



Figure 1: Examples of SP12 outreach in SGA1 1: SP12 at the HBP Open Day 2016, the STOA exhibition in the European Parliament and its foresight panel with science fiction writers and roboticists. The full list is in the report Section 8: Dissemination.



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Abstract:	The present document reports on the SGA1 work and progress of the Human Brain Project's Subproject 12 'Ethics and Society' for the first 12 months of the period. The report includes progress reports from the Foresight Lab (12.1), Neuroethics and Philosophy (12.2), Citizen Dialogue and Engagement (12.3) and Ethics Management (12.4).		
Keywords:	Ethics, society, review		



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1. SP Leader's Overview

1.1 Key Personnel

Subproject Leader: Kathinka EVERS (UU)

Subproject Deputy Leader: Jean Pierre CHANGEUX (IP)

Subproject Manager: Lise BITSCH (FT)

Science and Technology Coordinator: Christine AICARDI (KCL)

Community coordinator: Arleen SALLES (UU)

Ethics manager: Bernd STAHL (DMU)

1.2 Progress¹

In the first 12 months of the HBP SGA1 period, SP12 has been particularly successful in the following ways:

- Setting up connections across the HBP to work on community-building for the HBP infrastructure. The connections are developed to research and work on anticipating, reflecting and engaging, as well as raising awareness on users, user needs and infrastructure needs, and demands following from our analysis
- Drawing on our work in the Ramp-Up Phase (RUP) to host a first workshop on Consciousness co-organised with SP3, SP4, CDP3 to explore this particular scientific user community
- Drawing on our work in the RUP to develop an Opinion on Data Protection and Privacy, completed with and Action Plan for implementation of our recommendation in the HBP (D12.5.2)
- Development of a number of Standard Operating Procedures (SOPs) for ethics compliance (e.g. research integrity), and establishment of collaboration with SCOPE for monitoring compliance of partnering projects
- Reform and coordination and management of the Data Governance Working Group (DGWG) and Data Policy Manual
- Coordination, continued development and management of the Ethics rapporteur program
- Supported and participated the HBP Open Day at the 2016 Summit in Florence

¹ The SP would like to add as a general comment to the present report that it has not focused on its PLA representation for the SGA1 period. Efforts have been on the PLA as a collaboration tool for the SGA2 period. The SGA1 PLA representation of the SP therefore cannot be considered up to date.



- Supported SP11 in the 28-29 November 2016 STOA exhibition at the European Parliament, by advising on our experience with reaching high-level policy-makers and contributing a showcase on public engagement to the exhibition
- Piloted a new format for interactive online engagement with the public
- Participating on invitation to the 3rd Annual BRAIN Initiative Investigators Meeting, organised by the National Institutes of Health, 12-14 December 2016
- Participated in a number of conferences as HBP representatives to raise awareness on the HBP and search out opportunities for collaboration

1.3 Deviations

The SP feared delay as a result of the delayed SGA1 signature. However, such delays have been caught up. The SP had to amend some milestones to better fit its work plan. Overall the deviations do not have implications for the planned work of the SP or the HBP overall, since SP12 will still deliver its work on time i.e. the planned Opinions and progress reports.

1.4 Impact of work done to date

The work done is beginning to show impact in the broader project in terms of increased collaboration and attention to the work of SP12 overall. For example, there is ongoing collaboration with SP6 on the concept of simulation and with SPs 3 and 4 on the topic of consciousness. We are presently co-organising HBP's first science conference in 2018 "Windows into Consciousness" which is attracting a lot of public attention. Moreover, we are further developing research on community building in neuroscience. In addition, SP12 work is increasingly embedded in the HBP through its work on Standard Operating Procedures (SOPs), data policy manual, data governance working group, compliance and ethics rapporteurs programs. Finally, SP12 is very active in the field of public engagement, organising citizen dialogues across Europe (online and face-to-face), and representing the Project at events such as the STOA exhibition in Brussels in November 2016 (organised by SP11). The exhibition featured a special section on Responsible Research and Innovation showcasing the work of SP12.

1.5 Priorities for the remainder of the phase

For the remainder of SGA1, SP12 will prioritise its work along four main lines:

- Continued support on implementation of guidelines for good data management and implementation of the Action Plan on Data Protection and Privacy
- Research on its second Opinion on Dual Use (D12.5.4)
- Research and showcase for its contribution to community building and consciousness studies in SGA2
- Research and showcase for its contribution to community building in SGA2



2. WP12.1 Foresight Analyses and Researcher Awareness

2.1 Key Personnel

Work Package Leader: Nikolas ROSE (KCL)

2.2 WP Leader's Overview

The Foresight Analyses and Researcher Awareness Work Package is in charge of analysing the social and ethical implications of HBP research, using empirical social science approaches. When Foresight is coupled with work to build capacity within the research community, by means of Researcher Awareness, capacity for social and ethical reflection and scientific responsibility can be enhanced and informed debates and decisions as to strategy among researchers and managers of research can be facilitated.

During the first 12 months of SGA1, the Foresight Lab has focused primarily on the dual use implications of neurotechnologies, while Researcher Awareness followed up on the collaborative work realised by SP12 during the RUP around data protection and privacy, and focused, in collaboration with Ethics Management (WP12.4), on the elaboration and implementation of an action plan on data protection.

2.3 Priorities for the remainder of the phase

For the next 12 months WP12.1 will focus:

- On accompanying the transition to the infrastructure phase of the project, researching strategies for community building and infrastructure development and the role of the HBP in European open research infrastructures developments;
- On developing an action plan in relation to the 2nd SP12 Opinion, on the topic of dual use, broadly speaking.



2.4 Milestones

Table 1: Milestones for WP12.1 Foresight Analysis and Researcher Awareness

MS No.	Milestone Name	Leader	Task(s) involved	Expected Month	Achieved Month	Comments
MS12.1.1	Foresight Lab briefing report for Second Opinions Report	P38-KCL	T12.1.1	M18	M15	Uploaded to EMDESK. Contributes to the 'Second Opinions Report' D12.5.4 (due M24).
MS12.1.2	Foresight Lab Briefing report on Community Building	P38-KCL	T12.1.1	M24		

2.5 Task 12.1.1 Foresight Lab

2.5.1 Key Personnel

Task Leader: Nikolas ROSE (KCL)

Other Researcher: Christine AICARDI (KCL)

Other Researcher: Saheli DATTA (KCL)

Other Researcher: Tara MAHFOUD (KCL)

2.5.2 SGA1 DoA Goals

The Foresight Lab will carry out systematic foresight exercises to identify and evaluate the potential impact of the new knowledge and technologies produced by the HBP, adapting established foresight methods already in use in different areas of medicine and ICT, including modelling, horizon scanning and scenario planning. These methods involve recurring consultations with researchers, potential industrial and professional users of new technologies, civil society groups, regulators and other interested parties. On this basis, scenarios are developed which serve as frameworks and stimuli for evaluating the possible consequences of the HBP on different areas of society. These are further discussed with key informants from a range of communities, enabling the generation of a series of recommendations for best practices directed towards HBP researchers and managers, so that they can adopt strategies to maximise scientific and social benefits and be prepared for the potential social and ethical dilemmas raised by the research.

2.5.3 Component Progress

Table 2: Description of Components for T12.1.1 (from PLA):

Component	Progress
SP12-SGA1 Foresight Briefing Report 1 This briefing report will result of foresight research conducted during the first part of SGA1. Its outcome will be integrated into SP12 Second Opinions Report (Deliverable D12.5.4). The	First draft of report completed and circulated for comment.



<p>corresponding Milestone (M18) will be verified by upload of the report.</p>	<p>Second draft currently being refined and to be recirculated for further comment.</p>
<p>SP12-SGA1 Foresight Briefing Report 2</p> <p>This briefing report will result of foresight research conducted during the second part of SGA-1, which outcome will contribute to community building in the HBP, and possibly to joint SP12 Opinions report in SGA2. The Milestone (M24) will be verified by upload of the report.</p>	<p>Report will be developed following the completion of Foresight Briefing Report 1</p>

2.5.4 Quality Control:

2.5.4.1 [SP12-SGA1 Foresight Briefing Report 1](#)

- Upstream Component:
 - SP12-RUP Foresight Report on Future Computing and Robotics (report), Task responsible T12.1.1 (RUP), released M30
- Downstream Component:
 - SP12-SGA1 Second Opinions Report Dual Use (report), Task responsible T12.5.1, status: in progress, on schedule

2.5.4.2 [SP12-SGA1 Foresight Briefing Report 2](#)

- Upstream Component:
 - SP12-RUP Foresight Report on Future Medicine (report), Task responsible T12.1.1 (RUP), released M18
 - SP12-RUP Foresight Report on Future Neuroscience (report), Task responsible T12.1.1 (RUP), released M24
 - SP12-RUP Foresight Report on Future Computing and Robotics (report), Task responsible T12.1.1 (RUP), released M30
- Downstream Component:
 - planned for SGA2

2.6 Task 12.1.2 Researcher Awareness

2.6.1 Key Personnel

Task Leader: Bernd STAHL (DMU)

Other Researcher: Stephen RAINEY (DMU)

2.6.2 SGA1 DoA Goals

Central to the practice of RRI is the ambition to improve scientific researchers' capacity to consider consequences early in the development pathway, allowing them to make better-informed judgments. Because we cannot be certain which of many possible futures we will experience, anticipatory foresight is a type of engagement with communities or individuals



that helps them build the types of capacity that they require to be successful in differing future scenarios. Hence in this Task, the result of the work of the Foresight Lab, together with other research evidence concerning future potential impacts, will be fed back to HBP researchers and managers in order to enhance their capacity to understand and evaluate the potential social, ethical, legal and cultural impacts and implications of their research. The aim is to enable all those concerned to take action to modulate research directions and priorities in the light of such ethical and social reflection on potential impacts and implications.

2.6.3 Component Progress

Overall progress includes an emphasis upon:

- Leveraging existing communications among SPs (e.g. ethics management information and processes) to focus 12.1.2 activities
- Implementing an action plan derived from the SP12 Opinion on Data Protection and Privacy (see D71.2)
 - action here stands also as a template and learning exercise for the approach to the development of the second action plan
- Developing ways of engaging with researchers across the HBP, including webinars, workshops, ‘brown bag lunches’, and other engagements with researchers across the HBP
 - Based upon feedback from ethics rapporteurs and others in consultation, both formally and informally

Table 3: Description of Components for T12.1.2 (from PLA):

Component	Progress
SP12-SGA1 Ethics Action Plan 1 (data protection) Ethics issues action plans to implement the research finding in daily SP practice	19/09/16, Started Initial draft 11/10/16, Consultation opened; Florence meeting clarifying the nature and role of the Action Plan as annex to Opinion 24/11/16, Specific invitations to comment circulated to Opinion authors 12/12/16, Invitations circulated to SP5, SP8 leaderships to comment; Data governance Working Group (DGWG); SP12 06/02/17, Completed, HBP-wide survey on implementation and gaps in terms of Opinion recommendations; SP5, SP8, SP11, SP12, DGWG 27/02/17, Revisions made 20/03/17, Discussed at SP12 Steering Committee meeting
SP12-SGA1 Ethics Action Plan 2 (dual use) Ethics issues action plans to implement the research finding in daily SP practice	Until 10 / 2016, participated in dual use workshop during Florence summit 15/02/17, Planning for a pilot workshop on dual use with HBP colleagues in Manchester



<p>SOP on Informed Consent</p> <p>SOP providing guidance to researchers working with humans on principles of informed consent</p>	<p>16/06/16, Started Initial draft</p> <p>03/11/16, Circulated draft for peer consultation with SP2, 3, 8 ethics rapporteurs</p> <p>18/11/2016, Draft for peer consultation with SP2, 3, 8 SP managers</p> <p>06/02/17, Completed Webinar on IC co-organised with 12.3.2, including internal and external stakeholders, to provide feedback on, input to, and validation of SOP</p>
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2.6.4 Quality Control:

NB: Important dimensions of SP12 SOPs, reports and generated knowledge involve many people spread all over HBP and the outside community, which cannot be well represented via the mechanisms available in this type of reporting, such as 'release', and 'dependency'.

2.6.4.1 [SP12-SGA1 Ethics Action Plan 1 \(data protection\)](#)

- Upstream component [SP12-SGA1 First Opinions Report](#) [Essential]
- Downstream [SP12-SGA1 Second Opinions Report Dual Use](#) [important]
- Use case [SP12 SGA2 - Engagement: Infrastructure with policy and stakeholders](#)

2.6.4.2 [SP12-SGA1 Ethics Action Plan 2 \(dual use\)](#)

- Upstream component [SP12 SGA2 Workshop on dual use action plan](#) [important]
- Upstream component [SP12-SGA1 Second Opinions Report Dual Use](#) [important]
- Use cases [SGA2 - SP12 - Action Plan on Dual Use, SP12 SGA2 - Engagement: Infrastructure with policy and stakeholders](#)

2.6.4.3 [SOP on Informed Consent](#), involved tasks:

- [T5.3.2 \(SGA1\) Alignment and import of strategic data from external repositories,](#)
- [T12.4.7 \(SGA1\) Management and Support of the Ethics Advisory Board,](#)
- [T12.4.3 \(SGA1\) Identification and management triage of ethical issues \(PORE\),](#)
- [T12.1.2 \(SGA1\) Researcher Awareness in HBP,](#)
- [T8.3.9 \(SGA1\) Ontologies for describing data on neurological diseases, patients,](#)
- [T8.3.3 \(SGA1\) Introducing selective inference into dimensionality reduction and clustering methods,](#)
- [T8.3.11 \(SGA1\) Brain morphological features,](#)
- [T8.2.1 \(SGA1\) Hospitals,](#)
- [T8.1.5 \(SGA1\) Distributed complex workflow engine,](#)
- [T4.5.1 \(SGA1\) Comparing models with mouse and human brains,](#)
- [T3.4.3 \(SGA1\) Loss and recovery of consciousness: pathophysiological insights,](#)
- [T3.1.3 \(SGA1\) Visual deprivation and recovery- studies with cataract-reversal individuals,](#)



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- [T3.1.1 \(SGA1\) Deep learning network constraint to human brain imaging,](#)
 - [T2.2.5 \(SGA1\) Quantitative characterization of fibre tracts,](#)
 - [T2.1.1 \(SGA1\) Imaging Genomics of the Human Brain,](#)
 - [T12.4.5 \(SGA1\) Interface with the European Commission](#)



3. WP12.2 Neuroethics and Philosophy

3.1 Key Personnel

Work Package Leader: Kathinka EVERS (UU)

Deputy Leader: Arleen SALLES (UU)

3.2 WP Leader's Overview

The neuroethics and philosophy team is in charge of analysing the conceptual underpinnings and implications of HBP research, and of identifying and articulating philosophical, ethical (notably neuroethical), issues raised by such research.

- WP12.2 was particularly successful in: a) advances in studies of consciousness and collaboration with other SPs in this area; b) advances in studies of neuronal epigenesis and application to different areas of concern, including clinical, and planning further collaboration with other SPs in this area of research; and, c) advances in refining a novel neuroethical approach and in applying such approach to examine multiple issues, from consciousness to simulation.
- WP12.2's work resulted in a number of publications (listed in Publications, below), conferences (listed in Dissemination, below) and other organised events (listed below). The nature of the research significantly advances the discussion of issues such as consciousness which has not only theoretical, but also clinical impact.
- WP12.2 also worked on Dual Use and produced a Background Report on Dual Use in preparation of the SP12 second Opinion on Dual Use.

3.3 Priorities for the remainder of the phase

We prioritise the work with the SP12 Deliverable; the second SP12 Opinion on Dual Use (D12.5.4), and a continuation of the fruitful research collaboration begun with SPs 1 and 2 (cultural impact on brain architecture and neuronal epigenesis), SPs 3 and 4 (consciousness) and Sp6 (simulation) which also links to issues such as human identity to be further examined during SGA2.

3.4 Milestones

Table 4: Milestones for WP12.2 Neuroethics and Philosophy

MS No.	Milestone Name	Leader	Task(s) involved	Expected Month	Achieved Month	Comments
MS12.2.1	Philosophy briefing report for Second Opinions Report	P83-UU	T12.2.1 T12.2.2	M18		
MS12.2.2	Philosophy briefing report for Third Opinions Report	P83-UU	T12.2.1 T12.2.2	M24		



3.5 Task 12.2.1 The Role of Contexts and Cultural Imprinting in Understanding the Brain's Functional Architectures

3.5.1 Key Personnel

Task Leader: Kathinka EVERS (UU)

Other Researcher: Jean Pierre CHANGEUX (IP)

Other Researcher: Arleen SALLES (UU)

3.5.2 SGA1 DoA Goals

This Task analyses the relationships between genotype and brain phenotype; the paradox of non-linear evolution between genome and brain complexity; the selection of cultural circuits in the brain during development; and the genesis and epigenetic transmission of cultural imprints. This also concerns the acquisition of oral and written languages, symbolic, philosophical and religious systems, and connects to the issues of cultural diversity and universality of ethical predispositions. We proceed to discuss the combinatorial explosion of brain representations, and the channelling of behaviour through "epigenetic rules" and top-down control of decision-making. In neurobiological terms, these "rules" are viewed as acquired patterns of connections (scaffoldings), hypothetically stored in frontal cortex long-term memory, which frame the genesis of novel representations and regulate decision-making in a top-down manner. The relevance of this Task to the HBP's overall aims is strong: understanding the role of contexts and cultural imprinting is an essential aspect of understanding the brain's functional architectures.

Please see the list of publications under 'Publications' at the end of the present report.

3.5.3 Component Progress

Table 5: Description of Components for T12.2.1 (from PLA)

Component ²	Progress
SP12-SGA1 Philosophy briefing report 1 This is the first briefing report on conceptual and neuroethical issues, which outcomes will have been integrated into the First Opinions report (Deliverable D12.5.2).The Milestone will be verified by upload of the report	First draft of report completed and circulated for comment within WP12.2. Report finalised as MS12.1.1.
SP12-SGA1 Philosophy briefing report 2 This is the second briefing report on conceptual and neuroethical issues, which outcomes will have been integrated into the Second Opinions	Report will be developed following the completion of Philosophy Briefing Report 1 - the report is MS12.2.2.

² [1] Please note, both tasks have the same components. The reports collect up on the outcome of both tasks for integration into the Opinions of SP12. Please see the description of the report in the table.



report (Deliverable D12.5.4).The Milestone will be verified by upload of the report	
<p>SP12-SGA1 Second Opinions Report Dual Use</p> <p>This is the second “opinions” reports formulating SP12 observations and recommendations about ethical and social issues arising during the course of HBP</p>	WPs involved: WP12.1, WP12.2, WP12.3, WP12.4 & WP12.5. The Opinion is progressing according to plan. The contribution of WP12.2 and its tasks is described above.
<p>Ethics and Society Overview</p> <p>Representation and classification of all ethical issues in the HBP; serves the purpose of prioritising research and actions</p>	The overview is continuously updated. Last discussed during the Ethics rapporteur meeting in Bristol 28-29 March 2017.

3.5.4 *Quality Control:*

3.5.4.1 [SP12-SGA1 Philosophy briefing report 1](#)

- Upstream Components:
 - T3.3.3 Optogenetic manipulation of episodic encoding and retrieval in hippocampal, parahippocampal and mesencephalic dopamine cells [important]
 - T3.3.3 Decoded spike patterns of neural ensembles in cortex and hippocampus during multimodal scene representation [important]
 - T3.3.3 Multi-area recordings from visual and somatosensory cortices, perirhinal and entorhinal cortex and hippocampal CA1 [important]
 - SP6-T6.1.4-SGA1- Integration of Subcellular Models in Single Neuron Models [important]
 - Position paper on the workflows and strategies for intracellular and synaptic modelling [important]
 - Structure-function in healthy subjects [important]
 - Structure-function in DOC patients [important]
 - TMS-EEG data in sleep and anesthesia [important]
 - EEG data in DOC patients [important]
 - TMS-EEG data in DOC patients [important]
 - Large-scale modelling of TMS/EEG-PCI [important]
 - Mechanistic analysis of ERP in mice [important]
 - EEG in rodents [important]

All upstream Components: collaboration received for development of first joint workshop seminar of a series, providing input for philosophy briefing report 1 with good results.

- Downstream Components:



- SP12-SGA1 First Opinions Report [important]

Philosophy briefing report 1 developed for downstream Component, received and uploaded to HBP internal repository.

3.5.4.2 [SP12-SGA1 Philosophy briefing report 2](#)

- Upstream Components:
 - SP6-T6.1.4-SGA1- Integration of Subcellular Models in Single Neuron Models [important]
 - Position paper on the workflows and strategies for intracellular and synaptic modelling [important]
 - Structure-function in healthy subjects [important]
 - Structure-function in DOC patients [important]
 - TMS-EEG data in sleep and anesthesia [important]
 - EEG data in DOC patients [important]
 - TMS-EEG data in DOC patients [important]
 - Large-scale modelling of TMS/EEG-PCI [important]
 - Mechanistic analysis of ERP in mice [important]
 - EEG in rodents [important]

All upstream Components: collaboration received for development of first joint workshop seminar of a series, providing input for philosophy briefing report 1 with good results

- Downstream Components:
 - SP12-SGA1 Second Opinions Report Dual Use [essential]

D12.5.4, due in M24.

3.5.4.3 [SP12-SGA1 Second Opinions Report Dual Use](#)

- Upstream:
 - SP12-SGA1 Ethics Action Plan 1 (data protection) [important]
 - SP12-SGA1 Foresight Briefing Report 1 [essential]
 - SP12-SGA1 Philosophy briefing report 2 [essential]
 - SP12-SGA1 Policy and research recommendations 2 [essential]
 - SP12-SGA1 Briefing report on citizen dialogues [essential]

Upstream components received in good quality, except for Briefing report on citizen dialogues, which is due in the second half of SGA1.

- Downstream Components:
 - SP12-SGA2 Ethics Action Plan 2 (dual use) [important]

Several additional downstream Components are being explored (e.g. in SP11).



3.6 Task 12.2.2 Philosophical and Ethical Challenges of Modelling Cognitive Processes in Silica

3.6.1 Key Personnel

Task Leader: Arleen SALLES (UU)

Other researcher: Kathinka EVERS (UU)

Other researcher: Michele FARISCO (UU)

3.6.2 SGA1 DoA Goals

Problem-oriented computer simulations of specific systems and functions of the brain are extensively used to test predictions, validate conclusions and models, and to guide hypothesis-driven experiments and new models at various levels of analysis. Rapid advancements in neuroscience and in computing draw increasing attention to large-scale brain simulations, including the modelling of cognitive processes *in silico*.

These attempts raise numerous philosophical and ethical challenges that are explored in this Task. Many of them revolve around the notions of consciousness, self, and identity. Some of the questions that we are examining include how to understand the relationship between brain activity and consciousness; whether consciousness could be achieved via simulation; how this would relate to the human mind, self and identity; what cerebral features specifically characterise human identity; and whether clinical applications of neuroscientific advances (DBS, for example) change the identity of users. The examination of these issues has both theoretical value and clinical relevance.

3.6.3 Component Progress

Table 6: Description of Components for T12.2.2 (from PLA)

Component ³	Progress
SP12-SGA1 Philosophy briefing report 1 This is the first briefing report on conceptual and neuroethical issues, which outcomes will have been integrated into the First Opinion report (Deliverable D12.5.2). The Milestone will be verified by upload of the report	Philosophy Briefing report 1 (MS12.1.1) consists of the contribution of the WP to the reflections on privacy and in D12.5.2 and the First Opinion on Privacy and Data Protection which is completed. The report is the second half of MS12.1.1.
SP12-SGA1 Philosophy briefing report 2 This is the second briefing report on conceptual and neuroethical issues, which outcomes will be integrated into the Second Opinion report	Report will be developed following the completion of Philosophy Briefing Report 1 - the report is MS12.2.2.

³ Please note, both tasks have the same components. The reports collect up on the outcome of both tasks for integration into the Opinions of SP12. Please see the description of the report in the table.



(Deliverable D12.5.4).The Milestone will be verified by upload of the report	
SP12-SGA1 Second Opinions Report Dual Use This is the second “opinion” reports formulating SP12 observations and recommendations about ethical and social issues arising during the course of HBP	WPs involved: WP12.1, WP12.2, WP12.3, WP12.4 & WP12.5. The Opinion is progressing according to plan.
Ethics and Society Overview Representation and classification of all ethical issues in the HBP; serves the purpose of prioritising research and actions	The overview is continuously updated. Last discussed during the Ethics rapporteur meeting in Bristol 28-29 March 2017.

3.6.4 Quality Control:

3.6.4.1 [SP12-SGA1 Philosophy briefing report 1](#)

- Upstream Components:
 - T3.3.3 Optogenetic manipulation of episodic encoding and retrieval in hippocampal, parahippocampal and mesencephalic dopamine cells [important]
 - T3.3.3 Decoded spike patterns of neural ensembles in cortex and hippocampus during multimodal scene representation [important]
 - T3.3.3 Multi-area recordings from visual and somatosensory cortices, perirhinal and entorhinal cortex and hippocampal CA1 [important]
 - SP6-T6.1.4-SGA1- Integration of Subcellular Models in Single Neuron Models [important]
 - Position paper on the workflows and strategies for intracellular and synaptic modelling [important]
 - Structure-function in healthy subjects [important]
 - Structure-function in DOC patients [important]
 - TMS-EEG data in sleep and anesthesia [important]
 - EEG data in DOC patients [important]
 - TMS-EEG data in DOC patients [important]
 - Large-scale modelling of TMS/EEG-PCI [important]
 - Mechanistic analysis of ERP in mice [important]
 - EEG in rodents [important]

All upstream components received as collaboration on joint workshop seminar on consciousness disorders (list of events, point 5).

- Downstream Components:



- SP12-SGA1 First Opinions Report [important]

D12.5.1 is submitted for approval.

3.6.4.2 [SP12-SGA1 Philosophy briefing report 2](#)

- Upstream Components:
 - SP6-T6.1.4-SGA1- Integration of Subcellular Models in Single Neuron Models [important]
 - Position paper on the workflows and strategies for intracellular and synaptic modelling [important]
 - Structure-function in healthy subjects [important]
 - Structure-function in DOC patients [important]
 - TMS-EEG data in sleep and anesthesia [important]
 - EEG data in DOC patients [important]
 - TMS-EEG data in DOC patients [important]
 - Large-scale modelling of TMS/EEG-PCI [important]
 - Mechanistic analysis of ERP in mice [important]
 - EEG in rodents [important]

Collaborations are ongoing with owners of the mentioned components.

- Downstream Components:
 - SP12-SGA1 Second Opinions Report Dual Use [essential]

D12.5.4, due M24.

3.6.4.3 [SP12-SGA1 Second Opinions Report Dual Use](#)

- Upstream Components:
 - SP12-SGA1 Ethics Action Plan 1 (data protection) [important]
 - SP12-SGA1 Foresight Briefing Report 1 [essential]
 - SP12-SGA1 Philosophy briefing report 2 [essential]
 - SP12-SGA1 Policy and research recommendations 2 [essential]
 - SP12-SGA1 Briefing report on citizen dialogues [essential]

Upstream components received in good quality, except for Briefing report on citizen dialogues, which is due in the second half of SGA1.

- Downstream Components:
 - SP12-SGA2 Ethics Action Plan 2 (dual use) [important]

Several additional downstream Components are being exploring (e.g. in SP11).



4. WP12.3 Public Dialogue and Engagement

4.1 Key Personnel

Work Package Leader: Lars KLÜVER (FT)

4.2 WP Leader's Overview

WP12.3 is in charge of public engagement activities, including citizen meetings, citizen online consultations and Stakeholder Forums. During the first 12 months of the SGA1, the WP has been focusing on Dual Use and on collaborating with SP2, SP3 and SP8 on stakeholder engagement in clinical practices, data protection and informed consent. Dual use has been addressed by building on activities held during the RUP, to: develop an online survey; an information video; an online interactive public consultation space (will be launched in five languages during SGA1); a workshop at the HBP Summit on dual use with the EAB, Ethics Rapporteurs and all relevant SPs.

4.3 Priorities for the remainder of the phase

In the remaining 12 months WP12.3 will:

- Organise the citizen meetings focusing on Dual Use;
- Test and launch the online consultation on robotics and future computing;
- Establish a showcase for engaging new hospitals and centres in the Federated Network of Hospitals and Centres that constitutes the initial Medical Informatics Platform (SP8);
- Conduct interviews with stakeholders on research and policy recommendations related to data sharing policies in the MIP: legal aspects, informed consent and publication policies;
- Facilitate dialogue between relevant HBP researchers and policy stakeholders on how to develop a legal framework for the HBP Research infrastructure;
- Write up policy and research recommendations from the stakeholder engagement activities.

1.1 Milestones

Table 7: Milestones for WP12.3 Public dialogue and engagement

MS No.	Milestone Name	Leader	Task(s) involved	Expected Month	Achieved Month	Comments
MS12.3.1	Policy and research recommendations from stakeholder engagement (Round 1)	P19-FT	T12.3.2	M18		
MS12.3.2	Newsletters from citizen dialogues	P19-FT	T12.3.1	M18		



MS12.3.3	Policy and research recommendations from stakeholder engagement (Round 2)	P19-FT	T12.3.2	M24		
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4.4 Task 12.3.1 Citizen Dialogue and Consultation

4.4.1 Key Personnel

Task Leader: Marie Louise JØRGENSEN (FT)

Other researchers: Karen RIISGAARD (FT)

Other researchers: Lise BITSCH (FT)

4.4.2 SGA1 DoA Goals

This Task will include citizen consultations with the use of a diversity of methods, including online consultations. One citizen consultation will be carried out each second year, involving citizens with a geographic spread over Europe. The citizens will provide their assessments on an informed basis and in general the methods used will involve deliberation between citizens or between citizens and experts. The results, thus, will uncover the reflected answers of the citizens, in contrast to the reflex answers gathered through ordinary polling techniques. The methods will be chosen according to the topic at hand since there is no one-size-fits-all method in public participation methodology. The citizen dialogues and consultations will each be reported as concise reports and/or Briefs/Opinions.

4.4.3 Component Progress

Component description (from the PLA):

Three additional components have been added after the SGA1 Interim report (M1-M6). The added components reflect the work in the task more precise and provide in this way an accurate view of the components.

Table 8: Description of Components for T12.3.1 (from PLA)

Component	Progress
SP12-SGA1 -Citizens meeting Face-to-Face consultation with citizens	Results from citizen webinars held in different European countries during the RUP (February 2016) have been integrated in a newsletter on data federation and privacy. Based on the results from the RUP and the online consultation, FT has been analysing the topic 'Dual Use' for face-to-face citizen dialogues. A method for face-to-face consultations is currently being developed. Expected achievements include: Newsletter : EU citizens want to be informed of use of their personal data. Released: 2016/01/10. Poster on public engagement for HBP Summit 2016: presenting the objectives of the public engagement activities. Citizens workshop on Dual Use. Planned: Jan 2018.
SP12 SGA1 -Citizens online consultation	FT has developed a concept for an online forum that can host different issues related to HBP research on robotics and supercomputing. Based on previous discussions and analyses on Dual



<p>Online consultation on dual use</p>	<p>Use issues conducted by Foresight Lab and FT, an online survey has been developed by FT based on the software 'Engage Suite' originally developed for the method 'Global Say'. The survey was supported by a 4-minute information video highlighting the key arguments and point of views in the discussion. The online survey ran as a pilot in Denmark, but will be launched in five languages within SGA1. Expected achievements include:</p> <p>SP12 Booth on Dual Use. FT contributed to the booth with two posters on SP12 public engagement activities and an online survey on Dual Use at the Open Day, HBP Summit 2016. Held: 12 October 2016, Florence.</p> <p>Pilot version of online survey in Denmark: on robotics and supercomputing. Held 17-24 January 2017.</p> <p>Online survey in five languages: on robotics and supercomputing. Planned: Autumn 2017.</p>
<p>SP12-SGA1 Second Opinions Report Dual Use</p> <p>This is the second "opinions" reports formulating SP12 observations and recommendations about ethical and social issues arising during the course of HBP.</p> <p>WPs involved: WP12.1, WP12.2, WP12.3, WP12.4 & WP12.5</p>	<p>FT has contributed to the task by summarising recommendations from citizens and stakeholders collected during the public engagement activities held during RUP. The recommendations have been presented in a newsletter on Dual Use. In addition, FT held a workshop obligatory for SP12, EAB and HBP Ethics Rapporteurs on dual use issues. The Ethics Rapporteurs were asked to present dual use issues from their SP point of view and possible solutions were discussed in a plenary session.</p> <p>Achievements include:</p> <p>Joint workshop on Dual Use: FT organised an SP12, EAB and Ethics Rapporteurs joint workshop with the scope to provide input for the Dual Use Opinion. Held 14 October 2016, Florence.</p> <p>Newsletter: Opening up the discussion on dual use in the Human Brain Project (HBP). Released: 01 October 2016.</p> <p>Poster on stakeholder engagement for HBP Summit 2016: presenting Stakeholder Forum activities.</p>
<p>Ethics and Society Overview</p> <p>Representation and classification of all ethical issues in the HBP; serves the purpose of prioritising research and actions</p>	<p>The citizen dialogue and consultations aim at consolidating societal needs and concerns related to ethical and societal issues arising from the HBP research. The outcome of the coming citizen dialogues and consultations will contribute to this overview.</p>
<p>SP12-SGA1 Briefing report on citizen dialogues</p> <p>A collection of newsletters from online and face-to-face citizen dialogues and surveys, including recommendations of action for HBP policy and communication. Results will be integrated into the second and possibly third Opinions</p>	<p>FT has summarised recommendations collected from EU citizens during the RUP and presented them in a newsletter. The newsletter present citizens' recommendations on use of personal data in research projects and on use of personal data to the HBP. Achievements (KPIs) include:</p> <p>Newsletter: EU citizens want to be informed of use of their personal data. Released 01 October 2016.</p>

report. Deliverable verified by upload of the report.	
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Figure 2: From the information video developed in relation to the online citizens consultation on robotics and supercomputing.

4.4.4 Quality control:

4.4.4.1 [SP12-SGA1 -Citizens meeting](#)

- Upstream Components:
 - [SP12 SGA1 -Citizens online consultation](#) [important]

The prototype for the online consultations has been reviewed and new version is under implementation. Good complimentary tool for face-to-face meetings.

- Downstream Components:
 - [SP12-SGA1 Briefing report on citizen dialogues](#) [essential]

The downstream Component is due at the end of SGA1. More possibilities for downstream Components are being developed, including further collaboration with SP11. The briefing report is the basis for the T12.3.1 contribution to the SP12 second Opinion on dual use (D12.5.4)

4.4.4.2 [SP12 SGA1 -Citizens online consultation](#)

- Upstream Components:
 - [SP12 - RUP Newsletter Opening up the discussion on dual use in the HBP](#) [essential]
 - SP12-RUP Foresight Report on Future Computing and Robotics [essential]

Both upstream Components received in good quality.

- Downstream Components:



- [SP12-SGA1 -Citizens meeting](#) [important]
- [SP12-SGA1 Briefing report on citizen dialogues](#) [essential]

Downstream Components for second half of SGA1.

4.4.4.3 [SP12-SGA1 Second Opinions Report Dual Use](#)

- Upstream Components:
 - SP12-SGA1 Ethics Action Plan 1 (data protection) [important]
 - SP12-SGA1 Foresight Briefing Report 1 [essential]
 - SP12-SGA1 Philosophy briefing report 2 [essential]
 - SP12-SGA1 Policy and research recommendations 2 [essential]
 - SP12-SGA1 Briefing report on citizen dialogues [essential]

4.4.4.4 [Ethics and Society Overview](#)

- Upstream Components:
 - SP12-SGA1 Briefing report on citizen dialogues[important]
 - SP12-SGA1 Policy and research recommendations 2 [important]
 - SP12-SGA1 Policy and research recommendations 1 [important]
 - Ethics Registry [important]

4.4.4.5 [SP12-SGA1 Briefing report on citizen dialogues](#)

- Upstream Components:
 - [SP12 SGA1 -Citizens online consultation](#) [essential]
 - [SP12-SGA1 -Citizens meeting](#) [essential]
 - SP12-RUP - Webinar: Dual use and neuroscience - An online debate on current developments [essential]
 - Ethics and Society Overview [important]

Upstream Components received in good quality, online consultations in development, prototype reviewed. Citizens meetings are in planning, and Component only due end of SGA1.

- Downstream Components:
 - Ethics and Society Overview [important]
 - SP12-SGA1 Second Opinions Report Dual Use [essential]

Input not yet developed, since report not due yet.

4.5 Task 12.3.2 Stakeholder Forums

4.5.1 *Key Personnel*

Task Leader: Karen RIISGAARD (FT)

Other researchers: Marie Louise JØRGENSEN (FT)

Other researchers: Lise BITSCH (FT)



4.5.2 SGA1 DoA Goals

The main objectives of the Stakeholder Forums are to facilitate dialogue between HBP scientists and external stakeholders on issues of possible controversy and immediate relevance to the HBP. The Stakeholder Forums give stakeholders outside HBP an opportunity to comment on the ongoing research and give their concerns and provide input to future research directions. The activities include online webinars and face-to-face seminars and workshops. The outcome of the Stakeholder Forums will be communicated in a collection of newsletters with recommendations for protocols and policy options.

4.5.3 Component Progress

Three additional components have been added after the SGA1 Interim report (M1-M6). The added components reflect the work in the task more precise and provide in this way an accurate view of the components.

Table 9: Description of Components for T12.3.1 (from PLA)

Component description	Progress
<p>SP12 SGA1 Stakeholder workshop: on HBP research infrastructure</p> <p>Workshop to explore options for engaging stakeholders in developing the research infrastructure</p>	<p>FT is working on a workshop to explore options for engaging stakeholders and user communities in developing the HBP research infrastructure. The Component will facilitate dialogues between bureaucrats, HBP and policy makers to discuss and explore legal options for constructing a research infrastructure. Planned: January 2018</p>
<p>SP12 SGA1 Stakeholder workshop: patient and hospital engagement</p> <p>Workshop to explore options for collaboration between HBP researchers, hospitals and patient organisations/patient support groups</p>	<p>FT is working with SP8 on a strategy for engaging new hospitals in sharing data with HBP (SP8) Medical Informatics Platform. The strategy includes a pilot workshop in Denmark with major Danish hospitals, healthcare professionals, policy makers, patient organisations, experts on data protection and informed consent, and HBP researchers, with the scope to invite Danish hospitals to join a network of hospitals to share brain related data.</p>
<p>SP12-SGA1 - Webinar series with stakeholders</p> <p>Webinar to discuss issues on clinical implications of work with simulation and disease signatures with stakeholders external to the HBP.</p>	<p>FT has been looking at ways to increase stakeholder involvement to improve the quality and acceptance of the HBP research. Focus has been on traditional patient stakeholders such as patient organisations, but also unorganised stakeholders such as patients' custodies and health centred self-tracking communities. Activities in First twelve months of the SGA1 include 1) Webinar on Informed Consent. FT and SP12 Ethics Management co-organised a webinar to open a discussion on the issues related to informed consent from patients and research participants. Held 6 February 2017; 2) Support and participation in STOA Exhibition at the European Parliament: Held 29-30 November 2016.</p>
<p>SP12-SGA1 Second Opinions Report Dual Use</p> <p>WPs involved: WP12.1, WP12.2, WP12.3, WP12.4 & WP12.5 This is the second "opinions" reports formulating SP12 observations</p>	<p>FT contributes to the component through both its Stakeholder Forum activities on dual use, and its online and face-to-face citizen consultations. The newsletter from its stakeholder consultation on dual use can be found: http://www.tekno.dk/wp-content/uploads/2015/10/HBP_Newsletter_DualUse_Final.pdf</p>



<p>and recommendations about ethical and social issues arising during the course of HBP.</p>	<p>Or: https://flagship.kip.uni-heidelberg.de/jss/FileExchange/HBP_Newsletter_DualUse_Final.pdf?fID=1582&hbpUsID=166</p>
<p>SP12-SGA1 Policy and research recommendations 1</p> <p>A collection of newsletters from stakeholder forums (online and face-to-face) with external experts and HBP research on societal and ethical issues of immediate relevance to the HBP</p>	<p>During the Stakeholder Forums stakeholders and HBP researchers provides discuss different ethical and societal issues of relevance for HBP. In the first year of the SGA1, T12.3.2 developed a background report for the SP12-SGA1 Second Opinions Report (MS12.3.1).</p> <p>In addition, the webinar co-organised with ethics management provided input for the SOP on informed consent.</p>
<p>SP12-SGA1 Policy and research recommendations 2</p> <p>A collection of newsletters from stakeholder forums (online and face-to-face) with external experts and HBP research on social and ethical issues of immediate relevance to the HBP. Results will be integrated into the second and possibly third Opinions report.</p>	<p>Stakeholder Forums organised by T12.3.2 are open spaces taking on issues of immediate to near term relevance for the HBP. In the second year, the Task plans forums on involvement of hospitals in the MIP and on developing the demand side for the HBP ICT infrastructure. Recommendations will feed into the work of SP8 and SP11 mainly.</p>

4.5.4 Quality control:

4.5.4.1 [SP12 SGA1 Stakeholder workshop: on HBP research infrastructure](#)

- Upstream Components:
 - SP12-SGA1 - Webinar series with stakeholders [added value]

Upstream Component is under development.

4.5.4.2 [SP12 SGA1 Stakeholder workshop: patient and hospital engagement](#)

- Upstream Component:
 - SP12-SGA1 - Webinar series with stakeholders [important]

First webinars on informed consent held successfully in collaboration with T12.1.2.

- Downstream Component:
 - SP12 SGA2 - Webinars on use, user communities for development of the HBP research infrastructure [essential]

Under development.

4.5.4.3 [SP12-SGA1 - Webinar series with stakeholders](#)

- Upstream Components:
 - SP12-RUP Foresight Report on Future Medicine [essential]



- SP12-RUP Newsletter: Living up to privacy and informed consent in the Human Brain Project [essential]

Received in good quality.

- Downstream Components:
 - SP12 SGA1 Stakeholder workshop: on HBP research infrastructure [added value]
 - SP12 SGA1 Stakeholder workshop: patient and hospital engagement [important]

Both workshops are currently being planned in collaboration with SP8 and SP11 respectively. The PLA will be updated once collaboration progresses.

4.5.4.4 [SP12-SGA1 Second Opinions Report Dual Use](#)

- Upstream Components:
 - SP12-SGA1 Ethics Action Plan 1 (data protection) [important]
 - SP12-SGA1 Foresight Briefing Report 1 [essential]
 - SP12-SGA1 Philosophy briefing report 2 [essential]
 - SP12-SGA1 Policy and research recommendations 2 [essential]
 - SP12-SGA1 Briefing report on citizen dialogues [essential]

All Components are developed and received in good quality. Briefing report on citizen dialogues is set for later release.

- Downstream Components:
 - SP12-SGA2 Ethics Action Plan 2 (dual use) [important]

Not yet relevant for SGA1 ;1-M12.

4.5.4.5 [SP12-SGA1 Policy and research recommendations 1](#)

- Upstream Components:
 - Ethics and Society Overview [important]
 - SP12-RUP - Webinar: Dual use and neuroscience - An online debate on current developments [important]
 - SP12-RUP - Webinar: Future Computing and Robotics in the Human Brain Project [important]
 - SP12-RUP - Webinar part 2: Multi-level patient data federation and the development of personalised medicine for brain diseases [important]
 - SP12-RUP - Webinar part 1: Multi-level patient data federation and the development of personalised medicine for brain diseases [important]
 - SP12 RUP Newsletter: Opening up the Human Brain Project to the neuroscience community. [important]
 - SP12-RUP Newsletter: Living up to privacy and informed consent in the Human Brain Project [important]

All Components are developed and received in good quality. Briefing report on citizen dialogues is set for later release.



- Downstream Components:
 - Ethics and Society Overview [important]
 - SP12-SGA1 First Opinions Report [essential]

Contributions to both Components delivered.

4.5.4.6 SP12-SGA1 Policy and research recommendations 2

- Upstream Components:
 - [Ethics and Society Overview](#) [important]
 - [SP12-RUP - Webinar: Future Computing and Robotics in the Human Brain Project](#) [important]
 - [SP12-RUP - Webinar part 2: Multi-level patient data federation and the development of personalised medicine for brain diseases](#) [important]
 - [SP12-RUP - Webinar part 1: Multi-level patient data federation and the development of personalised medicine for brain diseases](#) [important]
 - [SP12-RUP - Webinar: Dual use and neuroscience - An online debate on current developments](#) [important]
 - [SP12-SGA1 First Opinions Report](#) [important]

For release in the second half of SGA1.

- Downstream Components:
 - [Ethics and Society Overview](#) [important]
 - [SP12-SGA1 Second Opinions Report Dual Use](#) [essential]

For release in the second half of SGA1.



5. WP12.4 Ethics Management

5.1 Key Personnel

Work Package Leader: Bernd Carsten STAHL (DMU)

5.2 WP Leader's Overview

During the first 12 months of SGA1, the Ethics Management WP has consolidated the work undertaken during the Ramp-Up Phase and further developed the various streams of work on ethics management.

Following the ethics review at the end of the Ramp-Up Phase, we modified a number of processes and instituted new ones. A key activity that was not explicitly covered in the SGA1 proposal but that turned out to occupy a significant amount of our efforts was the further development of data policy. This work was undertaken collaboratively with all SPs but led by Ethics Management.

The theme of data management is key to a number of policies / SOPs that were developed, notably the following:

- [SOP on Informed Consent](#)
- [SOP on Animal Data from non-European Countries](#)
- [Data Policy Manual](#)
- [Data protection Action Plan](#)
- [SOP Compliance management](#)
- [EAB SOP](#)
- [SOP ethics rapporteurs](#)
- [SOP Research integrity](#)

Work on compliance management was continued to the point where we now have a full Ethics Registry. The other Tasks described below went according to plan, with the EAB meeting three times during the first 12 months of the SGA1 and the Ethics Rapporteurs meeting twice.

The Ethics Check following the M6 submission was less positive than expected with the Ethics Reviewers raising a number of issues. These are now addressed and the rejected Deliverables are being resubmitted at the end of M12.

5.3 Priorities for the remainder of the phase

For the next 12 months we will focus on the transition to the infrastructure phase of the project. This means that the work on data governance will be further intensified, with the appointment of a Data Protection Officer / function agreed by SIB and DIR. Ethics Management will contribute to the other SP12 WPs, notably by contributing to the Dual Use Opinion and work with the EAB on issues of robotics.



5.4 Milestones

Table 10: Milestones for WP12.4 Ethics Management

MS No.	Milestone Name	Leader	Task(s) involved	Expected Month	Achieved Month	Comments
MS12.4.1	First report on ethics management activities	P16-DMU	WP12.4	M6		"Verification: his report will include action plan for EAB, rapporteurs and the list of issues reported in M1-M6 in the ethics registry. The Milestone will be verified by upload of the report."
MS12.4.2	Second report on ethics management activities	P16-DMU	WP12.4	M24		

5.5 Task 12.4.1 Principles and Implementation of Ethics Management

5.5.1 Key Personnel

Task Leader: Bernd STAHL (DMUI)

Other Researcher: Kevin GRIMES (Karolinska Institute)

Other Researcher: Abdul MOHAMMED (LNU)

5.5.2 SGA1 DoA Goals

- Continue development of Ethics Map (now Ethics and Society Overview)
- Contribute to HBP Education Programme
- Represent Ethics Management within HBP organisational structures (added in M6 reporting)
- Continuing to chair the Data Governance Working Group until such time as appropriate management structures have been Implemented

All goals are on target.

5.5.3 Component Progress

Table 11: Description of Components for T12.4.1 (from PLA)

Component Details	Progress Comments
<p><u>Data Governance Working Group</u></p> <p>The HBP Data Governance Working Group (DGW) was created by decision</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The DGWG has had teleconferences every 2 weeks.



<p>of the SIB on 20 May 2016. Its purpose is to identify cross-cutting data governance issues that affect different parts of the HBP, clarify them and find possible solutions. The DGWG collaborates with other bodies in the HBP, notably the SIB, Directorate, with the scientific and technical coordinators and with relevant bodies such as the Ethics Management team, or the Ethics Advisory Board.</p>	<ul style="list-style-type: none"> • There was also a physical meeting in Frankfurt at the beginning of February (M11). • The DGWG has produced a Data Policy Manual (release SGA2 M1) which outlines the processes and protocols for uploading, storing, using, and sharing data within the HBP. This includes issues of data protection and data from non-EU countries.
<p><u>First Report on Ethics Management Activities</u></p> <p>This report includes an action plan for EAB, rapporteurs and the list of issues reported in M1-M6 in the ethics registry. The Milestone will be verified by upload of the report.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The DGWG has been led by the Ethics Director and several SP12 members have contributed to the meetings and the Data Policy Manual. • These contributions have ensured that ethical considerations of data are included in the discussions and the manual. • Ethics Management has regular weekly meetings • Corresponds to the MS 12.4.1 and was released at M6.
<p><u>Second Report on Ethics Management Activities</u></p> <p>This report includes an updated version of the ethics registry and the ethics map, and activity reports for the EAB and the rapporteurs. The Milestone will be verified by upload of the report.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The DGWG has been led by the Ethics Director and several SP12 members have contributed to the meetings and the Data Policy Manual. • These contributions have ensured that ethical considerations of data are included in the discussions and the manual. • Ethics Management has regular weekly meetings
<p><u>SP12-SGA1 Second Opinions Report Dual Use</u></p> <p>WPs involved: WP12.1, WP12.2, WP12.3, WP12.4 & WP12.5 This is the second “opinions” reports formulating SP12 observations and recommendations about ethical and social issues arising during the course of HBP.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • There was a physical meeting of SP12 at which progress was made on the Dual Use Opinion. The Ethics Director contributed a flowchart.
<p><u>Trilateral Meetings</u></p> <p>These meetings are between SP Leaders, Ethics Rapporteurs, Ethics Management, the EAB, and any SP12 members who wish to join. The aim of each individual SP meetings is to:</p>	<p>Progress:</p> <ul style="list-style-type: none"> • Currently in progress (February to June 2017). • Several ethical issues, such as data protection, and compliance issues, such as missing surveys, have been resolved. • (Also see Trilateral Meetings below under 12.4.7: EAB Progress Table)



<ul style="list-style-type: none"> • Bring everyone up-to-date on the ethical issues in respective SPs, and • To go through the ethics parts of the SP, for the mid-term SGA1 EC review. <p>These are collaborative efforts to ensure ethical issues can be discussed and addressed.</p>	
<p><u>Ethics and Society Overview</u></p> <p>Prev. Ethics Map. The overview represents and classifies all ethical issues in the HBP, and it serves the purpose of prioritising research and actions in SP12.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • Meeting about Ethics Map at Summit in Oct 2016. Decision taken by SP to rename Ethics and Society Overview and to broaden scope away from a 'map' format, which was quite technical. • A 'Prezi' presentation has been produced by EM to help communicate the ideas easily.

5.6 Task 12.4.2 Standard Operating Procedures

5.6.1 Key Personnel

Task Leader: Bernd STAHL (DMU)

Other Researcher: Abdul MOHAMMED (KI)

5.6.2 SGA1 DoA Goals

- Identifying candidates for SOPs
- Formulating such SOPs
- Consulting with relevant stakeholders
- Integrating them into broader HBP management structures and monitoring their impact

All goals are progressing on target.

5.6.3 Component Progress

Table 12: Description of Components for T12.4.2 (from PLA)

Component	Progress Comments
<p><u>Ethics SOPs</u></p> <p>Standard Operating Procedures provide rules and guidelines on best practice for a number of ethical issues in the HBP</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The Research Integrity SOP will outline the HBP's position on Research Integrity and the research conduct it expects from researchers. It also covers what the process is for reporting and investigating research misconduct. • It will be discussed by the EAB at the physical meeting at the end of M12.



	<ul style="list-style-type: none"> • The Animal Data SOP outlines the processes for the use of animal data from third/non-EU countries. • The final consultation phase on this SOP was at the Ethics Advisory Board meeting in Bristol. There were also several workshops on animal research which allowed the sharing of best practice with those from other projects. • Informed Consent SOP updates are below.
<p><u>SOP on Informed Consent</u></p> <p>SOP providing guidance to researchers working with humans on principles of informed consent</p>	<p>Progress:</p> <ul style="list-style-type: none"> • Approaches, although equivalent, are disparate. • Since the original submission we have widely consulted on the informed consent SOP. • Experts inside and outside (via a webinar, and the independent EAB) the HBP have agreed its worth. This scrutiny and agreement is recorded in the SOP. • The current document outlines fundamental principles in one document from which PIs can draw from to ensure their work is in compliance with IC norms. • There is a variety of research activities, and of research contexts. Each of these must be taken into account in terms of the research tasks at hand -- consent must be keyed to research activity. • A general notion of 'consent' is insufficient for dealing with this detail. As such, a general template is not possible -- ether of the relevant guidelines and regulations such that PIs can read the SOP, select those factors relevant to their research, and construct their consent forms and information sheets in the light of them. • This single point of reference for H2020 regulation (and beyond) is the most ethically efficacious means of providing consistent compliance for this area. • This provides the touchstone whereby ethics management can provide consistent oversight. • A plan is underway to submit this current document as a proposal for streamlining international IC procedures in other multi-stakeholder research contexts. • The progress is that having identified the need for an SOP on Informed Consent, one has now been written, scrutinised, given approval and an action plan has been created for the SOP to be fully implemented.
<p><u>First Report on Ethics Management Activities</u></p> <p>This report includes an action plan for EAB, rapporteurs and the list of issues reported in M1-M6 in the ethics registry. The</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The development of these SOPs will fill gaps in the knowledge of researchers and the practical processes approved by the HBP. • Corresponds to the Milestones achieved in M6.



<p>milestone will be verified by upload of the report.</p>	
<p><u>Second Report on Ethics Management Activities</u></p> <p>This report includes an updated version of the ethics registry and the ethics map, and activity reports for the EAB and the rapporteurs. The milestone will be verified by upload of the report.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The development of these SOPs will fill gaps in the knowledge of researchers and the practical processes approved by the HBP. • This will be recorded in the report.
<p><u>PORE reports</u></p> <p>Point of Registration of Ethical Issues - Requests to address ethics, regulatory and social issues in HBP research may come from any corner, any time - during initial planning of an experiment through phases of implementation, from within the project community or from outside. Having a POint of REgistration (PORE) is a way to identify and keep track of these issues.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • Issues raised in PORE can inspire the need for SOPs. • During M1-12 of SGA1 the PORE reporting process became a fully implemented process which allowed people (either in the project or outside it) to raise concerns about ethical issues • There were a number of reports raised and these were discussed by the Ethics Management team and decisions regarding possible actions were taken. • In the process of these discussions it became clear that there were areas in the HBP that required SOPs, for example informed consent.



5.7 Task 12.4.3, Identification and Management Triage of Ethical Issues (PORE)

5.7.1 Key Personnel

Task Leader: Kevin GRIMES (KI)

5.7.2 SGA1 DoA Goals

T12.4.3, PORE (POint of Registration of Ethical, regulatory, social or philosophical issues), enables the registration of such issues, in order that they may be further examined, if appropriate, by a responsible body. The SP12 Steering Committee has final review responsibility. The PORE is maintained under this Task to create, and coordinate an online facility that any person can use to register an issue. The PORE SOP describes this utility, including how the information received is processed, and under what levels of accessibility for the purpose of data protection. The PORE registry reports to the Ethics Management in weekly meetings. The Ethics Manager manages the communication between the Ethics Management and the Steering Committee.

5.7.3 Component Progress

Table 13: Description of Components for T12.4.3 (from PLA)

Component Details	Progress Comments
<p><u>PORE reports</u></p> <p>Point of Registration of Ethical Issues - Requests to address ethics, regulatory and social issues in HBP research may come from any corner, any time - during initial planning of an experiment through phases of implementation, from within the project community or from outside. Having a POint of REgistration (PORE) is a way to identify and keep track of these issues.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • Ongoing overview by Ethics Manager • All reports are reviewed thoroughly by Ethics Management • Streamlined (for improvement) web form http://www.hbp-pore.eu/ by Ethics Management. • Three new requests (#35, 36 and 37) received between 30 April and 16 September 2016. • Modification of form on 16 September 16. • No new requests 16 September 2016 to 22 March 2017.
<p><u>SP12-SGA1 Second Opinions Report Dual Use</u></p> <p>WPs involved: WP12.1, WP12.2, WP12.3, WP12.4 & WP12.5 This is the second "opinions" reports formulating SP12 observations and recommendations about ethical and social issues arising during the course of HBP.</p>	<ul style="list-style-type: none"> • PORE reports can be a way for researchers or members of the public to raise concerns about Dual Use. • The existence or absence of these reports helps inform the Dual Use report and thus progress the writing of it.



<p><u>SOP on Informed Consent</u></p> <p>SOP providing guidance to researchers working with humans on principles of informed consent.</p>	<ul style="list-style-type: none"> • PORE issues raised identified a need for an SOP on informed consent. • See above for progress.
<p><u>First Report on Ethics Management Activities</u></p> <p>This report includes an action plan for EAB, rapporteurs and the list of issues reported in M1-M6 in the ethics registry. The milestone will be verified by upload of the report.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • Issues raised fed into activities outlined in report.
<p><u>Second Report on Ethics Management Activities</u></p> <p>This report includes an updated version of the ethics registry and the ethics map, and activity reports for the EAB and the rapporteurs. The milestone will be verified by upload of the report.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • Issues raised fed into activities outlined in report.

5.7.4 Quality control:

- Upstream Components:
 - Ethics Manager has final authority over the content of the online form, with discussion and recommendation by the Ethics management group. For example, the form has been streamlined to reduce content
- Downstream Components:
 - Ethics Management “hears” each case and determines together whether and to which body the request is sent. Ethics manager has final authority
 - Registered PORE requests are distributed as above. Progress and outcome are determined by Ethics management through various means and reported back to PORE (T12.4.3) in the weekly meeting minutes.

This process ensures quality control.

5.8 Task 12.4.4, Ethics Compliance

5.8.1 Key Personnel

Task Leader: Emma HARRIS (DMU)

Other Researcher: Shamim PATEL (KI)



5.8.2 SGA1 DoA Goals

- Ensure that all Task Leaders identify any ethical issues that their research raises and provided any necessary documentation.
- Record and monitor ethical status of all tasks in registry
- Collect ethical approval documents and provide guidance and advice on this process
- Conduct internal review of ethical approvals
- Conduct meetings with SP Leaders and Partnering Projects

(All on target, 95% response rate)

5.8.3 Component Progress

Table 14: Description of Components for T12.4.4 (from PLA)

Component	Progress Comments
<p><u>Ethics Registry</u> Overview of all ethical issues in the HBP, including repository of all approvals and related documents.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The registry has been updated to include information on Partnering Projects, the new and edited tasks in SP5, and on-going ethics information and documents supplied by task leaders. • There is now a 95% response rate across the HBP. This has been achieved by progressing the process through communication with Task Leaders and SP Managers. • The survey components have fed into these updates as they are the information collection system. • The registry allows SP12 to have an overview of what H2020 ethical issues are in the HBP for use in the ethics map and reports. • A copy of the registry is made available to EC reviewers only.
<p><u>Ethics Self-assessment Survey</u> This is an interactive version of the H2020 ethics self-assessment survey for all task leaders to complete</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The survey has been sent out to PPs and new Task Leaders in SP5. • Guidance and support has been provided as an ongoing process in M1-12. • The monitoring and storage of the ethical status of all Tasks has been constantly progressed in SGA1. • The survey format is completed for SGA1. • It will be updated and refined for SGA2. • Links are available via the PLA.
<p><u>Research Ethics Document Registration</u> Detailed information to be collected from all PIs regarding their research</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The survey has been sent out to PPs and new task leaders in SP5. • It will be updated and refined for SGA2.



<p>and ethical approvals, sent to those who indicate any ethical issues in their work in the Self-Assessment Survey</p>	<ul style="list-style-type: none"> • Guidance and support has been provided as an ongoing process in M1-12. • The monitoring and storage of the ethical status of all Tasks has been constantly progressed in SGA1.
<p><u>First Report on Ethics Management Activities</u></p> <p>This report includes an action plan for EAB, rapporteurs and the list of issues reported in M1-M6 in the ethics registry. The Milestone will be verified by upload of the report.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The registry allows SP12 to have an overview of what H2020 ethical issues are in the HBP for use in the report on ethics management activities. • Work to improve the response rate from Task Leaders has progressed the links between compliance and the wider ethics and society SP.
<p><u>Second Report on Ethics Management Activities</u></p> <p>This report includes an updated version of the ethics registry and the ethics map, and activity reports for the EAB and the rapporteurs. The Milestone will be verified by upload of the report.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The registry allows SP12 to have an overview of what H2020 ethical issues are in the HBP for use in the report on ethics management activities. • Work to improve the response rate from Task Leaders has progressed the links between compliance and the wider ethics and society SP.
<p><u>Trilateral Meetings</u></p> <p>These meetings are between SP Leaders, Ethics Rapporteurs, Ethics Management, the EAB, and any SP12 members who wish to join. The aim of each individual SP meetings is to:</p> <ul style="list-style-type: none"> • Bring everyone up-to-date on the ethical issues in respective SPs, and • To go through the ethics parts of the SP, for the mid-term SGA1 EC review. <p>These are collaborative efforts to ensure ethical issues can be discussed and addressed.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • Currently in progress (February to June 2017). • Several ethical issues, such as data protection, and compliance issues, such as missing surveys, have been resolved. • (Also see Trilateral Meetings below under 12.4.7: EAB Progress Table).

5.9 Task 12.4.5, Interface with the European Commission

5.9.1 Key Personnel

Task Leader: Bernd STAHL (DMU)



5.9.2 SGA1 DoA Goals

Key in this Task was the communication with the EC around the various ethics reviews and checks. In M06 an ethics submission was made that updated the various activities from the start of SGA1. This included a detailed response to the ethics review of the end of the Ramp-Up Phase.

Ensure quality in responses to ethics reviews.

Following this submission, a further ethics check was undertaken by the EC, which led to additional requests and activities. These are being addressed in parallel to this submission.

5.9.3 Component Progress

Table 15: Description of Components for T12.4.5 (from PLA)

Component Details	Progress Comments
<p><u>Data Governance Working Group</u></p> <p>The HBP Data Governance Working Group (DGWG) was created by decision of the SIB on 20 May 2016. Its purpose is to identify cross-cutting data governance issues that affect different parts of the HBP, clarify them and find possible solutions. The DGWG collaborates with other bodies in the HBP, notably the SIB, Directorate, with the scientific and technical coordinators and with relevant bodies such as the Ethics Management team, or the Ethics Advisory Board.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The DGWG has had teleconferences every 2 weeks. • There was also a physical meeting in Frankfurt at the beginning of February (M11). • The DGWG has produced a Data Policy Manual which outlines the processes and protocols for uploading, storing, using, and sharing data within the HBP. This includes issues of data protection and data from non-EU countries.
<p><u>SOP on Informed Consent</u></p> <p>SOP providing guidance to researchers working with humans on principles of informed consent</p>	<ul style="list-style-type: none"> • As part of the ethics review ethics management were requested by the EC to clarify the procedures for informed consent. • This has been progressed, see T12.4.2
<p><u>SP12-SGA1 Second Opinions Report Dual Use</u></p> <p>WPs involved: WP12.1, WP12.2, WP12.3, WP12.4 & WP12.5 This is the second "opinions" reports formulating SP12 observations and recommendations about ethical and social issues arising during the course of HBP.</p>	

5.10 Task 12.4.6 Management and Support of the Rapporteur Programme



5.10.1 Key Personnel

Task Leader: Kevin GRIMES (KI)

5.10.2 SGA1 DoA Goals

Task 12.4.6, Management and Support for the Rapporteur Programme, targets appropriate scientists and managers to act as HBP "Ethics Rapporteurs", who are assigned the responsibility to communicate with the Ethics and Society program about the ethics, and the science and technology work of their own Subproject, or cross-cutting projects. Overall, the programme aims to deepen understanding within and between both domains. Ethics Rapporteurs regularly communicate with Ethics Advisory Board members and with the Ethics Management team. Joint meetings between the three bodies are held biannually. Additional teleconference meetings as needed. A report is issued by each Rapporteur-EAB member match, pertaining to issues relevant to the specific subproject for which they are responsible.

5.10.3 Component Progress

Table 16: Description of Components for T12.4.6 (from PLA)

Component Details	Progress Comments
<p><u>Ethical Issues in the HBP: Report by EAB and Rapporteurs</u></p> <p>This Report, summarising identified ethical issues in each SP, will be updated approximately every 6 months.</p>	<p>Progress:</p> <ul style="list-style-type: none"> Covered under 12.4.7 EAB Progress Table (see below).
<p><u>Meetings of the Ethics Coordination Committee</u></p> <p>Meetings of the Ethics Rapporteurs of each SP who constitute the Ethics Coordination Committee. Meetings used to enlarge mutual (EAB and ER knowledge) understanding of the ethics and the science and technology of each SP.</p>	<p>Progress:</p> <ul style="list-style-type: none"> The full complement of Ethics Rapporteurs (ERs) is 17 (22 March 2017) The ERs convened the inaugural Ethics Coord Committee (ECC) meeting on 14 October 2016 (at the Summit). ERs convened as ECC in 3 hr meeting on 13 December 2016. Plans laid for ERs to attend Bristol and meet as ECC 29 March 2017. Website display of ER pics and info. Covered under 12.4.7 EAB Progress Table (see below).
<p><u>PORE reports</u></p> <p>Point of Registration of Ethical Issues - Requests to address ethics, regulatory and social issues in HBP research may come from any corner, any time - during initial planning of an experiment through phases of implementation, from within the project community or from outside. Having a Point of Registration (PORE) is a way to</p>	<p>Progress:</p> <ul style="list-style-type: none"> Ongoing overview. All reports are reviewed thoroughly. Streamlined (for improvement) web form http://www.hbp-pore.eu/ by Ethics Management. Three new requests (#35, 36 and 37) received between 30 April and 16 September 2016. Modification of form on 16 September 2016.



<p>identify and keep track of these issues.</p>	<ul style="list-style-type: none"> • No new requests 16 September 2016 to 22 March 2017. • The rapporteurs can use PORE to raise issues and also can advise other researchers to use it. • This process has been progressed by raising awareness of the PORE system via the rapporteurs.
<p>First Report on Ethics Management Activities</p> <p>This report includes an action plan for EAB, rapporteurs and the list of issues reported in M1-M6 in the ethics registry. The milestone will be verified by upload of the report</p>	<p>Progress:</p> <ul style="list-style-type: none"> • Issues raised fed into activities outlined in report.
<p>Second Report on Ethics Management Activities</p> <p>This report includes an updated version of the ethics registry and the ethics map, and activity reports for the EAB and the rapporteurs. The Milestone will be verified by upload of the report.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • Issues raised fed into activities outlined in report.
<p>Trilateral Meetings</p> <p>These meetings are between SP Leaders, Ethics Rapporteurs, Ethics Management, the EAB, and any SP12 members who wish to join. The aim of each individual SP meetings is to:</p> <ul style="list-style-type: none"> • Bring everyone up-to-date on the ethical issues in respective SPs, and • To go through the ethics parts of the SP, for the mid-term SGA1 EC review. <p>These are collaborative efforts to ensure ethical issues can be discussed and addressed.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • Covered under 12.4.7 EAB Progress Table (see below).

5.11 Task 12.4.7 Management and Support of the Ethics Advisory Board

5.11.1 Key Personnel

Task Leader: Shamim PATEL (LNU)



Other Researcher: Bernd STAHL - Ethics Manager/Director (DMU))

Other Researcher: Christine MITCHELL DMU)

5.11.2 SGA1 DoA Goals

The Ethics Advisory Board (EAB) is an independent, management-level body that provides advice to the HBP management on issues with ethical, regulatory, social and philosophical content. Task T12.4.7 provides the support required for the operation of the EAB.

- Support required for the operation of the EAB.

(On target)

5.11.3 Component Progress

Table 17: Description of Components for T12.4.7 (from PLA)

Component Details	Progress Comments
<p>Meetings of the Ethics Coordination Committee Meetings of the ethics rapporteurs of each SP who constitute the Ethics Coordination Committee. Meetings used to enlarge mutual (EAB and ER knowledge) understanding of the ethics & the sci and tech of each SP.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The Rapporteurs have had two physical meetings (October 2016 during the Florence summit and in March 2017 during the Bristol Meet-up - see below). They also had an adobe VC in Dec 2016. • The EAB and EM organised a meeting in Bristol (theme ethical issues re, AI and robotics). Most EAB and Rapporteurs attended. • A half day animal session was also included. Rapporteurs and EAB members collaborated with EM to address issues EC reviewers had on animal research and data from third countries. HBP animal research SOPs were also covered.
<p>Ethical Issues in the HBP: Report by EAB and Rapporteurs This Report, summarising identified ethical issues in each SP, will be updated approx every six months.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • EAB & Rapporteurs discussed ethical issues prior to the June 2016 EC review and produced a report of one-pagers. • The report was updated in October 2016 taking into account the EC review comments and changes in SGA1. • The one-pagers are currently being revisited during the trilateral EAB/EM/Rapporteur meetings (February-May 2017). • New issues have been fed into the Ethics and Society Overview Map.
<p>EAB Meetings Meetings of the EAB to discuss ethical issues in the HBP</p>	<p>Progress:</p> <ul style="list-style-type: none"> • 6 EAB members attended the Ramp-up final EC review in June 2016. (Not financed or an SGA1 activity, but it allowed for in-depth knowledge on ethical issues being carried over into SGA1 and to meet with Rapporteurs and SP leaders). • During the summit the EAB had their own Meeting, their annual Meeting with the SIB - where they made recommendations; and participated in the joint Dual-Use Workshop with SP12 and Rapporteurs. • A spring meeting in Bristol March 2016 was organised (see above). • In between physical meetings, hourly teleconferences were held, which were attended by Ethics Manager. This helped ensure the EAB were kept up to date and allowed for efficient communication which involved EAB input and discussion, e.g., Ombudsperson SOP.
<p>Trilateral Meetings These meetings are between SP Leaders, Ethics Rapporteurs, Ethics</p>	<p>Progress:</p> <ul style="list-style-type: none"> • Currently in progress (February to June 2017). • The meetings are achieving their objectives as stated in the Description. This includes coverage of outstanding compliance/ethics registry issues; discussion of



<p>Management, the EAB, and any SP12 members who wish to join. The aim of each individual SP meetings is to:</p> <ul style="list-style-type: none"> •Bring everyone up-to-date on the ethical issues in respective SPs, and •To go through the ethics parts of the SP, for the mid-term SGA1 EC review. These are collaborative efforts to ensure ethical issues can be discussed and addressed. 	<p>relevant EC ethics review comments and review of current HBP ethical SOPs (eg informed consent, animal data in non-EU countries). Additionally the action plan for the joint SP12/EAB data protection and privacy opinion is being disseminated.</p>
<p><u>SP12-SGA1 Second Opinions Report Dual Use</u> WPs involved: WP12.1, WP12.2, WP12.3, WP12.4 & WP12.5 This is the second “opinions” reports formulating SP12 observations and recommendations about ethical and social issues arising during the course of HBP.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The EAB have helped progress by inputting their ethical expertise
<p><u>PORE reports</u> Point of Registration of Ethical Issues - Requests to address ethics, regulatory and social issues in HBP research may come from any corner, any time - during initial planning of an experiment through phases of implementation, from within the project community or from outside. Having a POint of REgistration (PORE) is a way to identify and keep track of these issues.</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The PORE reports are referred to the EAB if needed, they have helped implement and progress the embedding of the PORE system
<p><u>SOP on Informed Consent</u> SOP providing guidance to researchers working with humans on principles of informed consent</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The EAB have helped progress by inputting their ethical expertise • Discussed at the March meeting in Bristol
<p><u>First Report on Ethics Management Activities</u> This report includes an action plan for EAB, rapporteurs and the list of issues reported in M1-M6 in</p>	<p>Progress:</p> <ul style="list-style-type: none"> • The EAB have helped progress by inputting their ethical expertise



<p>the ethics registry. The milestone will be verified by upload of the report</p>	
<p>Second Report on Ethics Management Activities This report includes an updated version of the ethics registry and the ethics map, and activity reports for the EAB and the rapporteurs. The milestone will be verified by upload of the report.</p>	<p>Progress:</p> <ul style="list-style-type: none"> The EAB have helped progress by inputting their ethical expertise



6. WP12.5 Scientific Coordination

6.1 Key Personnel

Work Package Leader: Kathinka EVERS (UU)

Other researchers: Lise BITSCH (FT)

Other researchers: Christine AICARDI (KCL)

Other researchers: Arleen SALLES (UU)

Other staff: Lone EGSDAL (FT)

6.2 WP Leader's Overview

In the first 12 months of SGA1, the WP12.5 has coordinated a number of tasks for SP12:

- Coordinating the SP in the transition from the RUP to the SGA1 phase
- Developed the SP Handbook and SP calendar
- Participation in SP Managers, Science & Technology Coordinators, and Community Coordinator meetings, and carrying out these management functions for the SP
- Monthly SP12 group and SP12 steering committee (SC) meetings
- Planned and held two half-yearly SP12 face-to-face meetings
- Coordinated HBP Summit Open Day participation and exhibition
- Supported and participated in the HBP STOA exhibition at the EU parliament, 29-30 November 2016
- Participated in the US Brain meeting 12-14 December 2016
- Coordinating M6 review and editing, including budget
- Coordinating M12 review, progress report
- SGA2 proposal writing, including budget in two different management systems (EMDESK and PLA)
- Coordinating preparation of the Second SP12 Opinion on Dual use (release M24)

6.3 Priorities for the remainder of the phase

The WP continues as backbone support for the SP.



6.4 Milestones

Table 18: Milestones for WP12.5 Scientific Coordination

MS No.	Milestone Name	Leader	Task(s) involved	Expected Month	Achieved Month	Comments
MS12.5.1	SP12 roadmap for SGA-2	P83-UU	ALL SP12 tasks	M12		SGA2 work plan is uploaded and finalised in EMDESK.
MS12.5.2	Report on Communication actions	P83-UU	T12.5.2	M24		

6.5 Task 12.5.1 Coordination and management of SP12 operations

6.5.1 Key Personnel

Task Leader: Lise BITSCH (FT)

Other researcher: Christine AICARDI (KCL)

6.5.2 SGA1 DoA Goals

The SGA1 DoA goals of the task include:

- Coordination and management of SP12 operations, including Deliverables, Milestones, reports, SP12 meetings and conferences, participation in HBP management meetings with other SP coordinators;
- Preparation of meetings, agendas and implementation of outcomes;
- Updating of shared technical tools for collaboration;
- Management and support (including travel budget) of the SP12 Steering Committee.
- Details of the project management of SP12 is provided in the SP12 Management Handbook

The goals of the Task have been fulfilled for the period. The Task of updating shared technical tools for collaboration i.e. the PLA work has been experienced as unnecessarily heavy during the period. Attention has mainly been devoted to the SP SGA2 PLA information. The PLA view for SGA1 of the SP can therefore not be considered completely up to date.

6.5.3 Component Progress

Table 19: Description of Components for T12.5.1 (from PLA)

Component	Progress
SP12-SGA1 SP12 Roadmap for SGA2 SP12 work plan for SGA2	The WP has coordinated the completion and editing of the work plan and finalised in EMDESK.
SP12-SGA1 First Opinions Report WPs involved: WP12.1, WP12.2, WP12.3, WP12.4 & WP12.5. This is the first "opinions" reports formulating SP12 observations and recommendations about ethical and social issues arising during the course of HBP.	The Opinion (D12.5.2) has been completed and sent for quality control.



SP12-SGA1 Second Opinions Report Dual Use

WPs involved: WP12.1, WP12.2, WP12.3, WP12.4 & WP12.5 This is the second “opinions” reports formulating SP12 observations and recommendations about ethical and social issues arising during the course of HBP.

The WP has set up a work plan for the SP to deliver the Opinion in M24 (D12.5.4).

6.5.4 Quality Control:

6.5.4.1 SP12-SGA1 SP12 Roadmap for SGA2

- Upstream Component:
 - None

No upstream Component needed.

- Downstream Component:
 - SGA2 proposal [Essential]

Work plan finalised in EMDESK.

6.5.4.2 SP12-SGA1 First Opinions Report

- Upstream Components:
 - SP12-RUP Foresight Report on Future Medicine Downstream component name [Important]
 - SP12-SGA1 Briefing report on citizen dialogues [Important]
 - SP12-SGA1 Philosophy briefing report 1 [Important]
 - SP12-SGA1 Policy and research recommendations 1 [Important]
 - Co-authored articles and/or special issues [Important]
 - Co-organised workshops and/or other work meetings [Important]

Component finalised.

- Downstream Components:
 - SP12-SGA1 Policy and research recommendations 2 [important]
 - SP12-SGA1 Ethics Action Plan 1 (data protection) [essential]

Report available for Task and Components mentioned.

6.5.4.3 SP12-SGA1 Second Opinions Report Dual Use

- Upstream component name
 - SP12-SGA1 Ethics Action Plan 1 (data protection) [important]
 - essential - SP12-SGA1 Foresight Briefing Report 1) [essential]
 - essential - SP12-SGA1 Philosophy briefing report 2) [essential]
 - essential - SP12-SGA1 Policy and research recommendations 2) [essential]
 - essential - SP12-SGA1 Briefing report on citizen dialogues) [essential]

Upstream Components received in good quality, except for Briefing report on citizen dialogues, which is due in the second half of SGA1.

- Downstream Component:



- SP12-SGA2 Ethics Action Plan 2 (dual use) [essential]

Several additional downstream Components are being exploring (e.g. in SP11).

6.6 Task 12.5.2 Communication

6.6.1 Key Personnel

Task leader: Arleen SALLES (UU)

6.6.2 SGA1 DoA Goals

The SGA1 DoA goals of the Task include setting up a cross SP team (one member per WP) to:

- Interfacing with HBP Communications function;
- Internal communication of SP12;
- External communication outside of the HBP

6.6.3 Component Progress

Table 20: Description of Components for T12.5.2 (from PLA)

Component	Progress
SP12-SGA1 Report on Communication actions Report on communications actions.	The WP has collected list with dissemination and publication activities of the SP, coordinated HBP Open Day and Summit communication activities as well as set up a cross SP communications group. The Task Leaders have begun to re-design the SP12 official website. Report is due in M24.

6.6.4 Quality Control:

6.6.4.1 [SP12-SGA1 Report on Communication actions](#)

- Upstream Component:
 - None
- Downstream Component:
 - None



7. Publications

- 1) Changeux JP. (2017). Climbing Brain Levels of Organisation from Genes to Consciousness. *Trends in cognitive sciences* 21(3):168-181.
- 2) Evers K, Changeux JP. (2016). Proactive epigenesis and ethical innovation: A neuronal hypothesis for the genesis of ethical rules. *EMBO Reports* 17(10):1361-1364.
- 3) Evers K. (2016). The contribution of neuroethics to international brain research initiatives. *Nature Reviews Neuroscience* 18:1-2.
- 4) Evers K. (2016). Neurotechnological assessment of consciousness disorders: five ethical imperatives. *Dialogues in Clinical Neuroscience* 18(2):155-162.
- 5) Salles A. (2016). Brain Imaging and Privacy Concerns. In Eds. M. Farisco and K. Evers *Neurotechnology and Direct Brain Communication* (New York, Routledge, 2016).
- 6) Farisco M, Evers K, Salles A. (2016). Big Science, Brain Simulation and Neuroethics. *AJOB Neuroscience* 7(1):28-30.
- 7) Farisco M, Evers K. (2016). *Neurotechnology and Direct Brain Communication* (New York, Routledge, 2016).
- 8) Aicardi C, Reinsborough M, Rose N. (2017, forthcoming). The integrated Ethics and Society Program of the Human Brain Project: Reflecting on an ongoing experience. Special Issue: Neurotechnology and Society. Towards Responsible Innovation. *Journal of Responsible Innovation*.
- 9) Rainey S, Stahl B, Shaw M, Reinsborough M. (2017). Ethics Management and Responsible Research and Innovation in the Human Brain Project. In: R von Schomberg (ed.), *Handbook - Responsible Innovation: A Global Resource*. Edward Elgar Publishing Ltd
- 10) Rose, N. (2016). Reading the Human Brain: How the Mind Became Legible, *Body & Society*, Online First, 1-38: DOI: 10.1177/1357034X15623363
- 11) Rose, N. (2016). Revitalizing sociology: urban life and mental illness between history and the present, with D. Fitzgerald and I. Singh. *British Journal of Sociology* 67(1):138-160.
- 12) Fitzgerald D, Rose, N, Singh I. Living well in the neopolis. (2016). *The Sociological Review*, 2016, Doi 10.1002/2059-7932.12022.

8. Dissemination

- 1) Evers K: **Simulation & Consciousness: A conceptual approach**. Presentation at the SP3 meeting, HBP Summit in Florence, 12 October 2016.
- 2) Evers K. **The contribution of neuroethics to neuroscience**. Key-note presentation at the 28th Technical Workshop of Institut Guttmann Barcelona, 18 October 2016.
- 3) Changeux JP. **Modeling the Brain: The Human Brain Program at a glance - Platforms & Ethics**. CRCNS 24 October 2016.
- 4) Changeux JP, Salles A. **HBP: The Ethical Issues** (video conference) NIH BRAIN MCWG Neuroethics Workgroup. Wednesday, 3 August 2016, at the Hilton Garden Inn Washington DC.
- 5) Changeux JP. Allosteric interaction, cell signalling and drug design: 50 years of development": 23 March 2017 at the 18th Servier -IGIS symposium at Juan les Pins on Endocrinology



- 6) Changeux JP. Allosteric mechanisms of receptor function and modulation: towards a new pharmacology: 2 April 2017 at the American Chemical Society National meeting in San Francisco.
- 7) Farisco M, Evers K, Salles A. **Focus on Consciousness and Simulation** (poster) HBP Summit. Florence, October 2016.
- 8) Farisco M, Evers K, Salles A. **The Computational Shift in Neuroscience: A Multifaceted neuroethical analysis.** (poster) forthcoming International Neuroethics Society Annual Meeting (San Diego, 10-11 November 2016).
- 9) Salles A. Privacidad mental y la discusión neuroética. *Simposio Internacional Racionalidad Práctica en Perspectiva Neuroética*. Universitat Jaume I, Castellón, Spain, 29 June 2016.
- 10) Evers K. Neuronal epigenesis and ethical innovation. *Simposio Internacional Racionalidad Práctica en Perspectiva Neuroética*. Universitat Jaume I, Castellón, Spain, 29 June 2016.
- 11) Salles A. **Some philosophical issues raised by the HBP.** Cambridge-ICM Neuroethics Network, Paris, France, 1 July 2016.
- 12) Salles A. **EU Human Brain Project: focus on SP12.** Ambassadors Program, International Neuroethics Society, 10th Annual Meeting. San Diego, 10 November 2016.
- 13) Evers K. Neuroethical implications of poverty research in neuroscience. *Simposio Neurociencia y pobreza infantil, consideraciones éticas*, Buenos Aires, 1 December 2016, Hospital Universitario CEMIC.
- 14) Evers K. The Mind that Came in From the Cold: cultures of ignorance in mind science “Consciousness in humans, animals & robots I: concepts, theories, and neural mechanisms”. EITN, Paris, 9-10 March 2017.
- 15) Salles A. Neuroethics: rethinking its role and its relation to philosophy. Buenos Aires, 31 March 2017.
- 16) Aicardi C, Mahfoud T. The complex and conflicted ethics of collaboration. Invited plenary keynote dialogue. *1st HBP Student Conference: Transdisciplinary Research Binding Neuroscience, Brain Medicine and Computer Science*. Vienna, 8-10 February 2017.
- 17) Aicardi C, Mahfoud T. Spurious categories: A study of data-model symbiosis in the Human Brain Project. *4S/EASST conference*. Barcelona, 31 August - 3 September 2016.
- 18) Aicardi C. Integrated social scientist, covert historian: A first-hand experience. Closed panel: Contemporary and Public Histories of Science, Technology and Medicine. *Science in Public 2016*. University of Kent, Canterbury, 15-17 July 2016.
- 19) Rose N. Masterclass on neurosciences, biopsychiatry and resilience, University of New South Wales, Sydney, 2 March 2017.
- 20) Rose N. Public Lecture on The Urban Brain: Living in the Neurosocial City, University of New South Wales, Sydney, 3 March 2017.
- 21) Rose N. Invited Lecture on Neurotechnologies and the criminal justice system, Macquarie University, Sydney. 7 March 2017.
- 22) Rose N. Invited Lecture on The Urban Brain: Living in the Neurosocial City, Western Sydney University, 9 March 2017.
- 23) Rose N. Masterclass on the neurosciences and the social sciences - rethinking the relations, Australian National University, Canberra, 14 March 2017.
- 24) Rose, N. Public Lecture on The Urban Brain: Living in the Neurosocial City, Australian National University, 15 March 2017.



- 25) Reinsborough M. Future of Anticipatory Governance working groups with 'Anticipatory Governance and the Developing World' at the CNS-ASU 10-year anniversary event, 3-5 May, 2016.
- 26) Aicardi C. Panellist, OECD workshop "Neurotechnology and Society: Strengthening Responsible Innovation in Brain Science" at the National Academy of Science in Washington DC.
- 27) Rose N. Keynote lecture. Governing the future, #DASTS16 Interpellating Future(s), the biannual Danish conference on STS, Aarhus University, 2-3 June 2016.

9. Events

Workshops and Symposia

- 1) SP12, EAB and Ethics Rapporteurs joint on Dual Use, organised by T12.3.2, 30 participants. Held: 14 October 2016, Florence, Italy.
- 2) Webinar on Informed Consent in the HBP, co-organised by T12.1.2 and T12.3.2, 20 registered participants. Held 6 February 2017.
- 3) Hospital Universitario CEMIC-CONICET Buenos Aires, la Universidad de Buenos Aires, el Laboratorio de Neurociencia de la Universidad Di Tella, Frontiers, Centro de Investigaciones Filosóficas (CIF), 1 December 2016. International symposium co-organised by T12.2.1: *Neuroscience and child poverty: Ethical considerations*.
- 4) Uppsala University, International Symposium organised by T12.2.2: *Neurotechnology and Direct Brain Communication*, 6 October 2016
- 5) EITN Workshop on Consciousness co-organized with SP03, SP06, CDP03, 9-10 March 2017.
- 6) Symposium CIF co-organized by T12.2.2 From neuroscience to ethics, from politics to neuroscience?, 31 March 2017.
- 7) Uppsala University, International Symposium co-organized by T12.2.2. From Neuroscience to the Classroom, 5-6 April 2017.
- 8) 2016 PLUS Alliance-VIRI, workshops at KCL presented by T12.1.1.
- 9) 2016 'RRI in the UK: the post-Brexit future?' workshop at UCL presented by Reinsborough, M. and Aicardi, C. (T12.1.1).
- 10) Rose, N. Public lecture. Beyond the 'Mind-Brain' Problem, Ralph Cohen Centre for Technological Humanism, James Madison University, Virginia, 1 April 2016.
- 11) Rose, N. Public lecture. Governing (through) The Brain, Ralph Cohen Centre for Technological Humanism, James Madison University, Virginia, 31 March 2016.
- 12) Rose, N. Public lecture. The Human Sciences in a Biological Age, Ralph Cohen Centre for Technological Humanism, James Madison University, Virginia, 31 March 2016.
- 13) Rose, N. Public lecture. If we can 'read' the mind in the brain itself, what then? Human Mind Project, School of Advanced Study, London. 6 June 2016.

10. Education

- Tara MAHFOUD (T12.1.1) was part of the Organising Committee of the 1st HBP Student Conference: Transdisciplinary Research Binding Neuroscience, Brain Medicine and Computer Science. Vienna, 8-10 February 2017. In partnership with Christine AICARDI (T12.1.1), they contributed a plenary keynote dialogue on 'The complex and conflicted ethics of collaboration.'
- SP12 contributed a series of six online lectures to the HBP Curriculum - Research, ethics and societal impact course.



11. Ethics

The SP coordinates and manages ethics and society activities in the HBP.

12. Innovation

N/A

13. Open Research Data

N/A