

DISCLAIMER: At present, the Intrinsic Consciousness Theory (ICT) as a conceptual model, is not empirically testable by quantitative measures, it is however not incompatible with empirical findings. Presently, work is on-going in SP12 and in collaboration with empirical neuroscientists in and beyond HBP to deepen the relevance of ICT to and its relation with cognitive neuroscience. Additionally SP12 has clarified its intentions to work on the possibilities and ethical consequences of brain-imaging research.

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Abstract:	<p>This deliverable is the annual summary of HBP deliveries and results (outputs and outcomes) from Sub Project (SP) 12 on Ethics and Society. The live complete catalogue of HBP deliveries is accessible online from the HBP portal. The report includes key results from all work-packages of this SP.</p> <p>The main deliveries from Apr 2017 to Mar 2018 were as follows.</p> <ol style="list-style-type: none"> 1) Foresight report 1 and 2 on dual use and community and infrastructure development. 2) Philosophical and fundamental neuroethics work on the brain and its organisation, leading to a new theory of consciousness. 3) Philosophical background report on dual use. 4) Public engagement in dialogue meeting and online surveys, reaching 2,289 European citizens. 5) Workshops and webinar with experts external to the HBP on diversity of issue from data protection to infrastructure development. 6) HBP data policy Manual and researcher awareness workshops and webinar on data governance and stewardship, strengthening HBP data governance with a data protection officer (DPO). 7) New communication profile and expression for SP12.
Keywords:	ethics, society, consciousness, neuroethics, foresight, engagement, data policy, general data protection regulation, GDPR, Human Brain Project



Human Brain Project



**& Ethics
Society**

Executive Summary

Opinion on 'Responsible Dual Use'

Political, Security, Intelligence and Military Research
of Concern in Neuroscience and Neurotechnology

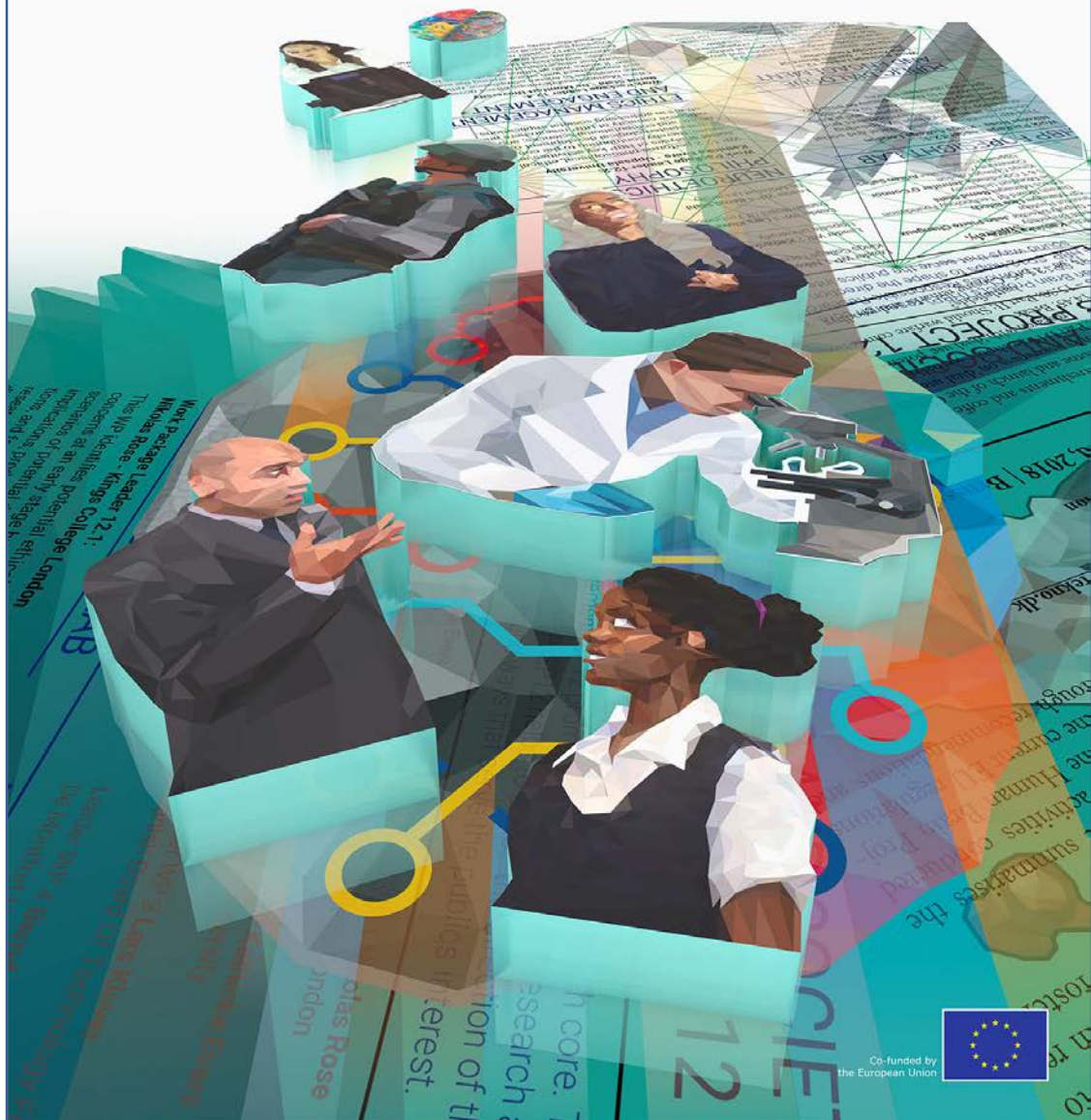


Figure 1

The front page of the executive summary of the Ethics and Society Opinion on Dual use (Picture by FT (P19))



Targeted users/readers	Researchers, policy, other interested parties
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1. Introduction

Ethics and Society is a research Sub Project (SP) of the Human Brain Project (HBP). The research activities of this SP (SP12) are chiefly based in the social sciences and the humanities. SP12 is structured on the AREA (Anticipate - Reflect - Engage - Act) framework, whose realisation it has worked for since the start of the HBP in October 2013. In the SGA1 phase (1 Apr 2016-1 Apr 2018) of the HBP, all four focal points of the AREA framework recorded key results for SP12.

ANTICIPATE: SP12 carried out collaborative research in foresight on dual use, community building and infrastructure development, resulting in two foresight briefing reports. The dual use foresight report contributed the social scientific anticipatory groundwork for the major SP12 result of the period; the SP12 Opinion on dual use. The report on community building and infrastructure building contributed part of the groundwork for the HBP to advance one of its key objectives, the development of a European research infrastructure, in the last phases of the project (details in section 2.1).

REFLECT: The dedication of SP12 to fundamental neuroethics and philosophy has recorded advances in a conceptual examination of the brain and its organisation. Importantly, the work has led to the development of a new conceptual model, the intrinsic consciousness theory, which includes an examination of the implications of this notion on the diagnosis and management of patients with awareness disorders. The result is particularly relevant for work done in HBP SP3, which has also reflected on and published its experience with application of the AREA framework (details in section 2.2).

ENGAGE: The engagement efforts of SP12 have resulted in a series of workshops and webinars inviting professional stakeholders outside the HBP to comment on issues concerning dual use, to data protection, privacy, data governance, and infrastructure development. Engagement has also resulted in engagement with 2,048 EU citizens in 19 countries through an online survey, and 2289 EU citizens took part in a face-to-face workshop from a total of nine countries. Engagement activities resulted in the addition of the views of citizens to recommendations given in the SP12 Opinion on dual use (details in section 2.3).

ACT: Key results supportive of responsible action are the HBP Data Policy Manual, and the SP12 Opinion on dual use. The latter document is the culmination of work on the anticipatory, reflective and engagement focal points of the AREA framework. The framework forms the basis of the Opinion, and its recommendations to the Human Brain Project, to the wider neuroscience and information and communication technology (ICT) community, to authorities and industry concerned with political, security, intelligence and military research and development in neuroscience, neurotechnology and brain ICT, and to EU member states and the European Union (details in sections 2.5, 2.6 and 2.7).

2. Results

2.1 Anticipate: Foresight analysis

Key Results of SP12 were the SP12-SGA1 Foresight Briefing Report 1 on *'Dual-Use' implications of neurotechnologies*, and the SP12-SGA1 Foresight Briefing Report 2 focusing on *Community Building and Infrastructure development*. These briefing reports are the result of foresight research during SGA-1, which utilise empirical social science approaches to provide Foresight Analyses to consider social and ethical implications of HBP research.

The SP12-SGA1 Foresight Briefing Report 1, has been integrated into SP12 Second Opinion Report (deliverable D12.5.4), and used to formulate recommendations and an Action Plan for embedding best practice strategies to manage potential social and ethical implications of 'Dual-Use' research and development in the Brain Sciences. This work of the Foresight Lab builds on empirical social

science approaches to provide analyses that consider social and ethical implications of HBP research, primarily focusing on 'Dual-Use' implications of neurotechnologies.

The SP12-SGA1 Foresight Briefing Report 2 focuses on community building and infrastructure development and the role of the HBP in European open research infrastructure developments.

2.1.1 Impact

2.1.1.1 Papers

- Aicardi C, Fothergill BT, Rainey S, Stahl B, Harris E. Accompanying technology development in the Human Brain Project: From foresight to ethics management. *Futures* (in press). <https://doi.org/10.1016/j.futures.2018.01.005>
- Aicardi C, Reinsborough M, Rose N. The integrated ethics and society programme of the Human Brain Project: Reflecting on an ongoing experience. *Journal of Responsible Innovation* 2017;5:13-37. <https://doi.org/10.1080/23299460.2017.1331101>
- Mahfoud T, McLean S, Rose N, editors. Vital models: The making and use of models in the brain sciences. *Progress in Brain Research*, 2017;233:2-226. <https://www.sciencedirect.com/science/journal/00796123/233/supp/C>
- Reinsborough M. Science fiction and science futures: Considering the role of fictions in public engagement and science communication work. *Journal of Science Communication* 2017;16:C07. https://jcom.sissa.it/sites/default/files/documents/JCOM_1604_2017_C07.pdf

2.1.1.2 Workshops and conferences

- 1) Science in Public 2016, University of Kent, Canterbury, 15-17 Jul 2016.
- 2) 4S-EASST conference, Barcelona, 31 Aug-3 Sep 2016.
- 3) 1st HBP Student Conference, Transdisciplinary Research Binding Neuroscience, Brain Medicine and Computer Science, Vienna, 8-10 Feb 2017.
- 4) Science in Public 2017, University of Sheffield, 10-12 Jul 2017.
- 5) Dual Use and Neuromorphic Computing, University of Heidelberg, 9-10 Nov 2017.
- 6) Science, technology and public value: Beyond responsible innovation, London, 8-9 Mar 2018.
- 7) HBP Innovation Expo, London, 23 Mar 2018

2.1.2 Component Dependencies

Component ID	Component Name	HBP Internal	Comment
625	SP12-SGA1 Foresight Briefing Report 1	Yes	This briefing report on dual-use was used as empirical background to elaborate SP12 Dual-Use Opinion (D12.5.4)
728	SP12-SGA1 Foresight Briefing Report 2	Yes	This briefing report will be used as empirical background for collaborative activities of SP12 in SGA2. It also provides the basis for the development of peer-reviewed publications.
1116	SP12-SGA1 Ethics Action Plan 1 (data protection) (report)	Yes	Dependency: SP12-SGA1 First Opinions Report (report)

1117	SP12-SGA2 Ethics Action Plan 2 (dual use)	Yes	Dependencies: SP12 SGA2 Workshop on dual use action plan (service) SP12-SGA1 Second Opinions Report Dual Use (report)
1256	SOP on informed consent	Yes	SOP providing guidance to researchers working with humans on principles of informed consent

2.2 Reflect: Theory of Consciousness and Neuronal Epigenesis

Ethics and Society has achieved substantial advances in developing a conceptual examination of the brain and its organisation.

First, the conceptual examination of neuronal epigenesis has led us to expand this theory to examine its explanatory potential for understanding the acquisition of culture, including oral and written languages; symbolic, philosophical and religious systems; and moral norms and rules. On the basis of available evidence, analysing the possibility of ethical innovation through “epigenetic proaction”, i.e. culturally shaping the functional architecture of human brains with the aim of improving, notably, well-being and health) and identifying the practical and theoretical implications of this possibility (impact publications 1-4).

Second, the conceptual examination of the brain has importantly led to the development of a new conceptual model of consciousness, the intrinsic consciousness theory (ICT), that considers the brain’s intrinsic activities (both aware and unaware) to be identical with consciousness, even if at times at a very basic level. This examination has included an examination of the implications of this notion of consciousness on the diagnosis and management of patients with disorders of consciousness (impact publications 5-9). The result is particularly relevant for work done in HBP SP3. SP12 wishes to add the disclaimer that although ICT as a conceptual model is not empirically testable by quantitative measures, it is not incompatible with empirical findings. Presently, work is on-going in SP12 and in collaboration with empirical neuroscientists in and beyond HBP to deepen the relevance of ICT to and its relation with cognitive neuroscience¹.

Third, SP12 has refined the methodology for philosophical reflection and conceptual work We call this type of philosophical reflection on neuroscientific research “fundamental neuroethics”: it uses conceptual analysis of foundational notions (concepts and methods) of neuroscience to provide the necessary background to examine the potential impact of neuroscience on topics such as the mind/brain relationship, criteria for consciousness, the question of what sets human beings apart from other species, personal responsibility, and freedom. As a starting point, SP12 takes the view that, in addition to its social and moral dimensions, brain research has important ontological and epistemic dimensions that need to be addressed, not least in order to adequately identify and manage ethical issues (impact publications 10-13). A research area for SGA2 includes investigating the possibilities and ethical consequences (including potential threats to mental privacy) of the fast progressing brain-imaging research. Members of WP12.2 have already published on some those issues elsewhere (Please see Evers & Sigman 2013²; Salles 2016³). In this work so far, the emphasis was put not just on scientific, and methodological issues but also on normative concerns (both ethical and regulatory). This work calls for the need to avoid hype and inflated interpretation of the information provided by neuroimaging, and underlines the need to engage conceptually with the topics, which includes an examination of the meaning of privacy, and of the values behind

¹ The mentioned collaborations were already enhanced by the recent HBP Consciousness conference in Barcelona, June 21-22, 2018, where the ICT was presented and discussed in very positive terms.

² Evers K, Sigman M. (2013) Possibilities and limits of mind-reading: a neurophilosophical perspective. *Consciousness and cognition*. 22(3):887-97.

³ Salles A Brain (2016) *Imaging and Privacy Concerns*. In *Neurotechnology and Direct Brain Communication*, Farisco M and Evers K (eds) (New York: Routledge) 143-156.

people's reactions when confronted with the possibility of a future in which mind reading is possible. SP12 will continue to research the topic.

The relevance of these advances to HBP's overall aims is strong: by furthering understanding of the brain's functional architectures, they enhance knowledge of what humans are and also have important practical implications, particularly in the clinic.

2.2.1 Impact

Publications

- 1) Evers K, Changeux JP. Proactive epigenesis and ethical innovation: A neuronal hypothesis for the genesis of ethical rules. Response by the authors. *EMBO Rep.* 2017; DOI 10.15252/embr.201744696.
- 2) Salles A. Neuronal epigenesis and ethics. DOI 10.15252/embr.201744697 | Published online 25.07.2017 *EMBO Rep.* 2017
- 3) Evers K, Changeux JP. Proactive epigenesis and ethical innovation: A neuronal hypothesis for the genesis of ethical rules. *EMBO Rep.* 2016;17: 1361-1364. DOI 10.15252/embr.201642783)
- 4) Changeux JP. Climbing brain levels of organisation from genes to consciousness. *Trends in Cognitive Sciences* 2017;21:168-181.
- 5) Changeux JP, Christopoulos A. Allosteric modulation as a unifying mechanism for receptor function and regulation. *Cell.* 2016;166:1084-102.
- 6) Edelstein SJ, Changeux JP. Biased allostery. *Biophys J.* 2016;111:902-8.
- 7) Koukoulis F, Rooy M, Changeux JP, Maskos U. Nicotinic receptors in mouse prefrontal cortex modulate ultraslow fluctuations related to conscious processing. *Proc Natl Acad Sci US.* 2016;113:14823-14828.
- 8) Farisco M, Evers K. The ethical relevance of the unconscious. *Philosophy, Ethics and Humanities in Medicine* 2017;12:11.
- 9) Farisco M, Laureys S, Evers K. The intrinsic activity of the brain and its relation to levels and disorders of consciousness. *Mind and Matter* 2017;15:197-219.
- 10) Salles A, Evers K. Social neuroscience and neuroethics: A fruitful synergy. In: Ibanez A, Sedeno, L., Garcia, A., editors. *Social neuroscience and social science: The missing link*, pp. 531-46. Springer; 2017.
- 11) Farisco M, Evers K, Salles A. The computational shift in neuroscience: A multifaceted neuroethical analysis. *AJOB Neuroscience* 2017;8(1):W4-W5. DOI 10.1080/21507740.2017.1293191
- 12) Evers K, Salles A, Farisco M. Theoretical framing of neuroethics: The need for a conceptual approach. In: Racine E, Aspler J, editors. *Debates about neuroethics*, pp. 89-107. Springer; 2017.;
- 13) Farisco M, Salles A, Evers K. Neuroethics: A conceptual approach. *Cambridge Quarterly of Healthcare Ethics.* (in press)

Invited conferences:

- Evers K. Simulation and consciousness: A conceptual approach. Presentation at the SP3 meeting, HBP Summit in Florence, 12 Oct 2016.
- Evers, K. The contribution of neuroethics to neuroscience. Keynote presentation at the 28th Technical Workshop, Institut Guttmann Barcelona, 18 Oct 2016.
- Evers K. Neuronal epigenesis and ethical innovation. Simposio Internacional Racionalidad Práctica en Perspectiva Neuroética. Universitat Jaume I, Castellón, Spain, 29 Jun 2016.

- Changeux JP. Toward a neuroscience of ethical normativity. Symposium Chili centre de Recherche Avancé en Education de l'université du Chili « Education des droits de l'homme: l'apport des neurosciences »
- Changeux JP. Second Ethics in Science Lecture Series Frankfurt: Conference «Toward a neuroscience of ethical normativity?» 13 Dec 2016, Frankfurt, Germany.
- Evers K. The mind that came in from the cold: Cultures of ignorance in mind science. Paper presented at: Consciousness in humans, animals and robots I: Concepts, theories, and neural mechanisms. European Institute for Theoretical Neuroscience (EITN), Paris, 9-10 Mar 2017.
- Evers, K. Neuroethics and neurotechnological developments. Swedish Parliament, 16 Mar 2017.
- Salles A. Neuroethics: Rethinking its role and its relation to philosophy. Symposium CIF. Buenos Aires, 31 Mar 2017.
- Salles A. Some philosophical issues raised by the HBP. Cambridge-ICM Neuroethics Network, Paris, France, 1 Jul 2016.
- Salles A. EU Human Brain Project: Focus on SP12. Ambassadors Program, International Neuroethics Society, 10th Annual Meeting. San Diego 10 Nov 2016.
- Salles A. participant, Ambassador Session "Reflecting on our international roots and planning our collaborative futures". International Neuroethics Society Annual Meeting, Washington DC, 9-10 Nov 2017.

Workshops:

- EITN Workshop: Consciousness in humans, animals and robots I: Concepts, theories, and neural mechanisms - co-organised by T12.2.2 with SP03, SP06, CDP03. 9-10 March 2017. <https://eitnconf-090317.sciencesconf.org/> A workshop organised by Kathinka Evers, Cyriel Pennartz, Johan Storm and Alain Destexhe (Participants: 42).
- Uppsala University, International Symposium co-organised by T12.2.2. From neuroscience to the classroom. 5-6 Apr 2017 <http://www.neuro.uu.se/kalendarium/kalendarium-detalsida/?eventId=25556> (Participants: 78).
- 6 Oct 2016. Uppsala University, International Symposium Neurotechnology and Direct Brain Communication organised by T12.2.2 (Participants: 50).
- 1 Dec 2016. at Hospital Universitario CEMIC-CONICET Buenos Aires, Universidad de Buenos Aires, el Laboratorio de Neurociencia de la Universidad Di Tella, Frontiers, Centro de Investigaciones Filosóficas (CIF) International symposium Neuroscience and child poverty: Ethical considerations co-organised by T12.2.1 (Participants: 60).
- 31 Mar 2017. CIF Buenos Aires, Argentina, Symposium From neuroscience to ethics, from politics to neuroscience? co-organised by T12.2.2 (Participants: 25).

2.2.2 Component Dependencies

Component ID	Component Name	HBP Internal	Comment
987	SP12-SGA1 Philosophy briefing report 1	Yes	This is the first briefing report on conceptual and neuroethical issues, whose outcomes will have been integrated into the First Opinions report
988	SP12-SGA1 Philosophy briefing report 2	Yes	This is the second briefing report on conceptual and neuroethical issues, whose outcomes will have been integrated into the Second Opinions report

2.3 Engagement: Public Engagement on Dual Use Issues across Europe

Ethics and Society citizen engagement activities are another key result of SP12 in SGA1 (see Table 1). Outcomes of consultations include insights about what citizens across Europe think about dual use in relation to neuroscientific research. The primary conclusion was that, although participating citizens were worried about the possible dual use of neuroscience, they still considered its positive to outweigh its negative aspects and that their worries had more to do with technological developments in general than with dual use as such. All results are available in the SP12-SGA1 Briefing report on citizen dialogues, country reports and newsletters. The results of citizen consultations feed into the SP12 Second Opinions Report (D12.5.4).

2.3.1 Achieved Impact

Publications (reports):

- Eight country reports: “Citizens’ view on neuroscience and dual use”, covering: Denmark (Jørgensen, M. L. Badum, N. B. (2018)), England (Patel, R. (2018)), Germany (Goerhs, M. Vergne, A. (2018)), Italy (Panzavolta, A. (2018)), Lithuania (Lekavičiūtė, J. (2018)), Malta (Giuliano, A. (2018)), Portugal (Mediatedomain (2018)) and Slovakia (Michalek, T. (2018)).
- Jørgensen, M. L. Badum, N. B. (forthcoming). Synthesis report on results from all eight national citizen workshops: “European citizens’ view on neuroscience and dual use”.
- Jørgensen, M. L. Badum, N. B. (forthcoming). Report on results from online citizen consultation in 10 EU member countries on neuroscience and dual use.
- Jørgensen, M. L. Badum, N. B. (forthcoming). Public perspectives on neuroscience and dual use, brief/newsletter

Table 1: Citizen dialogues and online citizen engagement^a

Online citizen engagement	Number of participants online engagement	Citizen dialogue workshop	Number of participants citizen dialogue workshop
Denmark between Oct and Dec 2017	177	Copenhagen, 25 Nov 2017, Denmark	34
Germany between Oct and Dec 2017	308	Berlin, 25 Nov 2017, Germany	24
Italy between Oct and Dec 2017	173	Modena, 25 Nov 2017, Italy	26
Portugal between Oct and Dec 2017	238	Lisbon, 25 Nov 2017, Portugal	29
Slovakia between Oct and Dec 2017	155	Bratislava, 25 Nov 2017, Slovakia	33
		Naxxar, 27 Feb 2018, Malta	32
		London, 3 Mar 2018, England	31
Lithuania between Oct and Dec 2017	273	Vilnius, 3 Mar 2018, Lithuania	32
Belgium between Oct and Dec 2017	172		
Bulgaria between Oct and Dec 2017	163		

France between Oct and Dec 2017	155		
Poland between Oct and Dec 2017	175		
	Total: 2,048		Total: 241
Participants in citizen dialogue workshops and online citizen engagement activity were randomly selected to reflect demographic criteria of the respective countries.			

Conferences/workshops:

- Human Brain Project, 2nd Curriculum Workshop series: Research, Ethics and Societal Impact, dual use and responsible research: Ethical challenges

2.3.2 Component Dependencies

Component ID	Component Name	HBP Internal	Comment
823	SP12-SGA1 Briefing report on citizen dialogues	No	Provides input for recommendations based on engagement with citizens across the EU
992	SP12-SGA1 Policy and research recommendations 2	No	Provides input for recommendations based on engagement with professional stakeholders
988	SP12-SGA1 Philosophy briefing report 2	Yes	Provides input for recommendations based in philosophical reflections on dual use
625	SP12-SGA1 Foresight Briefing Report 1	Yes	Provides input for recommendations based in empirical social scientific foresight work
1117	SP12-SGA2 Ethics Action Plan 2 (dual use)	Yes	Follows up on the Opinion with a development of an Action plan for the next phase of HBP

2.4 Engagement: Dialogue with external stakeholders

In SGA1, SP12 engaged with different communities of experts, stakeholders and possible future users of the HBP infrastructure. The workshops and webinars resulted in a better understanding of expert and stakeholder concerns from outside the HBP in relation to a number of ethical, legal and organisational issues. The themes for discussion included:

- 1) dual use;
- 2) personal data control;
- 3) privacy and data protection;
- 4) informed consent;
- 5) trust towards data-sharing platforms;
- 6) financial and organisational models for research infrastructures.

In total four workshops and four online webinars were organised. Detailed results can be found in the newsletters listed in 1.5.1, and links to the webinars are also included. Examples of recommendations coming from external experts are, for example, the following from the seminar on dual use:

- a) develop education on dual use issues to foster a culture of awareness and responsibility;
- b) continue its system of checks and balances for access to its ICT platforms, and continuously check that it offers sufficient protection against misuse;

- c) recognise that HBP leaders have a special responsibility to create a culture of responsibility and awareness of risks of misuse;
- d) initiate international discussion on use and misuse of neuroscience, robotics and ICT research with state actors and relevant international and global players.

The recommendations were taken into the project by SP12, and used to further develop its Opinion on dual use of concern, and are now also part of the policy seminar in Brussels, 22 March 2018. Participants from the 2016 seminar are also taking part in the HBP Educational Programme, e.g. Malcolm Dando at the 2nd HBP Curriculum workshop series, "Research, ethics and societal impact: Dual use and responsible research: Ethical challenges (<https://education.humanbrainproject.eu/web/2nd-hbp-curriculum-workshop-series/ethics-workshop>).

2.4.1 *Achieved Impact*

Publications and report

- 1) First series of newsletters (MS12.3.1):
 - a) Newsletter No. 3 : [Opening up the discussion on dual use in the Human Brain Project \(HBP\)](#) - used as engagement background report for SP12 Opinion on dual use;
 - b) Newsletter No. 4: [Directions for using federated data in clinical practice.](#)
- 2) Second series of newsletters (MS 12.3.3):
 - a) Newsletter No. 5: Data governance and informed consent in the Human Brain Project (in progress);
 - b) Newsletter No. 6: (on the policy seminar on dual use, 22 Mar 22, 2018).
- 3) Workshop (public engagement events)
 - a) Policy seminar on dual use, 22 Mar 2018: <http://hbp.tekno.dk/events/seminar-on-dual-use-and-research-policy/>
 - b) Seminar on data governance and informed consent in HBP, Paris, 11-12 Dec 2017: <http://hbp.tekno.dk/events/seminar-data-governance-and-informed-consent/>
 - c) Stakeholder workshop on using the Medical Informatics Platform (MIP) in clinical practice, Copenhagen, 3 Oct 2017: <http://hbp.tekno.dk/events/workshop-using-big-data-to-understand-the-human-brain-and-its-diseases/>
 - d) SP12, ethics rapporteur, Joint event on dual use, HBP Summit, Florence, October 2016
- 4) Webinars
 - a) Webinar on frameworks for European Research Infrastructures, 20 Feb 2018: <http://hbp.tekno.dk/events/webinar-frameworks-for-research-infrastructures-in-europe/>
 - b) Webinar on informed consent, 6 Feb 2017: <http://hbp.tekno.dk/events/webinar-informed-consent/>
 - c) Webinar on self-tracking in the HBP, 20 Apr 2017: <http://hbp.tekno.dk/events/webinar-self-tracking-in-the-human-brain-project/>
 - d) Webinar: HBP outreach event, 5 Mar 2018: <http://hbp.tekno.dk/events/webinar-human-brain-project-outreach-event/>

2.4.2 Component Dependencies

Component ID	Component Name	HBP Internal	Comment
2398	SP12 SGA1 Stakeholder seminar: Data governance and informed consent in HBP	No	Seminar held at EITN, Paris, Dec 2017. 35 participants of which 17 were from outside the HBP.
2392	SP12 SGA1 Stakeholder workshop: patient and hospital engagement	No	Workshop held in Copenhagen 3 Oct 2017 with 32 registered participants.
1889	SP12-SGA1 - Webinar series with stakeholders	No	Four webinars (>100 registered participants): 1) webinar on informed consent; 2) Webinar on self-tracking in the HBP; 3) Webinar on frameworks for European research infrastructures; 4) HBP outreach event to inform about options for partnering projects.
726	SP12-SGA1 Second Opinions Report Dual Use	No	Provision of one section for the report based on insights from experts on potential risks of dual use arising from R&I and on how to address these within HBP research and beyond. Organisation of a seminar at HBP Summit 2016, Florence on Dual Use.
3010	SP12-SGA1 Policy Seminar on Dual Use	No	Policy seminar on dual use, 22 Mar2018, Brussels. Participants: 30-50
991	SP12-SGA1 Policy and research recommendations 1	No	Two newsletters highlighting the key elements of the discussions from the stakeholder forums and dialogue meeting plus recommendations for the HBP.
992	SP12-SGA1 Policy and research recommendations 2	No	Two newsletters (plus one to be released in Mar 2018) highlight the key elements of the discussions from the stakeholder forums and dialogue meeting plus recommendations for the HBP.

2.5 SP12 Opinion on dual use

In SGA1, the SP12 executive summary of the first version of the SP12 Opinion on dual use was finalised. In Mar 2018, the SP12 Opinion on Dual Use (D12.5.4) is going through a comprehensive process of review by the HBP Ethics Advisory Board (EAB), the HBP Science and Infrastructure Board (SIB), and EU policy makers⁴. The Opinion is the culmination of RRI anticipation, reflection and engagement activities on dual use, ending in a report as a base for recommendations to act (the fourth key of the RRI definition followed by SP12). The collected work of the SP form the basis of this Opinion and its recommendations to the Human Brain Project, to the wider neuroscience and ICT community, to authorities and industry concerned with political, security, intelligence and military research and development in neuroscience, neurotechnology and brain ICT, and to EU member states and the European Union. In addition to its recommendations the Opinion applies the principles of Responsible Research and Innovation (RRI) to the concept of 'dual use' and distinguishes between 'responsible' and 'irresponsible' research and technological development. The opinion argues for the use of the term 'dual use research of concern (DURC)'. In addition to the recommendations the conceptual clarification is of importance for the productive engagement with the communities targeted by the opinion. The Opinion lays the

⁴ Once the review process has concluded the opinion will be available here: <https://www.humanbrainproject.eu/en/social-ethical-reflective/>

groundwork for the development of an Action plan on dual use for the next phase (SGA2) of the HBP.

2.5.1 *Achieved Impact*

Please see sections under the other key results.

2.5.2 *Component Dependencies*

Component ID	Component Name	HBP Internal	Comment
823	SP12-SGA1 Briefing report on citizen dialogues	No	Provides input for recommendations based on engagement with citizens across the EU
992	SP12-SGA1 Policy and research recommendations 2	No	Provides input for recommendations based on engagement with professional stakeholders
988	SP12-SGA1 Philosophy briefing report 2	Yes	Provides input for recommendations based in philosophical reflections on dual use
625	SP12-SGA1 Foresight Briefing Report 1	Yes	Provides input for recommendations based in empirical social scientific foresight work
1117	SP12-SGA2 Ethics Action Plan 2 (dual use)	Yes	Follows up on the Opinion with a development of an Action plan for the next phase of HBP

2.6 Act: Data Policy Manual and GDPR guidelines

Ethics and Society has also delivered a key result in terms of the data governance protocols, including the HBP Data Policy Manual and a deliverable on the upcoming EU General Data Protection Regulation (GDPR) as a key result in SGA1.

The HBP Data Policy Manual contains a set of data policy principles and practices that foster research collaboration. The Manual is a cross-SP collaboration with contributions from the EAB, and required internal review by members of all scientific and technical SPs, as well as external review by subject experts. A high standard of quality for the Data Policy Manual was ensured through a conference co-organised with ORBIT (the Observatory for Responsible Research and Innovation in ICT) to bring together international expertise and cutting-edge research on the topic of data governance in large collaborative neuro-ICT projects and seek clarification on current practice, identify obstacles and barriers, and propose future ways of organising data governance. This conference informed the completion of the Manual, ensuring that it was framed appropriately with respect to the GDPR and future collaborations within and outside of the HBP.

The deliverable on Data Protection and the GDPR in the HBP provides an overview of the Regulation, its relevance to the HBP, and an explanation of the ways in which requirements are implemented in the HBP. The deliverable was written and edited by legal experts in Ethics Management (Jo Samanta, Simisola Akintoye) and the HBP Data Protection Officers (Katrine Ore, Kevin McGillivray).

Together the Data Policy Manual and the GDPR deliverable will support the work of researchers across the project, and help ensure that HBP research conforms to legislative and regulatory requirements through the Ethics Compliance process.

2.6.1 *Achieved Impact*

These items reflect the work of Ethics Management and the HBP's investment in responsible research that benefits society. Considering the ongoing centrality of data governance to

collaborative science, the impact of these Data Policy developments has the potential to extend far beyond the HBP and the neuroscience community more broadly to support infrastructural enhancements and capacities in other large projects. Together, these constitute a result that not only meets requirements and expectations for data governance in advance of the GDPR coming into effect, but exceeds the state of the art in producing high-quality, stakeholder-informed guidelines and protocols explicitly designed to foster continuing and future excellence in collaborative neuroscience and ICT research.

Publications:

- Stahl BC, Rainey S, Harris E, Fothergill BT. The role of ethics in data governance of large neuro-ICT projects (forthcoming).

Workshops and Conferences:

- The Data Governance in International Neuro-ICT Collaborations conference, organised by members of Ethics Management and ORBIT, was an HBP conference attended by members of different brain initiatives and data platforms

Collaborations:

- Further internal and external collaboration toward ongoing development of the Data Policy Manual during SGA2

2.6.2 Component Dependencies

Component ID	Component Name	HBP Internal	Comment
1116	SP12-SGA1 Ethics Action Plan 1 (data protection)	Yes	The Data Policy Result addresses data protection.

2.7 Act: Researcher Awareness of Data Governance

Another key SP12 result is researcher awareness of Data Governance, particularly the implementation of the Data Protection Action Plan within the HBP. This included the creation of a Standard Operating Procedure for Informed Consent, and co-organisation of a webinar on data protection that incorporated input from a variety of sources and stakeholders from within and beyond the HBP. Work on awareness of data governance issues also resulted in the appointment of a Data Protection Officer following the acceptance of a proposal from Ethics Management by the SIB and DIR in Jan 2017. Additionally, a conference on Data Governance and Informed Consent was also co-organised by Ethics Management, Stakeholder engagement, and the EITN (SP4). The Data Policy Manual (mentioned in the Data Policy Manual and GDPR Guidelines section) and a GDPR Factsheet have also been made available for HBP researchers. These items will help to familiarise HBP members with legislative and policy changes that affect the ways in which they approach and carry out their research.

2.7.1 Achieved Impact

Papers:

- Aicardi C, Fothergill BT, Rainey S, Stahl BC, Harris E. Accompanying technology development in the Human Brain Project: From foresight to ethics management. *Futures* 2018. <https://doi.org/10.1016/j.futures.2018.01.005>

Workshops and conferences:

- Webinar on Data Protection (featuring Katrine Ore, the HBP DPO)
- Conference on Data Governance and Informed Consent

Other:

- Appointment of Data Protection Officer for SGA1 (Katrine Ore) and SGA2 (Kevin McGillivray)
- The Data Policy Manual can be accessed by all members of the HBP and will be publicly available through the project website.

2.7.2 Component Dependencies

Component ID	Component Name	HBP Internal	Comment
1116	SP12-SGA1 Ethics Action Plan 1 (data protection)	Yes	The Data Policy Result addresses data protection.

2.8 SP12 Communication

In SGA1, SP12 made an investment in its communication materials and dissemination efforts. The final key result we present is therefore our communication materials and dissemination plan for SGA2.

2.8.1 Communication

- 1) New design and content of the Ethics and Society tab on the HBP website.
- 2) Three videos on: a) SP12; b) Data Protection; and c) informed consent.
- 3) TED talks from each AREA focal point for the SP12 website.
- 4) SP12 logo, and logos for each aspect of the Area framework.
- 5) Templates and graphical design for SP12 newsletter and reports.

2.8.2 Dissemination

- a) Newspaper and newsletter articles [Bioedge (18 Nov 2017); Weekendavisen, International Neuroethics Society Newsletter, Brainstorm Newsletter].
- b) Blogs (CRB Ethics Blog; Neuroethics Blog).
- c) HBP Open Day booth at the Summit in Glasgow, October 2017.
- d) Twitter account (@HBPEthics).
- e) Ethics and Society contribution to The HBP dissemination plan for SGA1.

2.8.3 Achieved Impact

- i. SP12 talks at the Human Brain Project Open Day, at the Summit, Glasgow, Oct 2017.
- ii. Bioedge: <https://www.bioedge.org/indepth/view/we-need-a-more-comprehensive-ethics-of-disorders-of-consciousness/12522>.
- iii. ethicsblog: <https://ethicsblog.crb.uu.se/2018/01/10/the-unconscious-deserves-moral-attention/>.
- iv. Ethicsblog <https://ethicsblog.crb.uu.se/2018/01/31/new-concept-of-consciousness-challenges-language/>.

- v. Brainstorm newsletter: <https://www.humanbrainproject.eu/en/follow-hbp/events/understanding-consciousness-scientific-quest-21st-century/>.
- vi. See individual impacts of Work Packages (WPs).

2.8.4 *Component Dependencies*

Component ID	Component Name	HBP Internal	Comment
1170	SP12-SGA1 Report on Communication actions	Yes	Collects the communication effort of SP12.

3. Component Details

The following is a list of the newly released internal Components for this deliverable.

3.1 SP12 SGA1 Stakeholder seminar: Data governance and informed consent in HBP

Field Name	Field Content	Additional Information
ID	2398	Seminar held to increase awareness within HBP on legal and ethical issues related to personal data governance. The outcome of the meeting should bring insights on how HBP can improve its credibility and trust. The seminar was held at EITN, Paris, December 2017. 35 participants of which 17 were from outside the HBP
Component Type	Service	
Contact	KLÜVER, Lars	
Component Description		
Latest Release	2017-11-30	
TRL	NA	
Location	data hosted by task providing dataset	
Format		
Curation Status	NA	
Validation - QC	Checked	There has been internal validation (SP12 and SP4) of seminar relevance, agenda and the outcome in the format of a newsletter.
Validation - Users	Yes	There has been internal validation (SP12 and SP4) of seminar relevance, agenda and the outcome in the format of a newsletter.
Validation - Publications	No	No peer-reviewed, but newsletters
Privacy Constraints	no privacy constraints	
Sharing	anonymous - share with anonymous non-consortium members	
License	Attribution	
Component Access URL	http://hbp.tekno.dk/events/seminar-data-governance-and-informed-consent/	

Technical documentation URL		
Usage documentation URL	http://hbp.tekno.dk/events/seminar-data-governance-and-informed-consent/	
Component dissemination material URL	http://www.tekno.dk/wp-content/uploads/2016/04/Newsletter_Directions_federated_data_HBP_01.pdf	Newsletter on data governance and informed consent

3.2 SP12 SGA1 Stakeholder workshop: patient and hospital engagement

Field Name	Field Content	Additional Information
ID	2392	Workshop to explore options for collaboration between HBP researchers, hospitals and patient organisations/patient support groups. The workshop was held in Copenhagen October 3rd 2017 with 32 registered participants.
Component Type	Service	
Contact	KLÜVER, Lars	
Component Description		
Latest Release	2017-09-30	
TRL	NA	
Location	data hosted by task providing dataset	
Format		
Curation Status		
Validation - QC	Yes	There has been internal validation (SP12) and external (Prof. Gitte Moos Knudsen, Copenhagen University) of workshop relevance, agenda and the outcome in the format of a newsletter.
Validation - Users	Yes	There has been internal validation (SP12) and external (Prof. Gitte Moos Knudsen, Copenhagen University) of workshop relevance, agenda and the outcome in the format of a newsletter.
Validation - Publications	No	No peer-reviewed, but newsletters
Privacy Constraints	no privacy constraints	
Sharing	anonymous - share with anonymous non-consortium members	
License	Attribution	



Component Access URL	http://hbp.tekno.dk/events/workshop-using-big-data-to-understand-the-human-brain-and-its-diseases/ http://www.tekno.dk/wp-content/uploads/2016/04/Newsletter_Directions_federated_data_HBP_01.pdf	
Technical documentation URL	https://emdesk.humanbrainproject.eu/shared/5ae8374244a0c-a7fb262d094b944a75895d785987f95d	
Usage documentation URL		
Component dissemination material URL	http://www.tekno.dk/wp-content/uploads/2016/04/Newsletter_Directions_federated_data_HBP_01.pdf	Newsletter on directions for using federated data in clinical practise

3.3 SP12-SGA1 Webinar series with stakeholders

Field Name	Field Content	Additional Information
ID	1889	Four webinars (20-35 registered participants at each webinar): 1) webinar on informed consent, 2) Webinar on self-tracking in the HBP, 3) Webinar on frameworks for European research infrastructures, 4) HBP outreach event to inform about options for partnering projects.
Component Type	Service	
Contact	KLÜVER, Lars	
Component Description		
Latest Release	2017-11-30	
TRL	NA	
Location	data hosted by task providing dataset	
Format		
Curation Status	NA	
Validation - QC	Unchecked	
Validation - Users	No	
Validation - Publications	Yes	Background for workshops and additional info for newsletters
Privacy Constraints	no privacy constraints	
Sharing	anonymous - share with anonymous non-consortium members	
License	Attribution	

Component Access URL		
Technical documentation URL	-	
Usage documentation URL	http://hbp.tekno.dk/events/webinar-frameworks-for-research-infrastructures-in-europe/ http://hbp.tekno.dk/events/webinar-informed-consent/ http://hbp.tekno.dk/events/webinar-self-tracking-in-the-human-brain-project/ https://www.youtube.com/watch?v=ePXFwA6pe5g&list=PLJEjgXhD0rY_pwyAixvLiXvqmrWtU25ME http://hbp.tekno.dk/events/webinar-human-brain-project-outreach-event/	
Component dissemination material URL	https://emdesk.humanbrainproject.eu/s/hared/5ae84f75a9383-278bad15c7d6a413e43b47bc14a92846 https://emdesk.humanbrainproject.eu/s/hared/5abb938f8b835-d67f1716b9136934ddfaf4efdc654cc9	

3.4 SP12-SGA1 Second Opinions Report Dual Use (D12.5.4)

Field Name	Field Content	Additional Information
ID	726	This is the second "opinions" reports (D12.5.4) formulating SP12 observations and recommendations about ethical and social issues arising during the course of HBP. The component provides insights from experts on potential risks of dual use arising from R&I and on how to address these within HBP research and beyond.
Component Type	Report	
Contact	KLÜVER, Lars	
Component Description		
Latest Release	2017-09-30	
TRL	NA	
Location	data hosted by other non-HBP 3rd party	
Format		
Curation Status	NA	

Validation - QC	Yes	SP12 validation, SIB, EAB validation in progress, and Check also at the policy seminar in Brussels
Validation - Users	Yes	SP12 validation, SIB, EAB validation in progress, and Check also at the policy seminar in Brussels
Validation - Publications	No	
Privacy Constraints	no privacy constraints	
Sharing	anonymous - share with anonymous non-consortium members	
License	Attribution	
Component Access URL		
Technical documentation URL	-	
Usage documentation URL	-	
Component dissemination material URL	-	

3.5 SP12-SGA1 Policy Seminar on Dual Use

Field Name	Field Content	Additional Information
ID	3010	Workshop to open the discussion on the policy recommendations provided in the SP12 Opinion on Dual Use held in Brussels March 22 2018
Component Type	Service	
Contact	KLÜVER, Lars	
Component Description		
Latest Release	2018-03-31	
TRL	NA	
Location	data hosted by task providing dataset	
Format		
Curation Status	NA	
Validation - QC	Yes	SP12 validation, and validation by external experts
Validation - Users	Yes	Feedback will be provided by seminar participants to finalise opinion on dual use



Validation - Publications	Yes	Feedback will be provided by seminar participants to finalise opinion on dual use
Privacy Constraints	no privacy constraints	
Sharing	anonymous - share with anonymous non-consortium members	
License	Attribution	
Component Access URL		
Technical documentation URL	-	
Usage documentation URL	http://hbp.tekno.dk/events/seminar-on-dual-use-and-research-policy/	
Component dissemination material URL	https://emdesk.humanbrainproject.eu/shared/5ae84fdd82369-4e155e522602f2a7d19571ee27f9b1dd	

3.6 SP12-SGA1 Policy and research recommendations

1

Field Name	Field Content	Additional Information
ID	991	The newsletters comprise short briefing reports on the stakeholder forum activities. The newsletters include research and policy recommendations as well as suggestions to action points for the HBP.
Component Type	Report	
Contact	KLÜVER, Lars	
Component Description		
Latest Release	2017-09-30	
TRL	NA	
Location	data hosted by task providing dataset	
Format		
Curation Status	NA	
Validation - QC	Yes	SP12 validation, recommendations from external experts
Validation - Users	Yes	SP12 validation, recommendations from external experts
Validation - Publications	No	No peer-reviewed, but newsletters
Privacy Constraints	no privacy constraints	

Sharing	anonymous - share with anonymous non-consortium members	
License	Attribution	
Component Access URL		
Technical documentation URL	https://emdesk.humanbrainproject.eu/shared/5abb7a8267048-69e0dc7a295b0e6d0bf9b3e462dadcf	
Usage documentation URL	-	
Component dissemination material URL	http://www.tekno.dk/wp-content/uploads/2016/04/HBP_Newsletter_DualUse_Final_01.pdf http://www.tekno.dk/wp-content/uploads/2016/04/Newsletter_FutureNeuroscience_Community_HBP_01.pdf	

3.7 SP12-SGA1 Policy and research recommendations 2

Field Name	Field Content	Additional Information
ID	992	The newsletters comprise short briefing reports on the stakeholder forum activities. The newsletters include research and policy recommendations as well as suggestions to action points for the HBP. Results will be integrated into the second and possibly third Opinions report
Component Type	Report	
Contact	KLÜVER, Lars	
Component Description		
Latest Release	2018-03-31	
TRL	NA	
Location	data hosted by task providing dataset	
Format		
Curation Status	NA	
Validation - QC	Yes	SP12 validation, validation by external expert participants
Validation - Users	Yes	SP12 validation, validation by external expert participants
Validation - Publications	No	No peer-reviewed, but newsletters
Privacy Constraints	no privacy constraints	



Sharing	anonymous - share with anonymous non-consortium members	
License	Attribution	
Component Access URL	http://www.tekno.dk/wp-content/uploads/2016/04/Newsletter_Directions_federated_data_HBP_01.pdf http://www.tekno.dk/wp-content/uploads/2016/09/Newsletter_nr.-6.pdf	
Technical documentation URL	https://emdesk.humanbrainproject.eu/shared/5abb79ee9d1e9-b985163645d86a0649894cb8b8d58eba	
Usage documentation URL		
Component dissemination material URL	http://www.tekno.dk/wp-content/uploads/2016/04/Newsletter_Directions_federated_data_HBP_01.pdf http://www.tekno.dk/wp-content/uploads/2016/09/Newsletter_nr.-6.pdf	

3.8 SP12-SGA1 Briefing report on citizen dialogues

Field Name	Field Content	Additional Information
ID	823	Report on results from the citizen consultation. The report is based on the online citizen consultation carried out in 10 countries in autumn 2017 and the face-to-face consultations carried out in 8 countries in the autumn 2017 and winter of 2018. The consultation explored the opinions, values and concerns of citizens across Europe, regarding the potential risk of HBP research on neuroscience, brain inspired computing, and robotics being applied for political, security, intelligence or military purposes.
Component Type	Report	
Contact	KLÜVER, Lars	
Component Description		
Latest Release	2018-03-31	
TRL	NA	
Location	data hosted by task providing dataset	
Format		
Curation Status	NA	

Validation - QC	Unchecked	
Validation - Users	No	
Validation - Publications	No	No peer-reviewed, but newsletters
Privacy Constraints	no privacy constraints	
Sharing	anonymous - share with anonymous non-consortium members	
License	All Rights Reserved	
Component Access URL		
Technical documentation URL	https://emdesk.humanbrainproject.eu/shared/5ab92dee48647-f1dd60aaf2d76919e5a7fc7d8a69c371	
Usage documentation URL		
Component dissemination material URL		

3.9 SP12 SGA1 Citizens online consultation

Field Name	Field Content	Additional Information
ID	2397	Citizen Engagement: Online consultation on possible dual use of research. The DBT explored the opinions, values and concerns of citizens across Europe, regarding the potential risk of HPB research on neuroscience, brain inspired computing, and robotics being applied for political, security, intelligence or military purposes. The consultation was promoted in 10 countries across Europe. A total number of 2088 citizen participated in the online consultation in autumn 2017.
Component Type	Service	
Contact	KLÜVER, Lars	
Component Description		
Latest Release	2018-03-31	
TRL	NA	
Location	data hosted by task providing dataset	
Format		
Curation Status	NA	



Validation - QC	Unchecked	
Validation - Users	No	
Validation - Publications	No	No peer-reviewed, but newsletters
Privacy Constraints	no privacy constraints	
Sharing	anonymous - share with anonymous non-consortium members	
License	All Rights Reserved	
Component Access URL		
Technical documentation URL	https://emdesk.humanbrainproject.eu/shared/5ae9b18a740cb-b95dcf85e1bf94c4bd6a109cc650f7d0	
Usage documentation URL	http://hbp.tekno.dk/wp-content/uploads/2018/05/Online-citizens-view-report.pdf	
Component dissemination material URL	<p>https://fondenteknologiraadet-my.sharepoint.com/:f:/g/personal/nbb_tekno_dk/EjwYclZiFpIOk3HQxng2wzwBI9I3XSSJr1bO13Ryxvn4Vg?e=2chy9e</p> <p>Introduction videos for the online citizen consultation on neuroscience and dual use:</p> <ul style="list-style-type: none"> • English: https://www.youtube.com/watch?v=hVw-_MvyAo0 • Danish: https://www.youtube.com/watch?v=6PcFYKpspv4 • Polish: https://www.youtube.com/watch?v=UxuclaP1xnA&t=2s • Lithuanian: https://www.youtube.com/watch?v=-ZQhU7uXPjU • German: https://www.youtube.com/watch?v=yQuRXA5YJpA • Slovakian: https://www.youtube.com/watch?v=xvEBib2Nk4I • Portuguese: https://www.youtube.com/watch?v=WNQ00aC3OmM • Italian: https://www.youtube.com/watch?v=INHcqrqE1sE 	

	<ul style="list-style-type: none"> French: https://www.youtube.com/watch?v=tZPoPfs-YXI Bulgarian: https://www.youtube.com/watch?v=F6i7ea3BDaU 	
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3.10 SP12 SGA1 Citizens meeting

Field Name	Field Content	Additional Information
ID	2396	Citizen Engagement: Face-to-face consultation on possible dual use of research. The DBT explored the opinions, values and concerns of citizens across Europe, regarding the potential risk of HPB research on neuroscience, brain inspired computing, and robotics being applied for political, security, intelligence or military purposes. A total number of 156 citizen participated in the face-2-face meetings in autumn 2017. Additional 90 participated in the face-to-face workshops in winter 2018.
Component Type	Service	
Contact	KLÜVER, Lars	
Component Description		
Latest Release	2018-03-31	
TRL	NA	
Location	data hosted by task providing dataset	
Format		
Curation Status	NA	
Validation - QC	Unchecked	
Validation - Users	No	
Validation - Publications	No	No peer-reviewed, but newsletters
Privacy Constraints	no privacy constraints	
Sharing	anonymous - share with anonymous non-consortium members	
License		It is an event not a publication or protected material.
Component Access URL	-	



Technical documentation URL	https://emdesk.humanbrainproject.eu/shared/5ae9d95d63b77-18c0d9a730695520a92515721605d891	
Usage documentation URL	http://hbp.tekno.dk/wp-content/uploads/2018/05/f2f-synthesis-report.pdf	
Component dissemination material URL	<p>https://fondenteknologiraadet-my.sharepoint.com/:f:/g/personal/nbb_tekno_dk/EiFyic--m4dMmOO4L8rBPEgBwsEWGYpyv9miwoUxMgoUFw?e=i8YGr2</p> <p>Introduction videos for citizen consultation on neuroscience and dual use:</p> <ul style="list-style-type: none"> • English: https://www.youtube.com/watch?v=hVw-_MvyAo0 • Danish: https://www.youtube.com/watch?v=6PcFYKpspv4 • Lithuanian: https://www.youtube.com/watch?v=-ZQhU7uXPjU • German: https://www.youtube.com/watch?v=yQuRXA5YJpA • Slovakian: https://www.youtube.com/watch?v=xvEBib2Nk4I • Portuguese: https://www.youtube.com/watch?v=WNQ00aC3OmM • Italian: https://www.youtube.com/watch?v=INHcqrqE1sE 	

3.11 SP12-SGA1 Ethics Action Plan 1 (data protection)

Field Name	Field Content	Additional Information
ID	1116	This is the Action Plan following the Data Protection Opinion, which lays out the actions needed to address challenges of data governance in the HBP.
Component Type	Report	
Contact	STAHL, Bernd	
Component Description		

Latest Release	2017-03-31	
TRL	NA	
Location	data hosted by other non-HBP 3rd party	
Format		
Curation Status	n/a	
Validation - QC	Pass	
Validation - Users	Yes	
Validation - Publications	Yes	One publication in review
Privacy Constraints	no privacy constraints	
Sharing	collab - share only with members of private collab	
License		
Component Access URL		
Technical documentation URL	https://emdesk.humanbrainproject.eu/shared/5ae82bb139202-50d8a5fceb269f8f5f6ec1a967552bb	
Usage documentation URL		
Component dissemination material URL		

3.12 SP12-SGA1 Foresight Briefing Report 1

Field Name	Field Content	Additional Information
ID	625	This briefing report is the result of foresight research during the first part of SGA-1. Its outcome will be integrated into SP12 Second Opinions Report (deliverable D12.5.4). The milestone will be verified by upload of the report.
Component Type	Report	
Contact	ROSE, Nikolas	
Component Description		
Latest Release	2017-05-31	
TRL	NA	
Location	data hosted by task providing dataset	
Format		



Curation Status	NA	
Validation - QC	Unchecked	
Validation - Users	No	
Validation - Publications	Yes	https://www.sciencedirect.com/science/article/pii/S0016328717301064?via%3Dihub
Privacy Constraints	no privacy constraints	
Sharing	partner - share only with the originating partner	
License	n/a	Internal document
Component Access URL	https://collab.humanbrainproject.eu/-/collab/801/nav/1	
Technical documentation URL	https://emdesk.humanbrainproject.eu/shared/59a91f257d821-d25c396ba7cb40b23c0e3eb946b0a2fe	
Usage documentation URL	-	
Component dissemination material URL	https://www.sciencedirect.com/science/article/pii/S0016328717301064?via%3Dihub	

3.13 SP12-SGA1 Foresight Briefing Report 2

Field Name	Field Content	Additional Information
ID	728	This briefing report is the result of foresight research during the second part of SGA-1, which outcome will contribute to community building in the HBP, and to collaborative SP12 activities in SGA2. The milestone will be verified by upload of the report
Component Type	Report	
Contact	ROSE, Nikolas	
Component Description		
Latest Release	2018-03-31	
TRL	NA	
Location	data hosted by task providing dataset	
Format		
Curation Status	NA	



Validation - QC	Unchecked	
Validation - Users	No	
Validation - Publications	No	
Privacy Constraints	no privacy constraints	
Sharing	partner - share only with the originating partner	
License	n/a	Internal document
Component Access URL		
Technical documentation URL	https://emdesk.humanbrainproject.eu/shared/5adda8f60153a-0bfc8b18db6a58076e57abdada67c4ac	
Usage documentation URL	-	
Component dissemination material URL	-	

3.14 SP12-SGA1 Philosophy Background Report 1

Field Name	Field Content	Additional Information
ID	987	This report is the result of neuroethics and philosophy conceptual research on dual use during the first part of SGA-1. Its outcome will be integrated into SP12 Second Opinion Report on Dual Use. The milestone will be verified by upload of the report.
Component Type	Report	
Contact	GIORDANO, James	
Component Description		
Latest Release	2017-03-31	
TRL	NA	
Location	data hosted by task providing dataset	
Format		
Curation Status	NA	
Validation - QC	Yes	SP12 validation
Validation - Users	Yes	SP12 validation
Validation - Publications	No	

Privacy Constraints	no privacy constraints	
Sharing	partner - share only with the originating partner	
License	All Rights Reserved	Internal document
Component Access URL		
Technical documentation URL	https://emdesk.humanbrainproject.eu/shared/59a91ce60bc09-eaf6d4a7d5e56eae429298a426acc635	
Usage documentation URL	-	
Component dissemination material URL	https://link.springer.com/article/10.1007/s13238-017-0493-4 https://www.frontiersin.org/articles/10.3389/fsoc.2017.00021/full https://www.readbyqxd.com/read/29135312/rethinking-the-biological-and-toxin-weapons-convention	

3.15 SP12-SGA1 Philosophy Background Report 2

Field Name	Field Content	Additional Information
ID	988	This background report is the result of conceptual analysis on the ethical issues that arise from neurotechnological assessment of consciousness. Its outcome will be integrated into SP12 Third Opinion Report on Consciousness.
Component Type	Report	
Contact	EVERS, Kathinka	
Component Description		
Latest Release	2018-03-31	
TRL	NA	
Location	data hosted by task providing dataset	
Format		
Curation Status	NA	
Validation - QC	Yes	SP12 validation
Validation - Users	Yes	SP12 validation

Validation - Publications	Yes	
Privacy Constraints	no privacy constraints	
Sharing	partner - share only with the originating partner	
License	All Rights Reserved	Internal document
Component Access URL		
Technical documentation URL	https://emdesk.humanbrainproject.eu/shared/5accaa295e978-22bbe78410aa37b9a027f86eee37befc	
Usage documentation URL	https://emdesk.humanbrainproject.eu/shared/5accaa295e978-22bbe78410aa37b9a027f86eee37befc	
Component dissemination material URL	https://www.frontiersin.org/articles/10.3389/fnhum.2017.00564/full https://link.springer.com/chapter/10.1007/978-3-319-68421-5_22 https://onlinelibrary.wiley.com/doi/abs/10.15252/embr.201744696	

3.16 SP12-SGA1 Report on Communication actions

Field Name	Field Content	Additional Information
ID	1170	Report on SP12 communication and dissemination during SGA1.
Component Type	Report	
Contact	SALLES, Arleen	
Component Description		
Latest Release	2018-03-31	
TRL	NA	
Location	data hosted by other HBP party	
Format		
Curation Status	NA	
Validation - QC	Unchecked	
Validation - Users	Yes	SP12 validation
Validation - Publications	No	
Privacy Constraints	no privacy constraints	
Sharing	consortium - share with any consortium members	



License	Attribution	
Component Access URL	https://emdesk.humanbrainproject.eu/s/hared/5ae877fe3e2a9-8d55c7dbb8a9bc2d10be0b00024746e7	
Technical documentation URL	https://emdesk.humanbrainproject.eu/s/hared/5ab90c2737596-a623df7200f3a72ac9d7de72f4cc5bdc	
Usage documentation URL		
Component dissemination material URL	https://www.youtube.com/watch?v=PRi-iEGLnUA	

4. Conclusion and Outlook

During the period Apr 2016-Apr 2018, Ethics and Society Sub Project finalised its first Opinion on Data Protection and Privacy. Through work on the first Opinion, the group has contributed to the development of the HBP's approach to data governance and management. Outcomes include the Data Governance Working Group (DGWG), the Data Policy Manuel, the HBP data protection officer (DPO), and webinars and workshops on informed consent and data stewardship engaging HBP researchers with external experts and stakeholders, including legal experts, ethicists, and patient organisations.

The Ethics and Society group also finalised the executive summary of its second Opinion on dual use issues of concern. The opinion is based on substantial analytical work on social, ethical and conceptual issues related to dual use issues and neuroscience, combined with dialogues with international experts on military dual use issues, workshop dialogues and online engagement with citizens across Europe (reaching 2289 citizens), as well as the Ethics Advisory Board, the Science and Infrastructure Board (SIB), and EU policy-makers.

Ethics and Society also started working on the issues that it will carry into the next phase (SGA2) of the Human Brain Project: consciousness and community and infrastructure development. On the topic of consciousness, the work of the group led to the development of a new conceptual model of consciousness, the intrinsic consciousness theory. The theory has implications for diagnosis and management of patients with disorders of consciousness, a result which is particularly relevant for work done in HBP Sub Project 3. On community building and infrastructure development, the group developed a showcase for how to engage with hospitals and patient organisations for inclusion into the medical informatics platform (MIP), hosted a webinar on frameworks for European Research Infrastructures and an outreach event for partnering projects in Denmark, as well as writing a foresight report on community building and infrastructure development.

In SGA2, from Apr 2018 to Apr 2020, the Ethics and Society group will organise its work into three focused 'use cases'. Work on community and infrastructure development is developed under the heading "Engaging users, communities and publics". Here we are planning to develop our work strategically in collaboration with SP5 for user mapping and need development for the High-Level Support Team (HLST), SP8 on capacity building of the MIP clinical neuroscience network and SP11 working on strategic decisions on infrastructure development drawing on experience of existing research infrastructures in the European Strategy Forum for Research Infrastructures (ESFRI) roadmap, as well as the HBP Education Programme.

Work on consciousness is developed under the heading "Brain Disorders, Consciousness, and Clinical Practice", combining sociological and internal philosophical analysis to explore practical and conceptual questions that arise when scientific findings about the brain are carried into external philosophical analyses, medical practice, legal interpretations, plus health and social policy. Planned collaborations with CDP6, SP3, SP6, and SP8 will kick-off with the first HBP International Conference "Understanding Consciousness A scientific quest for the 21st century", 21-22 Jun 2018, Barcelona, Spain.

Data governance and management remains a priority for the ethics and society group, and for SGA2 work on data governance issues will be developed under the heading "Ethics-related data governance", covering questions of animal as well as human data, data governance and management. Close collaboration is planned with the Data Curation Support Lab; the Community-driven Neuroinformatics Platform and infrastructure operations; HBP Joint Platform Support and the attendant management and coordination, and with the MIP to ensure ethical governance of patients data sharing. The key capability provided by SP12 will be ethics support to ensure that data governance within the HBP is in line with GDPR and other relevant regulations.

Learning from the lessons of the last 2 years, Ethics and Society has also scheduled a timeline and milestones at which it may present and discuss its work with the HBP directorate (DIR).