ERA-NET NEURON

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

Joint Transnational Call 2015

Impact Report

by
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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
FCT	Foundation for Science and Technology, Portugal
FNRS	Fonds de la Recherche Scientifique, Belgium
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
PI	Principle investigator
WHO	World Health Organisation

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.

This first ELSA call under the umbrella of ERA-NET NEURON delivered important answers within five consortia working in international collaborations, as highlighted below (see box p. 15).

Using key performance indicators, we could show that this call successfully enhanced the excellent cooperation between scientists of various fields of research: new consortia were established, encompassing more than 50 persons as personnel, and showed a high interdisciplinary collaboration of researchers in humanities and neuroscience. The projects resulted in numerous publications of results to the scientific community and the lay public as well as other relevant stakeholders. This call delivered highly patient-centric results and research outcomes were fruitful in providing e.g. recommendations and support of patients and caregivers.

Monitoring of the projects’ progress and results is of high importance for NEURON. 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. As a first consequence NEURON decided to provide regular funding opportunities for ELSA research. Furthermore, for future improvement of the impact reporting, the questionnaire used is under revision to better tailored to the scope of ELSA outcomes.

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 WHO 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 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 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 fifteen annual biomedical calls, covering a variety of topics (Impact report JTC2015[1] 'European Research Projects on Neurodevelopmental Disorders'). With increasing visibility of the high societal relevance of neuroscientific research, the continuously high public interest and ongoing public discourse on this topic, a dedicated call for research on ethical, legal and societal was embedded in the ERA-NET NEURON and since 2015 three calls on "Ethical, Legal, and Social Aspects (ELSA) of Neuroscience" (Table 1) were launched.

Year of the call	Topic	Impact Report
2015	ELSA of Neuroscience	current
2017	ELSA of Neuroscience	Projects Ongoing
2020	ELSA of Neuroscience	Projects Ongoing

Table 1: Status of ELSA calls implemented within NEURON

Joint Transnational Call in 2015 "European 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, neuroscientific research has implications for the understanding, and thus potentially the control of human decision-making, behaviour, emotions, and social interactions.

In recognition of the high relevance of the advances in neurosciences for society, NEURON invites further research into this important multi-faceted topic of ethical, legal, and social aspects of neuroscience. Accordingly, this first JTC on "ELSA of Neuroscience" under NEURON enables studies on ethical, philosophical, legal and socio-cultural aspects related to neuroscientific research. It aims to help ensuring that neuroscientific methods and findings are utilized in ways which are of the best possible benefit for our society and for the individual.

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[1] https://www.neuron-eranet.eu/wp-content/uploads/Impact-Report_JTC2015_Final.pdf

Scientific topics invited under this call, to name a few, concerned issues arising from early disease prediction and incidental findings, decision-making capacity of patients, human-machine interaction, personality changes as side effects of neurological or psychiatric therapies, use of brain data or neural tissue, neuroenhancement or societal and cultural changes induced by neuroscientific knowledge and its application.

For this ELSA-JTC2015 six research funding organisations from six countries (Table Table 2) joined forces and funding, mobilizing overall 4.5 M€ earmarked budget to support international ELSA research.

Countries	Funding agencies
Belgium	Fonds de la Recherche Scientifique (FNRS)
Canada	Canadian Institutes of Health Research – Institute of Neurosciences, Mental Health and Addiction (CIHR-INMHA)
Finland	Academy of Finland (AKA)
Germany	Federal Ministry of Education and Research (BMBF)
Portugal	Foundation for Science and Technology (FCT)
Spain	National Institute of Health Carlos III (ISCIII)

Table 2: Funding agencies participating in ELSA- JTC2015

The research proposals submitted to this call were evaluated in a two-step procedure supported by a pool of 19 international and interdisciplinary peer reviewers. Twenty-four eligible pre-proposals were submitted by consortia composed by overall 84 principle investigators (PI’s) leading independent research groups, which were eligible for the participating funding bodies. This was a remarkable number for the first ELSA call in NEURON, demonstrating the importance of the ELSA topic for society and the need for international funding in this area.

The submitted pre-proposals offered a wide variety of subjects for research e.g. neurotechnologies, neuroenhancement, decision making and issues around early diagnosis in mental disorders, criminal justice, consciousness). This variety met the intention of the broad call topic (see Annex 1), only limiting ELSA approaches to the neuroscientific context. The proposals were reviewed by a multi-disciplinarity set of expert reviewers with scientific backgrounds concordant with the composition of a given consortium. Fifteen consortia were invited to the full proposal stage. Fourteen full proposals were submitted, and reviewed by four expert reviewers each. After detailed discussion in a peer review panel meeting a ranking list determined the best proposals.

In the end, five proposals including 17 eligible PI’s (overall 18 PI’s) in six countries were selected for funding (Table 3). The funded projects tackled a large variety of topics, including issues of psychiatric neurosurgery and dementia as well as brain computer interfaces and economic policies. Numerous methods were employed, among others were interview and questionnaire studies of different patients and stakeholders, legal analyses and conceptual ethical, philosophical studies. They conducted and completed their research between April 2016 and May 2021.

Acronym	Project Title	Principal Investigators (Coordinator bold)	Country, Agency
Ensure	Enhancing the Informed Consent Process: Supported decision-making and capacity assessment in clinical dementia research	**Julia Haberstroh**	Germany, BMBF
		José Antonio Seoane	Spain, ISCIII
		Jochen Vollmann	Germany, BMBF
		Ana Sofia Carvalho	Portugal, FCT
INSOSCI	The integration of cross-disciplinary research in neuroscience and social science – a methodological case study on economic policies and the neuroscience of agency	**Jens Harbecke**	Germany, BMBF
		Jaakko Kuorikoski	Finland, AKA
		Bernard Feltz	Belgium, FNRS
INTERFACES	Intelligent Neuro-Technologies Restoring Functions of Action and Communication: an Evaluation Study	**Ralf Jox / Orsolya Friedrich**[2]	Germany, BMBF
		Eric Racine	Canada, FRQS
		Jan Christoph Bublitz	Germany, BMBF
		David Rodríguez-Arias	Spain, ISCIII
PNS	Psychiatric Neurosurgery – Ethical, Legal, and Societal Issues	**Sabine Müller**	Germany, BMBF
		Tade Matthias Spranger	Germany, BMBF
		Judy Iles	Canada, FRQS
		Roberto Martínez-Alvarez	Spain, ISCIII
		Chris Bevoets	*own funds*
PreDADQoL	Ethical and Legal Framework for Predictive Diagnosis of Alzheimer’s Disease Quality of Life of Subjects at Risk and their Close Others	**Christiane Woopen**	Germany, BMBF
		Mercè Boada	Spain, ISCIII

Table 3: ELSA-JTC2015 funded consortia

Midterm Symposium

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

In 2015 two parallel JTC’s were launched, one on ‘ELSA of Neuroscience’ with 5 consortia and a biomedical call on ‘Neurodevelopmental Disorders’ with 15 consortia funded. In 2017, a joint midterm symposium took place in Riga, Latvia.
The general feedback on the symposium from perspective of the PI’s was very positive. Both, networking with the other funded PI’s as well as getting in touch with their funders was deemed highly beneficial. Especially ELSA researchers appreciated the chance to form international consortia in this funding scheme as a unique opportunity of high importance. They stated that an on national and international level ELSA funding opportunities were scarce.

Overall, bringing together researchers from biomedical and ELSA projects was considered valuable and enhanced the exchange between scientific communities. Nevertheless, the PI’s would have appreciated some sort of “icebreaker” to facilitate active networking as well as additional separate sessions to allow more in-depth discussions. These suggestions were taken into account when planning the next midterm symposium for the following calls.

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[2] Personnel change was performed during the project’s runtime

Key Performance Indicators

In 2013 NEURON developed a series of key performance indicators[3] (KPIs) to evaluate different aspects of the impact of the finalised projects (Table 4). As part of the final reporting researchers filled out a questionnaire to assess these KPIs (page 20[4]). A summary of the different aspects evaluated by this questionnaire is described below and organised according to the overarching objectives of NEURON. This impact report focusses on ELSA-NEURON’s aims 1 and 2, as they are most relevant for the ELSA field of research.

In addition to the indicators used for this final analysis, NEURON constantly monitors the progress of the funded research projects through annual and final reports summarizing the most important scientific results and consortia achievements. Furthermore, coordinators of the funded projects are invited to present interim results at a midterm symposium (page 6), 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.

In the following section, the outcomes of the funded projects in the context of NEURON objectives 1 and 2 are outlined. A summary of the major achievements expressed as percentage from the total number of consortia funded can be found in Table 5.

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[3] The indicators originally were developed for evaluation of biomedical projects. Accordingly, some indicators are not representative for ELSA research and will thus not be reported (grey font in Table 4). For future ELSA calls the questionnaire has been meanwhile improved and tailored.

[4] Due to an organisational flaw, two projects used a questionnaire version, excluding the question on prizes and awards.

Objective of the Funding Programme	Key performance indicators	Measures
1. Enhance excellent cooperation between scientists working in the field of neuroscience	Communication of results	List of publications and communications - level of co publication, bibliometric indicators.
	NEURON JTC as starter of new collaborations	Have the partners participating in the NEURON project collaborated before applying for the NEURON JTC2015?
	New research groups from other countries joining the consortium	During the life time of the project has the consortium established collaboration(s) with other teams (not already participating in the JTC 2015 project)?
	Sustainability of the collaboration (obtaining further funding for the same consortium)	Have the results led to new initiatives in other types of funding programmes?
	Intensity of collaboration, early researcher participation (mobility)	List of meetings, young researchers involved in the project, prizes and awards[3], lab visits/exchange of researchers, and training within the consortium.
2. Promote multi-disciplinary consortia and to encourage translational research proposals	Consortium Composition	List of research groups
	Patient Involvement	patients/patient representatives involved in planning and/or conducting the research project?
	Patents and other outcomes with public health impacts	Patents and other outcomes with impact to health
3. Support the development of innovative or shared resources and technologies	Evaluation of the development and the use of new resources	Has the consortium created a new or further developed an existing transnational patient registry, database or biobank? Have the consortium partners exchanged biomaterials (DNA, tissues, cells, animals)? Including data management
4. Support research to develop new strategies for diagnosis, therapy, and rehabilitation procedures	Evaluation of the development of new strategies for diagnosis, therapy, and rehabilitation procedures for neuroinflammation.	Have the results of the NEURON research projects allowed the development of new strategies for: diagnosis, therapy (preparation of clinical trials), and rehabilitation procedures, prevention or anything else?
	Major achievements	Please list the major achievement of the consortium.

Table 4: Key performance indicators[1] in relation to the objectives of the funding programme. Grey font: questions not feasible for evaluation of ELSA scope.

Objective of the funding programme	Key performance indicators	Results (percent of funded consortia, if not specified).
1. Enhance cooperation between European scientists working in the field of neuroscience	NEURON JTC as starter of new collaboration	→ Average size of consortia: 3.6 → no fully pre-existing consortia (all PI's collaborated before) → 60% partially pre-existing consortia (2 PI's collaborated before)
	New research groups from other countries joining the consortium	→ 60% acquired new collaborations during the lifetime of the project
	Sustainability of the collaboration (obtaining further funding for the same consortium)	→ 20% had at least 2 PI's applying jointly for further funding
	Intensity of collaboration (meetings, mobility, joint publications)	→ 100% attended the midterm symposium → Each consortium held at least 3 and up to 24 meetings, (mean = 10); 37% of the meetings were attended by all partners → 60% consortia reported online meeting formats for additional exchange →~13% of all publications were published jointly in peer reviewed journals (at least 2 PI's) → 80% published at least one joint publication (at least 2 PI's)
	Level of excellence of the funded research	→ 40% of consortia reported prizes and awards (3 poster prizes, 1 travel award)
2. Promote multidisciplinary consortia and to encourage translational research proposals (from bench to beside)	Composition of the consortium	→ 58 non-permanent personnel were involved in the consortia Multi-disciplinarity PI's: → 30% of PI held dual expertise (1 per consortium or more) → average of 4 disciplines / consortia →100% included at least one philosopher / ethicist → In 80% at least one PI was a medical doctor → 60% included a legal expert
	Involvement of patients	→ Patients were involved in 60% of the projects
	Patents and other outcomes with impact to health	→ 60% produced outcomes with impact to health care including material for counselling on early Alzheimer's Disease, international recommendations and a patient database

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. This section evaluates the outcomes related to the consortium composition in terms of history and sustainability of collaboration, the interactions with other research teams, the participation of young researchers and their mobility between partner groups and lastly also the communication and dissemination of project results in joint scientific publications.

Intensity of Collaboration

The five consortia encompass overall 17 funded partners, i.e. PI’s and their research groups, plus one partner with own funds. In average 3.6 partners collaborate per funded consortia.

Previous history of collaboration between the members of a consortium before applying to ELSA-JTC2015 is used to estimate and 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 were newly formed in their individual constellation. While three consortia were based on an earlier cooperation of two partners, two of the consortia have established completely new collaborations.

NEURON funding enables the establishment of new collaborations mainly through the enlargement of pre-existing consortia (i.e. members having worked together before the project and adding new partners in the framework of ELSA-JTC2015) but also through the establishment of fully new consortia.

During the lifetime of the project, four out of five of the consortia established collaborations with other teams in Germany, Italy, Switzerland, Spain, Croatia, Poland, Romania and Moldova. One consortium applied to another funding opportunity in a new composition.

Active interactions between partners within a consortium are very relevant for the accomplishment of the project: During the lifetime of the projects, each consortium organised between three and 24 meetings; ten meetings on average. Each group organised at least two full consortium meetings and every group participated in the midterm symposium organised by NEURON.

Most meetings took place in person, but more than half of the consortia used online meetings for additional exchange.

A total of 58 persons were involved as non-permanent personnel in the projects funded: 21 postdocs/ MDs, 30 students (PhD, Masters candidates, interns), and 7 scientific personnel (e.g. translator) were involved (see Figure 1). No lab- visits or mobility periods were included in the consortia work plans.

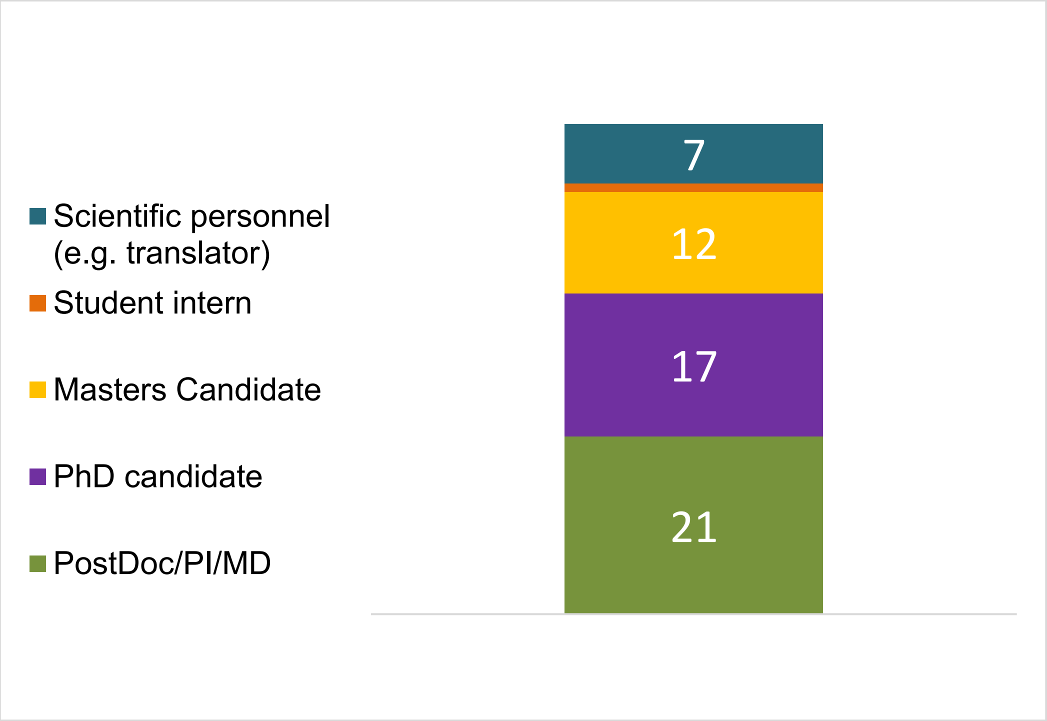

Figure 1: Academic staff participating in the funded projects by category.

Communication of Funded Research Results

The project results were communicated in scientific journals, dissertations, books, scientific meetings, and other publications (summary depicted in Table 6).

Type of publication	# overall	# joint publications
Peer reviewed articles	72	15
Books or book's chapters	24	2
Reviews	3	1
Other Communications (e.g. scientific meetings, lay audiences, new media)	185	11
Dissertations	4	0

Table 6: Total publications resulting from projects funded through JTC 2015

A total of 72 published peer reviewed articles were reported by the ELSA consortia at the time of the final reports, 6 months after finalization. Moreover, 24 books or book chapters were published. Furthermore, various routes of communications were used to disseminate results to stakeholders of relevance and public. Those encompassed posters and oral presentations at scientific congresses, presentations for further education of personnel in medicine and health care as well as students, and new media addressing the interested and broad public. Modern approaches were employed as well, e.g. blogging, webinars or a TEDxTalk.

The peer review publication rate is quite variable amongst the consortia and ranges between 2 to 22 peer reviewed[5] articles. All consortia published articles at the end of the project, and most of them declared to be still preparing further publications.

Publications including at least two partners (i.e. multi-partner publications) were considered to partially account for the intensity of cooperation within the consortium. Around 21 percent of published articles (15 articles) encompass more than one consortium partner. Four out of five consortia produced at least one multi-partner article and only one consortium produced solely single-partner articles.

Prizes and Awards

Most of the consortia proved outstanding performance. Overall, at least three poster prizes and a travel award were awarded to four early-career researchers from two consortia[3]. One consortium was able to acquire a 2-year fellowship and a studentship by a foundation to further support their project.

Summary

NEURON in general and the ELSA call specifically aims to foster international and interdisciplinary collaboration by supporting the formation of new consortia, and by cultivating them during and beyond the project lifetime as seed for new collaborations.

While the majority of the consortia was formed around two PI’s with a history of previous collaboration, none of the consortia was fully pre-existing. Thus, this funding served to establish new international scientific collaborations. Firstly, by extending previous or forming new consortia, and at a later stage by establishing collaborations with additional partners (not funded under NEURON). The overall number of involved researchers, either established PI’s or early-career researchers, is quite substantial. Especially the high quality of the early-career researchers’ project participation is noteworthy as reflected by the number of awards and fellowships.

Within the funded consortia constant scientific exchange was maintained, with single consortia being exceptionally well connected, as reflected in the number of meetings and confirmed during the midterm symposium.

In terms of sustainability, the underlying funding enables foremost a short and medium-term interaction between research partners in different countries. Only one consortium reported to have written a new grant application in the run-time. This may be due to the fact that only few alternative (national or international) funding schemes are available to apply for funding in ELSA of Neuroscience. Not surprisingly, the midterm symposium researchers stressed the need for further funding opportunities in order to form more sustainable collaborations.

Taking this feedback into account, NEURON decided to substantiate ELSA as regular call topic in the future.

The research outcomes of NEURON projects resulted in several scientific publications, dissertations, chapters in books, communications in meetings and a variety of additional dissemination paths to the broad public. A considerable number of scientific publications was co-authored by multiple partners, attesting for a constructive exchange and interdisciplinary work.

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[5] While the questionnaire did ask for Impact Factors, this indicator is not feasible for publications in the humanities. Accordingly, it will not be taken into account here.

This impact report was informed by the status six months after the formal end of the projects for comparability. At this state all consortia were still preparing further publications and therefore the outcomes will certainly be even higher then reflected in this report.

When comparing the communication paths of this ELSA call to biomedical calls funded under NEURON, it is noteworthy to highlight the variety of a) the groups addressed by the projects and b) the choice of media used for the respective dissemination. While biomedical neuroscientific dissemination is mostly focussed on peer reviewed journals, the ELSA disciplines utilize more diverse and tailored paths. Dissemination and communication overall involved a high number of channels and formats directed to the general public, including digital media like own homepages, blogs etc. This paved the way for an easier access of the general public to the progress and results of these interactions beside a scientific dissemination within the expert community.

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.

Therefore, the interaction between disciplines as well as the involvement of patients into the projects was analysed. And secondly the outcomes with impact to health were evaluated.

In order to evaluate the contribution of ELSA-JTC2015 projects in this aspect an analysis of the and second the outcomes with impact to health care was conducted.

Composition of the Consortium

The ELSA-JTC2015 consortia were very interdisciplinary as reflected in the disciplines of the PI's (not taking other staff into account). In average, PI's of four disciplines were involved per consortium. Disciplines involved were (in alphabetical order): biology, (bio)ethics, law, medicine (neurology and psychiatry), philosophy, and psychology (see Figure 2).

Each consortium held expertise in philosophy or ethics. Four out of five involved a medical researcher while the fifth consortium held expertise in biology. Three out of five included a legal expert. At least one PI per consortium held dual expertise, e.g. ethics and medicine (overall six out of the 18), in two cases this was the coordinator.

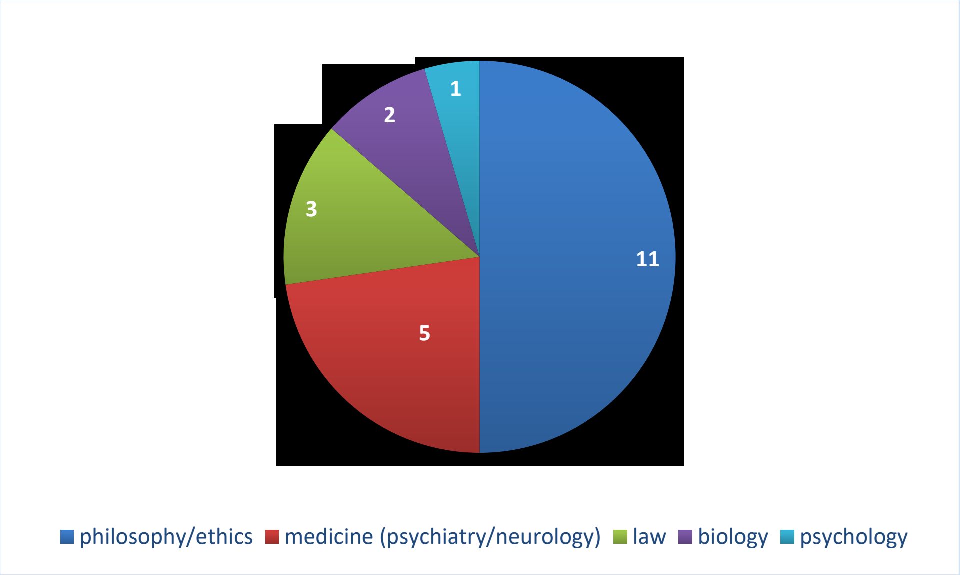

Figure 2: Disciplines involved in ELSA JTC2015 (18 PI’s; incl. own funding)

Involvement of Patients

Involvement of patients occurred in most consortia and on different levels depending on the research topic. Patients and/or patient organisations were involved in the study conduct as participants (3/3), designing of the studies (2/3), designing the study as advisory board, and interpretation of data.

Two consortia did not report patient involvement at any stage, one because no patient relevant research was conducted.

HIGHLIGHTS

Some formats for involvement have been shortly outlined and resulted in a variety of outcomes:

- Involvement as study participants, patients, and carers
- Engagement of patient representatives and other stakeholders in meeting discussions,
    - as speaker in own conference (ENSURE),
    - Workshop resulting in a paper (Interfaces).
- Engagement with stakeholders in research design
    - patient interviews for support of development of consent procedures (ENSURE),
    - e.g. rehab professionals, advocacy organisations, persons with disabilities (Interfaces),
    - patients and carers for improvement of research tools for interviews (PreDADQoL, ENSURE).

Engagement of patients and carers in analysis/interpretation (PreDADQoL).

Outcomes with Impact to Health

A positive impact to health care was generated by different outputs: an international recommendation, a patient database, guidance for counselling and risk disclosure and hand sheets for counselling on early Alzheimer’s disease detection and risk communication.

HIGHLIGHTS

- Development of hand sheets for patients and caregivers, in terms of visual aids for counselling on early Alzheimer’s Disease detection and risk communication,
- New diagnostic instrument: Development of new instruments to investigate the effects of early Alzheimer’s disease detection and dementia risk prediction (risk communication, expectations, lifestyle). These instruments may be modified for other studies or even be used in clinical practice,
- Recommendations that provide clinical researchers with tangible applications on how to a) enhance the capacity to consent of people with dementia, b) improve the assessment of decision-making capacity, c) protect those who do not have the capacity to consent, and d) ensure the inclusion of people with dementia in neuroscientific and medical research is ethically justifiable.

Summary

The encouragement of interdisciplinary collaborations in this analysed call was very successful. Two to six disciplines were represented per consortium, and each consortium held expertise in both, humanities (i.e. ethics / philosophy) and natural science (medicine or biology). It is noteworthy, that each consortium held at least one PI with multidisciplinary background (e.g. in medicine and philosophy).

The impact to health and patient care became visible, mainly in the quality of patient engagement way beyond the involvement of patients as study-subjects. In three patient centred studies, either patients or patient representatives, as well as other relevant stakeholders were involved in critical reflections of research design, tools, and interpretations of results.

Research outcomes were fruitful in providing e.g. recommendations and support of patients and caregivers. These achievements are very likely to have positive impacts in health care in future.

Annex I- Call Text JTC 2015 Excerpt

Call for Proposals for

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

Submission deadline for pre-proposals: March 09, 2015, 14:00 CET

Electronic proposal submission

For further information, please visit us on the web

http://www.neuron-eranet.eu

or contact

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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, neuroscientific research has implications for the understanding, and thus potentially also the control, of human decision-making, behaviour, emotions, and social interactions. Findings from neuroscientific research 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 neuroscientific research and recent advances in the field. 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 neuroscientific research is underlined by continuously high public interest and ongoing public discourse on this topic.

The 'Network of European Funding for Neuroscience Research' (NEURON) was established under the ERA-NET scheme of the European Commission (http://www.neuron-eranet.eu). The aim of ERA-NET NEURON is to co-ordinate research efforts and funding programmes of European and partner countries in the field of disease-related neuroscience. Under the umbrella of NEURON, seven joint transnational calls (JTCs) have been launched on different neuroscientific topics from 2008 to 2014. In acknowledgement of the high societal relevance of neuroscientific research, this year, a separate and additional JTC on "European Research Projects on Ethical, Legal, and Social Aspects (ELSA) of Neuroscience" will be launched in parallel with the regular NEURON JTC, which focusses on "European Research Projects on Neurodevelopmental Disorders" (JTC-8).

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

- Fonds de la Recherche Scientifique (FNRS), Belgium
- Canadian Institutes of Health Research – Institute of Neurosciences, Mental Health and Addiction (CIHR-INMHA), Canada
- Academy of Finland (AKA), Finland
- Federal Ministry of Education and Research (BMBF), Germany
- Foundation for Science and Technology (FCT), Portugal
- National 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 neuroscientific research and recent advances in the field.

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 interactions (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)
f) 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) bio-banking of neural tissue (e.g., tissue donation, deceased donor tissues, data protection, possible consequences for relatives)
h) 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 proposed 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 industry (e.g., pharmaceutical, medical instrumentation, etc.), health insurance companies, 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 presence. 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.

With this funding measure no empirical neuroscientific or biomedical research can be funded.

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 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

Q.1.1 Publications and communications

Type of publication	Total N°
Peer Reviewed Research Articles (acknowledging NEURON support)	
Peer Reviewed Review Articles (acknowledging NEURON support)	
Books or Book Chapters	
Dissemination Articles (to lay audiences, news articles, press releases etc.)	
Communications in Scientific Meetings	
Dissertations	
Others (letters to the editor, comments, responses, etc.)	

Add lines as appropriate

Q.1.2 List of publications and communications

A. 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, journal, year, issue, pp.)	PMID	DOI	Partner(s)	Impact factor	Open access (Y/N)
1							
PASTE ACKNOWLEDGMENT SNAPSHOT HERE							
2							
PASTE ACKNOWLEDGMENT SNAPSHOT HERE							
3							
PASTE ACKNOWLEDGMENT SNAPSHOT HERE							
4							
SUBMITTED / IN PREPARATION							

Add lines as appropriate

B. List of other communications of NEURON funded project

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

Presentation Number	Presentation Type (Oral, poster)	Venue (congress/meeting, date and location)	Partner(s)	Invited (Y/N)
1				
2				
3				
4				

Add lines as appropriate

Q.1.3 *Has the consortium communicated “negative results” as an outcome of the project?*
YES ☐ NO ☐

►If YES, please (i) indicate the publication numbers concerned (table above) (ii) specify the nature of those negative results (e.g. a murine transgenic model without phenotype):

…

Q.2 Prizes and awards

Q.2.1 *Have any 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 confered it, (ii) the individual who received it, and (ii) the work for which it was confered:

…

Q.3 Patents and other outputs with impact to health

Q.3.1 List of patents/licences

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)	Stage (deposited/granted)	Main partner	Partner(s) involved

Add lines as appropriate

Q.3.2 List of other outputs with impact to health

Please list below:

Category	Description	Partner(s) involved
Software or Prototype		
Launching a product or service		
Creation of a platform available to a community		
Creation of an enterprise		

(Startup/SME)		
fundraising		
Other (please specify)		

Q.3.3 Data management

Has a Data Management Plan been produced? YES ☐ NO ☐
If yes, do you intend to publish this plan? YES ☐ NO ☐
►If YES, please provide the link:

From JTC2019 onward the default is that NEURON will publish the final DMPs after termination of the projects.

Please list below how the consortium stored, treated and gave access to the data generated

Category	Description	Accessible by whom?	Partner(s) involved
Database or Registry			
Data Repository or Storage			
Data harmonization or simplification for international standards			
Other (please specify)			

Q.4 Consortium collaboration and sustainability

Please tick when applicable

Q.4.1 Have the partners participating in the NEURON project collaborated before applying to this NEURON call? YES ☐ NO ☐

►If YES, please indicate which partners collaborated (e.g. partner 1 with partner 2, partner 3 with partner 5):

…

Q.4.2 Has the development of the project funded by NEURON motivated the establishment of new collaboration(s) with other team(s)? YES ☐ NO ☐

►If YES, please name the institutions and countries and specify the collaboration:

…

Q.4.3 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 programme (e.g. partners 1 , 3, and 4: HORIZON 2020 call xy) :

…

Q.4.4 Intensity of collaboration: Meetings, human mobility and training within the consortium

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

Description (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, PI…)	Gender	Last degree obtained	Employed using NEURON funds?

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

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

Q.5 Development of innovative or shared resources and technologies

Q.5.1 Has the consortium created a new or further developed an existing transnational…
Patient registry ☐ Patient database ☐ Biobank ☐ N/A ☐ ?
►If YES, please complete (repeat this section as many times as necessary):
Name of the registry/database/biobank: …
How was the registry/database/biobank created?
Totally new set-up ☐ By compiling existing national sources ☐
How were new patients recruited?
Via existing network of clinicians ☐
Through the development of NEW networks of clinicians ☐
Please specify how the registry/database/biobank will be maintained/financed after the end of this project: …
Is the the registry/database/biobank in open acces?

Q.5.2 Have the consortium partners exchanged resources?
Biological samples (DNA, RNA, tissue samples, cell lines, etc.) ☐
Viral vectors ☐
Reagents (indicators, chemical compounds, etc.) ☐
Animals ☐
Clinical data ☐
N/A ☐
►If YES, please specify:
Have the shared samples allowed common studies? YES ☐ NO ☐
Did the number of samples suffice to reach the goal? YES ☐ NO ☐
Are data / materials made openly accessible (beyond the consortium) YES ☐ NO ☐
If yes, please specify: …

Q.6 Potential health impact / achievements

Please list the major acheivements of the consortium.

Achievements	Brief description of achievement	Expected impact (research, treatment, policy, etc.)

Identification of new genes	☐		
Development of innovative screening systems	☐		
Identification and characterisation of biomarkers	☐		
Validation of biomarkers	☐		
Generation of novel model systems (animal or cellular)	☐		
Development of innovative therapies	☐		
New medical treatments	☐		
New medical devices	☐		
Neurosurgical innovation	☐		
Rehabilitation procedures	☐		
Prevention	☐		
Other (please specify)	☐		

Add lines as appropriate

Q. 7 Patient engagement

Were patients/patient representatives involved in planning and/or conducting the research project?
YES ☐ NO ☐

►If YES, please specify:
designing the research project ☐
conducting / coordinating the research project (e.g. patient committee / advisory board) ☐
analysing / interpreting research data ☐
dissemination of results ☐

►Please briefly describe the patient engagement:
…

►If NO, please explain why patients were not involved:
…

Annex III: Data excerpt

Indicator/Measure	ENSURE	INSOSCI	INTERFACES	PNS	PreDADQoL	Total
Full new consortium	NO	YES	NO	NO	YES	2
Addition of research group	YES	NO	YES	NO	YES	3
Subsequent applications	YES	NO	NO	NO	NO	1
Intensity of Collaboration						
- number of meetings	5	4	3	17	22	51
- meetings with all partners	2	4	2	2	9	19
Excellence						
- total number of peer reveiwed publications	21	10	17	22	2	72
- number of joint publications	4	0	8	3	3	18
- Books or book’s chapters	1	8	9	3	3	24
- Reviews	1	1	0	0	1	3
- Dissertations	0	3	0	1	0	4
- other	1	51	27	59	47	185
- number of granted prizes and awards	0	0	2	2	2	6
Composition of consortia						
- coordinator is a medical doctor	NO	NO	YES	NO	YES	2
- number of medical doctors	3	0	2	3	2	10
- number of multidisciplinary PIs	2	1	1	1	1	6
- number of disciplines involved in the consortium	6	2	4	5	3	20
Involvement of patients or patient-derived material	YES	NO	YES	NO	YES	3
designing the research project	NO	NO	YES	NO	YES	2
conducting/coordinating research project	YES	NO	YES	NO	NO	2
analysis/interpreting data	YES	NO	YES	NO	YES	3
Databases/registries/biobanks created	0	0	0	0	1	3
Exchange of:						
- clinical data	NO	NO	NO	NO	YES	1
Outcome with impact to health	YES	NO	YES	NO	YES	3
Major achievements:						
- other	YES	NO	NO	NO	YES	2