the project, with two consortia co-authored and published overall two publications with multiple partners already at the timepoint of reporting, and had five more in preparation or submitted.

Moreover, 14 books or book chapters were published. Regular participation in scientific meetings resulted in 131 presentations [range 13-91], thereof 94 oral and 28 poster presentations plus nine seminars or workshop contributions. Due to the COVID restrictions about a third of the oral presentations were presented in virtual meetings.

Additionally, various routes of communications were used to disseminate results to not primarily scientific audience, see for details Aim 3 (p 14).

### Sustainability of the collaboration

Researchers were asked to report follow-on collaborations including further funding applications by consortia members. This measure indicates the impact of consortium development, both in continuing to advance projects beyond the ERA-NET funding period, and the ongoing value of the academic collaboration.

All consortia reported that new grants have been or will be applied for by parts of their consortia. As international funding schemes of relevance the next call of ERA-NET NEURON (ELSA-JTC2020) has been named as well as EU Horizon, specifically project IANUS. Also, national



programmes such as the Finnish Sigen&Ane Gyllenberg's Foundation Grants and Eemil Aaltonen foundation young researcher grant provide opportunities for further research.

### Summary

NEURON aims to foster international and interdisciplinary collaboration by supporting the formation and widening of consortia. Additionally, it strives to enhance their development during and beyond the project lifetime as seed for new collaborations. The analysis shows that NEU-RON funding resulted in an adequate number of successful interactions in terms of research outcomes and networking and sustainability, especially in light of the pandemic situation, in which international interaction, scientific exchange, and networking was aggravated.

All funded consortia were formed around at least two Pl's with a history of previous collaboration. During their lifetime, all consortia established additional collaborations. Thus, NEURON's funding in this year's call served to further develop, extend and consolidate previously established collaborations, and foster new cooperation, including researchers from counties not partaking in the call.

Within the funded consortia constant scientific exchange was maintained, adapting to virtual meetings throughout the pandemic crisis. The research outcomes resulted in a variety of scientific publications (journals, books, presentations) with about a third of the articles being published open access. It is of note that the high number of books or book-chapters published is a characteristic of the ELSA research community as compared to the neuroscientific biomedical calls in NEURON. While only few scientific publications were co-authored by multiple partners, as of the timepoint of reporting, the preparation of manuscripts and sharing of material attested for the attempt and first successes for a constructive exchange and outreach.

In terms of sustainability, the underlying funding enabled foremost a short and medium-term interaction between research partners in different countries, beyond the funding period of consortia. Two consortia reported to have written new grant applications already within their runtime. One of the consortia indeed applied for the next round of NEURON ELSA call in 2020.

Respective the overall limited number of (national or international) ELSA funding this is regarded a good sustainability.

# **Aim 2.** Promote Multi-disciplinary Consortia and Translational Research Proposals

NEURON aims to advance science through integration of interdisciplinary expertise and to contribute to fill the gap for the translation of research results to relevant stakeholders.

Therefore, the interaction between disciplines as well as the involvement of patients and the public into the projects were analysed.



### Composition of the Consortium

NEURON aims at fostering interdisciplinary collaboration of pan-European consortia. Each consortium included partners from three countries. Overall the three consortia encompass 11 funded partners, i.e. Pl's and their research groups. In average 3.7 partners collaborate per funded consortia.

In addition to the 11 PIs, a total of 36 persons were involved as non-permanent personnel in the projects funded: 15 postdocs/ MDs (6 women/9 men), ten graduate students (5 women/6 men; PhD, Masters), and ten undergraduate students (e.g. bachelor; 6 women/4 men) were involved (Figure 1), as well as one medical writer as scientific personnel.

Furthermore, three additional undergrad students were involved in the projects using external funding.

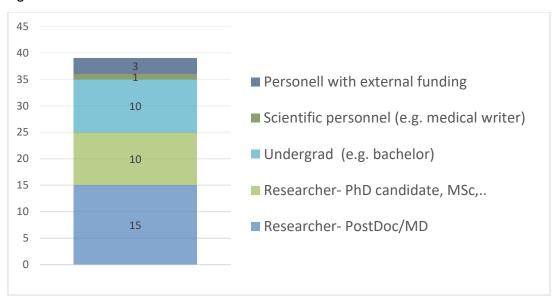


Figure 1: Academic staff participating in the funded projects by category.

In terms of disciplines, each consortium holds at least one PI of interdisciplinary background, i.e. of dual or triple expertise, e.g. law and biology or medicine and philosophy. Overall nine different disciplines were represented in the consortia (range 3-7; average 4.3). Each consortium included at least one philosopher. Two consortia held expertise in both, humanities (i.e. philosophy) and natural science (medicine or neuroscience). Again, two out of three included a social scientist. Moreover, expertise from cultural science (2), law (1), medicine (1), psychology (1), and patient representation (1) were represented in the consortia.

#### Involvement of Patients and Public

For research projects to be translational to the clinic, public and other stakeholders of interest, collaborative efforts are encouraged towards public and patient engagement. Researchers were asked to report the involvement of patients or patient groups as active members of the project. This includes involvement in the design, coordination (as part of a committee or advisory board), analysis or interpretation of research data, or in the dissemination of results.

One of three consortia involved patients actively, FUTUREBODY. Indeed, this project's approach acknowledged public engagement as one key-element. Relevant professional groups and citizens were actively involved already. A patient representative was part of the staff and with that involved in the conduct of the research. But more than that disability scholars and



activists in academic and public discourse on neurotechnologies, partook in project meetings and presentations e.g. as panellists or interviewees. Further, public involvement encompassed also dissemination on a broader scale.

Two consortia did not report patient involvement at any stage, one because no patient relevant research was conducted. No patients were included as classical subjects of research.

### Summary

NEURON encourages international collaborations in the interdisciplinary field of ELSA of neuroscience. The overall number of involved researchers, from established Pl's to early-career researchers at different stages, is quite substantial and reflects on the enabling of networking and collaboration in consortia under NEURON.

The success of interdisciplinary collaborations is reflected in the absolute number of 47 researchers from nine disciplines involved in three consortia. But also in the distribution of disciplines per consortium, covering both, humanities and natural sciences and also each consortium held at least one PI with multidisciplinary background (e.g. in medicine <u>and</u> philosophy).

Beyond research, active patient and public involvement has been commendably implemented by one consortium. The engagement of different significant groups throughout the runtime was part of the concept, both targeted and on a broader scale, and added to the (public) debate of the project's topic.

### Aim 3 Support exploitable outputs with impact for society or health

NEURON aims to promote research outcomes that help to ensure that neuroscientific methods and findings are utilized in ways which are of the best possible benefit for our society. Accordingly, communication and other output with impact to health and society were analysed.

Type of publication	# overall
Communication activities to non-scientific audiences	28
(newpaper, magazines, interviews etc.)	
newspaper article/ public magazine	7
interview	6
blog entry	3
public lecture	5
Panel discussion	6
Government Stakeholders	1

Table 7: Non-scientific communications resulting from projects funded through JTC 2017

### Outcomes with Impact to Society or Health

Dissemination routes may target different groups of interest. For a better understanding of the outreach formats, types of publication were reported.

Various routes of communications were used to disseminate results to a non-scientific audience: the general public and other stakeholders of relevance (Table 7). Each consortium employed at least six routes of communication [range 6-15; average 9.3]. Here, both, print media and talk formats were used for outreach. Print media (newspaper, magazine and interview



articles) were engaged by two consortia, directed mostly to the national general public in the respective language. All consortia used interview formats for outreach to the interested public, either on the radio, online-formats such as the neurohub.org blog or the university websites.

Additionally, two consortia employed e.g. public lectures at special occasions as the Brain Health Awareness Week (THERENIA), or Bain Week 2019 and the 60<sup>th</sup> anniversary of the Finnish Association for Alcohol, Drug and Gambling (A-BRAIN). Panel discussions were another means for outreach and dissemination used by two consortia in the context of scientific conferences or exhibitions, while the third directed its outreach to government stakeholders. At least four formats targeted an international audience.

### Major achievements of the research consortia

All consortia reported they had successfully achieved the main objectives of their projects.

Further positive impact to society was generated by various further achievements:

The general population was informed about the research of all consortia by a variety of means, including interviews, newspaper article or blogs.

Public lectures and public events were used to raise public awareness in two of the projects, specifically related to neurotechnology (FUTUREBODY) and to information on addiction in order to reduce stigma and for better understanding of its nature (A-BRAIN).

Moreover, novel methods of transdisciplinary research have been tested. Among the high-lights, FUTUREBODY organized the BIO·FICTION Science Art Film Festival in Vienna in 2018. Additionally, they developed the format of Film World Cafes, that were arranged as satellites to other related meetings such as International Society for the History, Philosophy and Social Studies of Biology meeting in New York or EFFEKTE city science festival in Karlsruhe, both in 2021. Du to the pandemic, the film world cafes took place mostly as virtual meetings.

None of the projects declared having filed patents or licences or any products like software or services

### **HIGHLIGHTS**

In terms of impact of outcomes to health, all three projects reported a positive effect and translational value.

**A-BRAINS** results are indeed questioning the value of a currently used model "Brain Disease Model of Addiction" for understanding and explaining addiction. They established an alternative concept, the Epistemic Project of Addiction in the Brain (EPAB) theory, as summarized in the book "Addiction and the brain" book (Palgrave Mcmillan 2021). Further research and treatment approaches may e.g. invite for a critical verification of this alternative model by the research community. This new view may lead in the health practice to a more appropriate treatment and better tailoring of resources.

**FUTUREBODY** achieved deeper understanding of how bio-hackers use neurotechnologies for unconventional purposes. The project stimulated the debate on ramifications of neurotechnology for society and further educated and informed the academic and general population on the use of neurotechnologies. In this regard the PIs have been active in advisory boards to maximise their impact on policy and decision making.

**THERENIA**, researching the use of neuroscientific techniques in therapy *vs* enhancement, highlight the importance of their results in relation to ethical and legal decision-making, i.e. related to using neuroscientific techniques to modulate human mental states and capacities.



### Summary

A variety of dissemination paths to the broad and non-scientific public were successfully employed by every consortium, thus aiding NEURONS overarching aims for outreach to society.

It is of note, that the communication paths of this ELSA call, as already seen in the previous call, has a high outreach to non-scientific stakeholders as compared to biomedical calls funded under NEURON. Interestingly, it was not only limited to classical print media. All consortia additionally used talk formats, either public lectures or panel discussions, or both, to convey their research approaches and results. This approach paves the way for an easier access of the general public and to governmental/political stakeholders to the progress and results of research projects as well as the expert community.

An impact to society and health was reported by all consortia. One project stood out though, in using a strong patient and public centred approach.

Research outcomes were fruitful in developing new methods, a new concept and deeper understanding in the three topics of research (see highlights above) and will contribute to the further developments in the respective fields.



### **Annex I- Call Text JTC 2017 Excerpt**

## Call for Proposals for

# 'Research Projects on Ethical, Legal, and Social Aspects (ELSA) of Neuroscience'

Submission deadline for proposals: May 03 2017, 14:00 CET

For further information, please visit us on the web

### http://www.neuron-eranet.eu

or contact

### Dr Katja Kuhlmann

ELSA Neurosciences Joint Call Secretariat

Project Management Agency

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### 1. Purpose

Neuroscientific research yields constant progress regarding our basic understanding of the structure and function of the human brain under healthy and pathological conditions. This knowledge is fundamental for the development of new diagnostics and treatments for patients suffering from neurological or psychiatric diseases. At the same time, the neurosciences have implications for the understanding, and thus potentially also the control, of human decision-making, behaviour, emotions, and social interactions. Findings of the neurosciences can furthermore deeply affect human self-understanding and conscience as such. Therefore, it is of major importance to investigate the ethical, legal, and social aspects (ELSA) of the neurosciences and their recent advances. This knowledge helps to ensure that neuroscientific methods and findings are utilized in ways which are of the best possible benefit for our society. The high societal relevance of the neurosciences is underlined by continuously high public interest and ongoing public discourse on this topic.

The 'Network of European Funding for Neuroscience Research' (NEURON) has been established under the ERA-NET scheme of the European Commission (<a href="http://www.neuron-era-net.eu">http://www.neuron-era-net.eu</a>). The aim of the ERA-NET NEURON is to co-ordinate research efforts and funding programmes of European countries in the field of disease related neuroscience. Under the umbrella of NEURON, several joint transnational calls (JTCs) have been launched on different neuroscientific topics from 2008 to 2016. In acknowledgement of the high societal relevance of the neurosciences, this year, the second separate and additional JTC on "Research Projects on Ethical, Legal, and Social Aspects (ELSA) of Neuroscience" will be launched in parallel to the regular NEURON JTC, which focusses on "Research Projects on Synaptic Dysfunction in Disorders of the Central Nervous System".

The following funding organizations have agreed to fund the joint call for multinational research projects on ELSA of Neuroscience. The call will be conducted simultaneously by the funding organizations in their respective countries and co-ordinated centrally by the ELSA Neurosciences Joint Call Secretariat.

- Austrian Science Fund (FWF), Austria
- Fonds de la Recherche Scientifique (FNRS), Belgium
- Canadian Institutes of Health Research Institute of Neurosciences, Mental Health and Addiction (CIHR-INMHA), Canada
- Fonds de Recherche du Quebec Sante (FRQS), Canada
- Academy of Finland (AKA), Finland
- Federal Ministry of Education and Research (BMBF), Germany
- State Education Development Agency (VIAA), Latvia
- Institute of Health Carlos III (ISCIII), Spain\*

### 2. Aim of the call

The aim of the call is to facilitate multinational, collaborative research projects that will address important questions regarding ethical, philosophical, legal and socio-cultural aspects related to the neurosciences and their recent advances.

<sup>\*</sup>final decision on participation pending



Subjects under this general heading include but are not limited to:

- a) the consequences of the development of neuroscientific diagnostic methods (e.g. handling of incidental findings; the "right not to know"; very early disease prediction before symptoms occur; diagnosis in absence of treatment options; interactions between socio-culturally diverse patients and health personnel; availability of novel expensive methods)
- b) abnormal behaviour reduced to deviant brain states (e.g. expansion of the concept of illness; seeing psychiatric symptoms merely as specific neurochemical imbalances); use of brain data and brain interventions in legal contexts (e.g. "brain reading" for the detection of deception; brain intervention of offenders; psychosurgery; insurance law)
- c) neuroenhancement such as alteration of mental states (cognitive, affective) and abilities (e.g. cognition, sleep, appetite, sexual behaviour) in healthy subjects by pharmacological or by electrical/magnetic brain stimulation
- d) intelligent technologies and close human-machine interaction (e.g. Ambient Assisted Living, Brain-Computer Interfaces)
- e) personality changes as side effects of neurological or psychiatric therapies (e.g. Deep Brain Stimulation; brain implants)
- the impact of modern neuroscience on traditional philosophical questions, concepts and theories regarding fundamental aspects of human nature (e.g. the relationship between mind and brain, the nature of consciousness, self- and personal identity, free will)
- g) biobanking of neural tissue (e.g. tissue donation, deceased donor, data protection, possible consequences for relatives)
- clinical research with patients suffering from neurological or psychiatric diseases (e.g. developing tools to improve the assessment of decision-making capacity of the patients, analysis of legal measures to protect those who do not have the capacity to consent)
- i) societal and cultural changes induced by neuroscientific knowledge and its application. The individual components of joint applications should be complementary and should contain novel, ambitious ideas to answer key questions or lead to a step-wise change in understanding. There should be clear added value in funding the collaboration over the individual projects.

All scientific disciplines and stakeholders, which are relevant for the specific ELSA-research question, should be integrated. This could be for instance experts from the fields of neuroscience, psychology, medicine, informatics, engineering, philosophy, theology, law, social sciences, cultural studies or healthcare economy. Depending on the research question, it may also be necessary to integrate (pharmaceutical) industry, health insurances, patients, relatives, patient representatives or other groups of persons who are directly affected.

Projects should go beyond purely analytical or descriptive levels related to the past or present. Based on their analyses, the applicants should aim at giving prospects for the future and developing proposals for socio-compatible use of neuroscientific advances. Additionally, the applicants should develop and implement concepts for effective public communication of their results. Communication of the results on an international level is desirable.

No empirical neuroscientific or biomedical research can be funded in this call.

### 3. Application



### 3.1 Eligibility

Joint transnational research proposals may be submitted by research teams working in universities (or other higher education institutions), non-university public research institutes, hospitals, non-profit organizations as well as in commercial companies, particularly small and medium-size enterprises. The eligibility of the afore-mentioned institutions, together with details of eligible costs (e.g., personnel, material, consumables, travel money, investments), are subject to the administrative requirements of individual funding organizations and will therefore differ. Please note that, for some funding organizations, commercial companies are not eligible or are only eligible under certain conditions (e.g., only in partnership with academic institutions in the consortium). Clarification should be obtained from the individual funding agencies (see contact details below). It is advised to read carefully all national annexes regarding eligibility and funding by the respective funding agencies.

Only transnational projects will be funded. Each consortium submitting a proposal must be comprised of a minimum of three research groups from three different countries eligible for funding by organizations listed in this call text (see above). The total number of research groups in a consortium must not exceed five. Not more than two research groups can be from the same country. Therefore, the maximum number of countries involved in one consortium is five.

Research groups not eligible to their national funding organizations or from countries which are not involved in this call may participate in projects only if their participation clearly provides an added value to the consortium and if they present evidence on secured budget for their part in the project. In any case, the total number of research groups in one consortium must not exceed five.

Each consortium should have the critical mass to achieve ambitious scientific goals and **should clearly demonstrate added value** from working together. Each project must nominate a project coordinator who represents the consortium externally and is responsible for its internal management (e.g. application, Consortium Agreement, reporting, etc.). It is obligatory that the coordinator of a consortium is eligible to be funded by one of the organizations listed in this call text.

Although applications must be submitted jointly by groups from several countries, the individual research groups will be funded by the individual NEURON funding organization(s) of their respective countries. Eligibility criteria are the matter of individual partner funding organizations.

Therefore, applicants are strongly advised to follow the instructions contained in the country-specific eligibility tables which are published on the NEURON webpage and to contact their national/regional funding organization to confirm eligibility matters before submitting an application.

### 3.2 Submission of joint transnational proposals

There will be a **one-stage procedure** for joint applications. One joint **proposal document** (in English) shall be prepared by the partners of a joint transnational proposal, and must be submitted to the ELSA Joint Call Secretariat by one spokesperson, the coordinator.

Proposals must be submitted in electronic format no later than **May 03, 2017** (14:00:00 CET) via the <u>electronic submission</u> system.



#### 3.3 Further information

For further details, please refer to the respective submission forms available through the NEU-RON web site. If you need additional information, please contact the ELSA Neurosciences Joint Call Secretariat, or your funding organization representative (see Annex for contact data).

#### 4. Evaluation and decision

The review process will be in two stages.

### 4.1 Formal check of proposals

The ELSA Neurosciences Joint Call Secretariat will check the proposals to ensure that they meet the call's formal criteria (e.g. date of submission; number of participating countries; inclusion of all necessary information in English). The ELSA Neurosciences Joint Call Secretariat will also forward the proposals to the national/regional funding organisations, which will perform a formal check of compliance with their respective regulations. Proposals not meeting the formal criteria will be rejected at this stage.

The Call Steering Committee<sup>1</sup> may reject proposals if they are clearly outside the scope of the call.

Proposals passing these check points will be forwarded to the joint Peer Review Panel for evaluation.

### 4.2 Peer-review of proposals

The reviewers will carry out the evaluation according to the following specific evaluation criteria:

- 1. Relevance of the research question to the aim(s) of the call
- 2. Scientific quality of the proposal (originality, methodology)
- 3. Feasibility of the project (adequacy of project work plan and related risk analysis, budgetary and other resources, time schedule)
- 4. Qualification and expertise of participating institutions and research groups in the field(s) of the proposal
- Quality of collaborative interaction between participating groups, and added value of the network, from both scientific and transnational perspectives, of the research consortium.
- 6. Impact of the expected results on society and future scientific applications.

### 4.3 Decision

An international Peer Review Panel will evaluate the proposals based on the above mentioned evaluation criteria and establish a ranking list of the fundable proposals by scientific assessment. Based on this ranking list the Call Steering Committee will determine the projects to be funded, taking into account the national budgets available. These recommendations will inform the final decisions which will be made by the funding agencies and will be subject to budgetary considerations.

<sup>&</sup>lt;sup>1 1</sup> The composition and the responsibilities of the Call Steering Committee are detailed in the document "Procedures for the joint transnational call on ELSA of the Neurosciences 2017 and the evaluation process".



### 5. Funding procedure / Responsibilities / Reporting requirements

### 5.1 Funding procedure

Projects can be funded for a period of up to three years and according to funding organizations' regulations. Funding is expected to start **early in 2018**.

Successful research groups will be funded directly by the respective funding organizations.

Funding will be administered according to the terms and conditions of the responsible funding organizations, taking into account all other applicable regulations and legal requirements.

### 5.2 Responsibilities

Within a joint proposal, each group leader will be the contact person for the relevant national/regional funding organization. The coordinators of funded projects together with the respective funding agencies shall make every effort to seek a common start date for all research groups in the consortium.

After the evaluation and selection procedures are completed, each consortium selected to be funded is required to draft and sign a Consortium Agreement (CA) suitable to their own team. The CA will agree a common project start date, manage the delivery of project activities, finances and intellectual property rights (IPR), and avoid disputes which might be detrimental to the completion of the project. All consortia are strongly encouraged to sign the CA before the official project start date. The CA must be signed within the first six months after the project start date.

### 5.3 Reporting Requirements

On behalf of the research consortium, the project coordinator will be required to submit a brief annual scientific progress report on the project and one final report in the end, to the ELSA Neurosciences Joint Call Secretariat. Group leaders may be required to submit reports separately to their national funding organization; reporting guidance will be forwarded by the relevant funding organization, as applicable.

Annual reports should be submitted by April-30 the following year. Annual reports do not need to be submitted if the project ends in the first three months of the following year (i.e. between January and March). In this case, the submission of a final report will suffice. However, instead of submitting the final report within the usual six month period (see below), the final report will be required within four months of project completion.

The deadline for submitting final reports is six months after the end of the project. It is the task of the coordinators to determine a formal end date for project completion. This is required, as partners may be granted extensions of differing duration. Coordinators will be informed about this procedure by the ELSA Neurosciences Joint Call Secretariat and will receive the report template in due course.

The coordinator will be asked to present a progress reports during an intermediate status symposium. The attendance is obligatory for all coordinators and Principal Investigators (Pls). Early-career scientists working on the projects are welcome to join the status symposium together with the Pls. Accordingly, travel expenses to attend the symposium should be encumbered in the proposal budget plans.



Funding recipients must ensure that all outcomes (publications, etc.) of transnational NEURON projects include a proper acknowledgement of ERA-NET NEURON and the respective funding partner organizations, and are in line with the relevant publication requirements.



## **Annex II- Questionnaire / Impact of the Project**

This section will be used by ERA-NET NEURON partner organisations to analyse the joint call results. Information from this questionnaire **may be published** for reporting the call output.

Q.1 Consortium constellation, collaboration and sustainability

<b>Q1.1</b> Which expertise was represented in the consortium?  Please tick when applicable		
neuroscience,		
psychology,		
medicine,		
informatics,		
engineering,		
philosophy,		
theology,		
social sciences, cultural studies,		
healthcare economy,		
industry,		
health insurances,		
patients / patient representatives,		
law,		
other groups:		
Q.1.2 Have the partners participating in the ELSA-NEURON project		
collaborated before applying to this NEURON call?	YES 🗌	NO 🗌
▶ If YES, please indicate which partners collaborated (e.g. partner 1 with partner 4 and 5, all):	vith partner	2, partner 3
•••		
<b>Q.1.3</b> Has the development of the project funded by ELSA-NEURON motivated the establishment of new collaboration(s) with other team(s)?	d YES □	NO 🗌
▶If YES, please name the institutions and countries and specify the co	ollaboration:	
, , , , , , , , , , , , , , , , , , ,		
•••		
Q.1.4 Has the consortium collaboration led to new applications/grants in other funding programmes?	YES 🗌	NO 🗌
▶ If YES, please specify the partners involved and the corresponding pr 1, 3, and 4: HORIZON 2020 call xy):	ogramme (e	e.g. partners
Q.1.5 Intensity of collaboration: Meetings and exchanges (e.g. visits and tr	aining) with	nin the con-

23

A. Collaboration meetings (involving at least two consortium partners)

sortium



<b>Description</b> (type of meeting, location, date)	Partners present

Add lines as appropriate

### **B.** Please list **all non-permanent personnel** involved in the project.

Partner	Position (PhD Student, Technician, Postdoc, Pl)	Gender	Last degree obtained	Employed using NEURON funds?

Add lines as appropriate

### C. Training and mobility between partners

Please indicate the nature and duration of personal exchanges and visits between consortium partners, based on NEURON funding.

Partners in- volved (from X to Y)	Position (PhD Student, Technician, Post- doc, PI, etc.)	Purpose of the exchange

### **Q.2 Publications and communications**

Please indicate the number of publications and communications in which **NEURON support was acknowledged**. Publications in preparation or submitted must be indicated.

### Do not include:

- · articles published before the project start date
- articles that do not acknowledge NEURON funding

Type of publication	Total N°
Peer Reviewed Research Articles (acknowledging NEURON support)	
Peer Reviewed Review Articles (acknowledging NEURON support)	



Books or Book Chapters	
Presentations in Scientific Meetings (e.g. talks, posters)	
Communication activities (to lay audiences, news articles, press releases etc.)	
Doctoral or master's thesis, etc.	
Others (letters to the editor, comments, responses, etc.)	

Add lines as appropriate

### Q.2.1 Scientific publications, presentations and communications

List the publications resulting from the funded project.

**Highlight the name of the NEURON partners** and indicate the partner number according to the numbering designation in section I (e.g. partner 1 or P1). Please only add publications that acknowledge NEURON support and **provide a snapshot of the relevant acknowledgment section** for each of the listed publications.

No.	Publication Type (Article, Book)	Publication (authors, title, jour- nal, year, issue, pp.)	PMID	DOI	Partner(s)	Impact factor	Open access (Y/N)
1							
	Р	ASTE ACKNOWLED	SMENT S	NAPSH	OT HERE		
2							
	Р	ASTE ACKNOWLEDO	SMENT S	NAPSH	OT HERE		
3							
PASTE ACKNOWLEDGMENT SNAPSHOT HERE							
4							
SUBMITTED / IN PREPARATION							

Add lines as appropriate

### List of other scientific communications from the NEURON funded project

List presentations to scientific congress (oral and poster), institutional lectures, seminars, workshops, summer schools, etc.

Presentation Number	Presentation Type (Oral, poster)	<b>Venue</b> (congress/meeting, date and location)	Partner(s)	Invited (Y/N)
1				
2				

Add lines as appropriate

Q.2.1.2 Has the	consortiu	ım commu	ınicated "ı	negative re	esults" a	s an outcome	of the project?
YES	☐ NC	)					



**☑If YES**, please (i) indicate the publication numbers concerned (table above) (ii) specify the nature of those negative results (initial hypothesis was not confirmed)

...

### Q. 2.2 Other (non-scientific) Communication

Please indicate additional formats of communication and dissemination to stakeholders beyond research, i.e. the general public, policy makers.

List presentations to stakeholders beyond research (written or oral), e.g. white papers, guidelines, draft directives, public lectures, exhibitions, workshops, educational material, media contributions in radio/press/blog/podcast/social media.

Number	Format	<b>Venue</b> (date and location)	Partner(s)	International outreach (Y/N)
1				
2				

Add lines as appropriate

Add liftes as appropriate
Q. 2.3 Public and patient engagement
Q. 2.3.1 Was the public involved in any stages of the research project? YES NO
☑ If YES, please specify:
design of research projects (e.g. design of questionnaires, selection of test setting)
conducting the research project (e.g. roundtable discussion, workshop, public discours)
analysing / interpreting research data (e.g. citizen science)
dissemination of results
⇒ Please briefly describe the public engagement:
Q. 2.3.2 Were patients or patient representatives involved in any stages of the research project?
If YES, please specify:
designing the research project (e.g. study protocol)
conducting / coordinating the research project (e.g. patient committee / advisory board
analysing / interpreting research data
dissemination of results

⇒ Please briefly describe the patient engagement:



...

Q.3	<b>Prizes</b>	and	awa	rds
-----	---------------	-----	-----	-----

Q.O I II200 and awardo	
Q.3.1 Have prizes or awards been received for the work funded in this project? YES	NO 🗌
▶If YES, please detail (i) the name of the award and organisation that confer individual who received it, and (ii) the work for which it was confered:	ed it, (ii) the

### Q.4 Exploitable outputs with impact for society or health

### Q.4.1 List of outputs with impact for society or health

Please list below:

Category	Description	Partner(s) in- volved
Guidelines, draft directives		
Launching a product, software or service		
Creation of a platform available to a community		
Fundraising		
Other (please specify)		

Add lines as appropriate

### Q.4.2 List of patents/licences, if applicable

Please indicate if details regarding the listed patents need to be treated confidentially. Please indicate the project partners involved using the numbering designation in section I (e.g. partner 1 or P1).

Patent/licence description (patent no., name, description)	<b>Stage</b> (depos- ited/granted)	Main partner	Partner(s) involved

Add lines as appropriate

Has a Data Management Plan (DMP) been produced?	YES	ΝО □



<u> </u>							
►If YES When has the DMP la	st been updated?	months before	e/after pı	roject end date			
Will the DMP be publis	shed?	YES	s □	NO 🗌			
► If YES, please provid	e the link:						
Please list below how the consc		nd gave acces	es to the	data generated	1		
r lease list below flow the consc	rtium storeu, treateu a	nd gave acces	55 10 1116	data generated	4.		
Category	Descriptio	n		essible by vhom?	Partner(s) involved		
Database or Registry							
Data Repository or Storage							
Data harmonization or simplification for international standards							
Other (please specify)							
Q.5 Development of innovative Q.5.1 Has the consortium create ☐ database /registry ☐ ► If applicable, please core	ed a new or further dev	veloped an exi sletter) ☐ ed	sting trai	al tools	N/A ? ):		
Name of the registry/da	tabase:						
How was the registry/database created?							
newly created compilation of existing (national) sources							
How were new patients      Via existing a	recruited? network of clinicians						
_	development of NEW	networks of cl	inicians				
	eer recruitment (i.e., tl			olic involvement	t initiatives)		
☐ via advertise	ement (e.g. flyers, onlin	ne or classical	media a	ds)			
How will the registry/date	abase be maintained/t	inanced after	the end	of this project?			
<ul> <li>Is the the registry/datab</li> </ul>	ase open acces?	YES	3 🗆	NO 🗌			
If Yes, please provided in the provid	le the link:						
►lf applicable, please cor	nplete per education	<b>al tool</b> (repeat	section	as necessary):			
Name of the educational	ıl tool:						
What is the target group	?						



sch	ool					
univ	versity curriculum					
oth	er education curriculum					
Is the educatio	nal tool open acces?		YES		NO 🗌	
If Yes, plea	se provide the link:					
► If applicable, please	e complete per media:					
<ul> <li>Type of media:</li> </ul>	(link, if available)					
What is the target.	get group?					
pro	fessionals (medical staff,	researcher	s)			
☐ ger	eral public					
indu	ustry					
☐ poli	cy and decision makers					
othe	er:					
How will the many	edia be maintained/financ	ed after the	e end of this	projec	ct?	
Please specify where a	tium partners exchanged applicable estionnaire data:	resources'?				
spe	cific methods (expertise a	and/or softv	vare and/or	other r	naterial) :	
☐ clin	ical data:					
oth	er:					
□ N/A						
►lf applicable, pl	ease specify:					
Have shared re	esources allowed commo	n studies?			YES 🗌	NO 🗌
Did the planner	d number of cases suffice	to reach th	ne goal?		YES 🗌	NO 🗌
<ul> <li>Is data / materi If yes, please s</li> </ul>	al made openly accessible pecify:	e (beyond	the consorti	ium)	YES 🗌	NO 🗌
Q.6 Potential impact /	achievements					
DI 11.44		" DI				
Please list the major ac	chievements of the conso	rılum. Pleas	se indicate y	your to	p three highl	ignts.
Achievements	Brief descript achievement	ion of	Expected search, treetc.)	impa eatmen		Highlights
New methods						



Development of decision making tools							
Information for general population							
Information for policy and decision makers							
Added value for education							
New guidelines							
Other (please specify)							
Add lines as appropria	te						
Q.7 Resume							
Q.7.1 Did your conso	rtium ach	ieve its mair	objective	?			
YES 🗌 I	NO 🗌						
Q.7.2 What is your most important result?							
Q.7.3 Which problems to reach your objectives did you encounter?							
···							
Q.7.4 Please indicate further ideas for future calls/formats:							



## **Annex III: Data excerpt**

Indicator/Measure	A-BRAIN	FUTUREBODY	THERENIA
Full new consortium	no	no	no
Addition of research group	yes	yes	yes
Subsequent applications	yes	n/a	yes
Intensity of Collaboration			
- meetings with all partners	2	4	3
- mobility	yes	informal	no
Excellence			
Peer Reviewed Research Articles	11	22	10
(acknowledging NEURON support)			
Peer Reviewed Review Articles	0	0	1
(acknowledging NEURON support)			
Books or Book Chapters	2	7	5
Presentations in Scientific Meetings (e.g. talks, posters)	13	91	27
Communication activities (to lay audiences,	7	15	6
news articles, press releases etc.)			
Doctoral or master's thesis, etc.	2	0	0
Others (letters to the editor, comments, responses, etc.)	2	0	0
Composition of consortia			
Overall non-permanent staff	13	11	12
- number of multidisciplinary PIs	1	1	2
- number of disciplines involved	7	3	3
Other (non-scientific) Communication	7	15	6
newspaper article/ public magazine	0	6	1
interview	1	4	1
blog entry	1	0	2
public lecture	4	0	1
Panel discussion	1	5	0
Government Stakeholders	0	0	1
thereof international outreach	1	n/a	3
Public and patient engagement			
Public Involvement	no	yes	n/a
-conducting/coordinating research project	n/a	Х	n/a
-dissemination of results	n/a	Х	n/a
Patient Involvement	no	yes	no
-dissemination of results	n/a	Х	n/a
Exchange of data	yes	yes	n/a
common studies through shared data	yes	yes	n/a