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Abstract:	<p>This report describes progress in implementing the plans formulated in D12.6.1, Ethics and Society Research Plan (submitted in M7). SP12 met all Milestones planned in M1-M12 except one. The ELSA and REC committees began operating in M6. WP12.4 conducted, analysed and reported on qualitative interviews with senior staff to identify the major ethical and social issues facing the Consortium. Nikolas Rose, leader of WP12.1, published an article in <i>Neuron</i> that illustrates some of the main ethical challenges of the HBP. WP12.3 and WP12.1 held a first stakeholder forum. WP12.2 members wrote several papers on conceptual and philosophical issues raised by HBP research; one has been published and several others have been accepted. Three SP12 conferences were held in Paris to bring together scientists from ICT, medicine and neuroscience, as well as researchers in the social sciences, philosophy and ethics. SP12 has experienced no major delays. Nevertheless, a series of minor delays reflect initial organisational issues due to the size and complexity of the HBP. In response, SP12 made several adjustments via internal meetings, and work is progressing faster. In M13-M18, SP12 will deliver both of the M18 Deliverables, D12.1.1 and D12.6. It is on track to meet the three M18 Milestones. SP12 will hold a workshop in M16 with key stakeholders to present and to discuss the main findings that will be reported in the first Foresight report. From M13, SP12 will also focus on future neuroscience.</p>		
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## 1. Introduction

### 1.1 The Human Brain Project (HBP)

The Human Brain Project (HBP) is a major international scientific research project, involving over 100 academic and corporate entities in more than 20 countries. Funded by the European Commission (EC), the ten-year, EUR 1 billion Project was launched in 2013 with the goal of building “a completely new ICT infrastructure for neuroscience, and for brain-related research in medicine and computing, catalysing a global collaborative effort to understand the human brain and its diseases and ultimately to emulate its computational capabilities.” The fields of neuroscience, medicine and information technology each have important roles to play in addressing this challenge, but the knowledge and data that each is generating have been very fragmented. The HBP is driving integration of these different contributions.

During the Ramp-Up Phase, the HBP will collect strategic data, develop theoretical frameworks, and perform technical work necessary for the development of six Information and Communication Technology (ICT) Platforms during the Operational Phase. The ICT Platforms, offering services to neuroscientists, clinical researchers and technology developers, comprise Neuroinformatics (a data repository, including brain atlases and analysing tools); Brain Simulation (building ICT models and multi-scale simulations of brains and brain components); Medical Informatics (bringing together information on brain diseases); Neuromorphic Computing (ICT which mimics the functioning of the brain); and Neurorobotics (allowing testing of brain models and simulations in virtual environments). A High Performance Computing Platform will support these Platforms.

### 1.2 HBP Subproject 12: Ethics and Society

HBP research and technology development has numerous short-term and long-term social, ethical and philosophical implications. The Project has a commitment to identify these concerns early and to address them transparently. In particular, early engagement will provide scientists with opportunities to understand public reactions to their work and its implications, and to hone their research objectives and processes in the light of these reactions. The Ethics and Society Subproject will draw upon methods developed during empirical investigations of emerging technologies in genomics, neuroscience, synthetic biology, nanotechnology and information and communication technologies. It will also use methods based on the biomedical tradition of engaging ethical issues through the application of formal principles – now usually implemented through ethical review processes.

The Ethics and Society Programme has five main goals for the Ramp-Up Phase:

- Establish and support two independent, management-level committees to provide ethical governance within the Project –
  - An Ethical, Legal and Social Aspects Committee (ELSA; WP12.5.1) to monitor and provide guidance on the Project’s long-term ethical and social implications
  - A Research Ethics Committee (REC; WP12.5.2) to manage and provide advice on issues related to practical and procedural research ethics (studies using human volunteers, animal research, use of clinical data collected for other purposes, applications to ethics committees, etc.)
- Set up and start operating the Foresight Lab, which will be responsible for monitoring HBP research and investigating its social and ethical implications for European citizens, industry, economy and society. The lab (WP12.1) should be fully operational by the end of Month 9 (M9).



- Investigate conceptual and philosophical implications of brain simulation and the emergence of new insights into the relationship between brain and mind. We will publish the first results before the end of the Ramp-Up Phase (WP12.2).
- Launch the HBP online deliberation, a European Citizens' Convention and a stakeholders' forum - all part of the HBP's broader programme of public dialogue and engagement (WP12.3).
- Launch a survey of ethical perceptions among HBP researchers. This will form the basis for a broader programme of researcher awareness during the Operational Phase (WP12.4).

## 1.3 Purpose of this Document

This report describes progress in M1-M12 in implementing the plan formulated in D12.6.1, Ethics and Society Research Plan.

## 1.4 Structure of this Document

The remainder of this chapter provides an SP-level overview, highlighting the SP's main accomplishments and issues encountered in the period M1-M12. Subsequent chapters look at accomplishments and issues within individual components of the SP, as defined in D12.6.1, Ethics and Society Research Plan.

- WP12.1: Foresight - Industrial, Economic and Social Consequences of the HBP
- WP12.2: Conceptual and Philosophical Issues
- WP12.3: The Public, Dialogue and Engagement
- WP12.4: Researcher Awareness
- WP12.5: Ethics, Governance and Regulation
- WP12.6: Scientific Coordination

The Annexes present in tabular form what the Subproject planned to achieve in this period and what it actually achieved, including the Subproject's Scientific Key Performance Indicators (SKPIs).

## 1.5 Overview of Subproject 12 Achievements

SP12's M6 Deliverable D12.6.1 - Ethics and Society Research Plan, was submitted in M7. It establishes a precise roadmap for each of the Tasks included in the HBP Ethics and Society Subproject.

SP12 has met all the Milestones planned for M1-M12, except one (see section 1.6). Most Milestones were achieved in a timely fashion. Milestones MS227, MS228, MS229 and MS230, pertaining to the establishment of the ELSA and REC committees, were reached before M6. This made it possible for the two committees to begin operating in M6 as planned. Milestones MS213, MS218, MS221 and MS224, pertaining to the definition of the frameworks and methods that SP12 will use in its research and public engagement activities, was achieved in M6. Activities of the Foresight Lab, activities on philosophical and conceptual issues, and public dialogue and researcher awareness activities have been fully specified for the Ethics and Society Research Plan. MS214 was reached in M12 as planned.

Between M3 and M9, WP12.4 conducted, analysed and reported on qualitative interviews with senior staff to determine the major ethical and social issues facing the Consortium. The insights gained during this work are of crucial importance to the HBP as a whole, because they can be used to highlight potential issues that could jeopardise the HBP's work.



Nikolas Rose, leader of WP12.1, published an article in *Neuron*<sup>1</sup> in M9, in which he illustrated some of the HBP's main ethical challenges.

In M9, WP12.3 and WP12.1 held a first stakeholder forum on 'Multi-level data federation and data protection' and 'Disease signatures and personalised medicine', which facilitated a constructive dialogue between SP8 researchers and external high-level specialists in different relevant fields (law, ethics, social sciences). Participants explored the concepts of privacy, informed consent, and anonymisation from a legal and ethical perspective. They made tentative connections to the development of SP8's Medical Informatics Platform. Furthermore, they reflected on possible challenges and implications of developing new disease signatures for categories such as 'disability,' 'normality' and 'biological determinism'. The results of this forum will be included in the first Foresight Report (D12.1.1, M18) and the online deliberation (MS222, M18).

During the first year of the Project, WP12.2 members wrote several papers on conceptual and philosophical issues raised by HBP research. One has been published: Evers, K., Sigman, M., *Possibilities and limits of mind-reading: A neurophilosophical perspective*, *Consciousness and Cognition* 22, 2013. 887-897. Several other articles have been accepted for publication. In particular, Kathinka Evers, Co-Director of SP12, and Yadin Dudai co-authored a paper on the meaning of 'simulation' in the context of the HBP<sup>2</sup>. Dudai and Evers have submitted a first draft of this article for comments from a dozen leading experts in philosophy, neuroscience, computer science and engineering. This has launched a fruitful dialogue on the nature and status of simulation in scientific practice, especially in neuroscience.

SP12 organised the first two SP12 Conferences in Paris as part of a cycle of public academic meetings. The conferences brought together scientists from ICT, medicine and neuroscience, as well as the social sciences, philosophy and ethics. The first conference, in M6, entitled "How can neurotechnology - notably brain simulation as developed in the HBP - help assess, understand and access consciousness?" hosted lectures by Steven Laureys (Coma Science Group, Liège) and Jacobo Sitt (Unicog, INSERM U992CEA/Saclay). The second conference in M9 was entitled, "The Epistemology of Simulation: How can *in silico* simulation help understand and reproduce complex processes such as higher brain functions?" and hosted lectures by Henry Markram (EPFL), Alain Destexhe (CNRS), Hervé Le Treut (CNRS) and Julie Jebeile (IHPST Paris 1- CNRS). Both events facilitated dialogues between scientists specialising in the three main HBP research areas (neuroscience, ICT and medicine), social scientists, and philosophers on the implications of new knowledge and technologies arising from HBP research.

SP12 did not modify its objectives or structure in the first 12 months. One personnel change happened in Fonden Teknologirådet (FT, P16): Lise Bitsch joined FT as project manager, while Nanna Engberg and Anders Jacobi left.





## 1.6 Overview of Subproject 12 Problems

SP12 has not experienced major delays during M1-M12. Nevertheless, a series of minor delays occurred and these are detailed below. Most of them reflect initial organisational issues due to the size and complexity of the HBP, and occurred both within SP12 and between SP12 and other SPs. SP12 has made several adjustments through internal meetings (physical or online), and work is progressing faster now. In particular, the decision to align the roadmaps for WP12.1, WP12.2, WP12.3 and WP12.4 (detailed in D12.6.1) helped to speed-up and improve collaboration between the different SP12 Partners.

The main problem experienced by WP12.4 was arranging interviews with SP Leaders in a way that accommodated their schedules. This delayed completion of the recordings and transcripts until three months after the planned deadline in M6. The knock-on effect was to delay the production of the final report by two months, because a thorough analysis could only be finalised when most of the data were available. This has also affected the delivery of Milestone MS225, which is likely to be delayed by one month.

MS228 (Selection committee formulates proposal for ELSA and REC membership, planned for M3) and MS229 (Board of Directors approves committees; EU informed, planned for M4) were each achieved with a one-month delay, in M4 and M5, respectively. This delay was due to the fact that more time was needed to convene the Selection Committee.

Due to personnel changes at FT, the first stakeholder seminar organised by WP12.3 was delayed. However, FT will still finish its first round of stakeholder activities in 2014. The development of materials for the first online deliberation took more time than expected, since it built on previous work in the other SP12 Tasks and WPs. Therefore, the first deliberation, which was planned in M12, will not take place before M15. This will not affect the delivery of MS222, planned in M18. The start-up off of the foresight activities in WP12.1 required longer than expected; this was mainly due to the lengthy procedures required for recruiting team members, and to the coordination of the activities with SP12 Partners.

## 1.7 The Next Six Months for Subproject 12

In M13-M18, SP12 will submit the two following Deliverables: D12.1.1 (M18) - The HBP Foresight lab: first report on Future Medicine, and D12.6.3 (M18) - First ethics and society report.

SP12 is on track to achieve the three Milestones scheduled in M18 on time (MS215 - The HBP Foresight Lab: first report on Future Medicine; MS219 - First report on how far brain simulation can explain mechanisms of the mind; and MS222 - First online public debate on the ethics of brain simulation, Future Medicine, and Future Computing).

The third SP12 conference, planned for 30 September 2014 during the HBP Summit in Heidelberg, was cancelled. It was supposed to feature a talk by Thomas R. Insel (National Institute of Mental Health) on "Transforming Diagnosis in Psychiatry: The Research Domain Criteria (RDoC) Project," who could not come. Another similar conference, focusing on conceptual and ethical issues related to the transformation of medicine and psychiatry, will be scheduled in 2015.

WP12.1 finalised the first scenarios at the seminar co-organised with WP12.3 in M12. WP12.1 will undertake further research with special focus on Future medicine. In M16, we will hold a workshop with key stakeholders to present and to discuss the main findings that will be reported in the first Foresight report. In M13, WP12.1 also started working on its second theme, Future Neuroscience.

WP12.2 will focus on conceptual and philosophical topics relevant to future psychiatry and brain medicine. We plan to extend our collaboration with SP8. This work will hopefully result in new





publications in high-impact, peer-reviewed journals. At the same time, we will continue the analyses of simulations and brain-mind relationships.

In WP12.3, FT (P16) hosted a seminar on 9 October 2014 in Copenhagen with SP8 and other Partners in SP12 (IP (P27), KCL (P32), DMU (P11)). We will develop a workshop (to take place in 2015) on the changes in the legal landscape on privacy and data protection, involving SP8 researchers and external experts, dedicated to solutions to problems identified and discussed in the webinar and seminar in May and October 2014. We will produce our first newsletter to the European Commission, reporting on the outcome of the first round of stakeholder activities, including recommendations for future actions. In parallel, FT will hold a webinar and a two-day seminar on "Future neuroscience," and plan a follow-up to its seminar on data federation and personalised disease from October 2014.

FT will begin planning the European Citizens' Convention (MS223) to be held before M30. IP will finalise the preparation of the first online deliberation, and conduct the fieldwork in M15 or M16 at the latest. Before M18, the outcomes of the first online deliberation on future medicine will be circulated among the SP12 and then be communicated to the HBP community. In parallel, during M13-M18, we will start preliminary work for the second online deliberation on future neuroscience.

The process intended to deliver Milestone 225 commenced during M12 with the development and piloting (within SP12) of a survey that will ultimately be aimed at all HBP researchers. During M13, the survey was implemented by making it available to all HBP researchers in an appropriately secure manner. We are still waiting for the emailing list of the whole Consortium to be available. Offers have been received from the HBP management team to assist, and these will be followed up.

The REC met in M12, and will meet again via teleconference in M15. ELSA was scheduled to meet in M12.



## 2. WP12.1: Foresight - Industrial, Economic and Social Consequences of the HBP

### 2.1 WP12.1: Overall Goals

The aim of WP12.1 is to evaluate the potential industrial, economic and social consequences for Europe of the new knowledge and technologies produced by the HBP. The work, which is the responsibility of the HBP Foresight Lab (T12.1.1) focuses on conducting systematic foresight exercises to identify and evaluate these impacts along three themes. Exercise results from each theme will be used to generate a separate Foresight Report: Foresight Report on Future Medicine (D12.1.1), Foresight Report on Future Neuroscience (D12.1.2) and Foresight Report on Future Computing/Robotics (D12.1.3).

### 2.2 WP12.1: Main Achievements

In the first 12 months of the Project, WP12.1 reached each of the Milestones planned in the Description of Work. The first Milestone was reached in M6 (MS213-Activities Specified). The research activities of the Foresight Lab were specified and agreed upon by King's College London (KCL, P32) team members. The goals of the Foresight Lab's activities are to evaluate the potential industrial, economic and social consequences for Europe of the knowledge and technologies produced by the HBP; to organise seminars and workshops with selected stakeholders; and to communicate research outcomes within the HBP and to the public.

In M12, WP12.1 also achieved MS214 - Methods defined: Membership, scope, and methods of analysis for the Foresight Lab. On the basis of an initial literature analysis and formal and informal discussions with key stakeholders, WP12.1 will draft a range of scenarios on possible developments of future medicine, neuroscience and computing technologies. These scenarios will describe the potential impacts of these technologies over five, ten, and twenty-year horizons. These scenarios will be discussed with the selected stakeholders during internal HBP meeting and workshops. Depending on the topic, we will involve stakeholders (HBP and non-HBP members, neuroscientists, experts from academia and industry, members of relevant regulatory bodies, etc.), who will be invited to actively contribute to the discussion about the possible future scenarios. Following the discussions, we will refine the scenarios and assess related key social and ethical concerns. These scenarios will form the basis for our Deliverables.

To ensure integration and maximise collaboration, a number of the Foresight Lab activities have been organised in coordination with WP12.3 (T12.3.3), including a joint webinar with SP8 researchers and non-HBP scientists and stakeholders in the domain of Future Medicine, held in May 2014. We are also working together to plan a one-day seminar in Copenhagen with non-HBP stakeholders and SP8 researchers in the domain of Future Medicine. The seminar will provide an opportunity for the scenarios that we have developed to be discussed and developed with participants.

We are actively collaborating with WP12.4 by contributing suggestions and feedback, while they provide us with ideas and materials for our work. Specifically, the interviews conducted in WP12.4 will provide us with data for our research on ethical and social perceptions among HBP researchers.

Since the beginning of the Project, Nikolas Rose has participated in a number of events where he explored the social and ethical implications of the HBP's work. He has recently published an article in *Neuron*,<sup>3</sup> in which he illustrates some of the main ethical challenges of the Project.

The implementation of the Foresight Lab's work is progressing as planned. KCL teams meet on a weekly basis, and this ensures constant monitoring of activities. Prof. Claire



Marris has joined the team; Prof. Marris will advise on the development of the Responsible Research and Innovation (RRI) approach in the HBP context.

## 2.3 WP12.1: Main Problems

While we have met all our Milestones in a timely fashion, the start-up of WP12.1 activities required longer than expected. This was mainly due to the lengthy procedures required for recruiting team members, and to the coordination of activities with our SP12 Partners.

Regarding KPIs, we are planning to achieve the estimated number of citations of our Foresight Reports in HBP internal reports, scientific publications and media articles by Month 30, when our research will be completed and our reports delivered.

## 2.4 WP12.1: The Next Six Months

Once the first scenarios have been finalised at the seminar co-organised with T12.3.3, which will involve SP8 members and external stakeholders, we will conduct further research with a special focus on Future Medicine. We will collect all feedback on the discussions held during the seminar and include it in our research, as will be explained in D12.1.1 (M18) - The HBP Foresight Lab: first report on Future Medicine. In M16, we will hold a workshop with key stakeholders to present and to discuss the main findings of the first Foresight report.

From M13 onward, we will focus on Future Neuroscience. We will organise activities to prepare for the second Foresight report, and for the scoping workshop on Future Neuroscience in M21.



## 3. WP12.2: Conceptual and Philosophical Issues

### 3.1 WP12.2: Overall Goals

The goal of WP12.2 is to provide a conceptual analysis of human brain simulation in the HBP, including distinct theoretical approaches, underlying assumptions, and implications for understanding the mind and consciousness. T12.2.1 focuses on the concept of simulation in the HBP context, clarifying the epistemological assumptions and implications of 'top-down' versus 'bottom up' approaches and examining how and to what extent these historically conflicting concepts can be reconciled. T12.2.2 focuses on the role of consciousness in brain simulation, and studies how brain simulation can improve our understanding of consciousness and of the mind-brain relationship.

### 3.2 WP12.2: Main Achievements

During the first year of the Project, WP12.2 members have written several papers. One is already published: Evers, K., Sigman, M., *Possibilities and limits of mind-reading: A neurophilosophical perspective*, *Consciousness and Cognition* 22, 2013. 887-897. (Impact factor 2.31). The following articles have been accepted for publication:

- Farisco, M. Evers, K., Petrini, C., *Biomedical research involving patients with disorders of consciousness: ethical and legal dimensions, Part I*, to appear in a special issue of the "Annali dell'Istituto Superiore di Sanità" (impact factor 0.76, registered in pubmed).
- Farisco, M., Laureys, S., Evers, K., *Externalization of consciousness. Scientific possibilities and clinical implications*, accepted for publication in *Ethical Issues in Behavioral Neuroscience*, Eds. Frauke Ohi, Grace Lee and Judy Illes, Springer Verlag, 2014.
- Dudai, Y., Evers, K., *To simulate or not to simulate: What are the questions?* Accepted for publication in *Neuron*, 2014 (impact factor 15.982).
- Evers, K., Changeux, J.-P., *Can we be epigenetically proactive?* Accepted for publication in *MIND Matters*, ed. Metzinger, Barbara-Wengeler-Stiftung, Frankfurt, 2014.

Dudai and Evers submitted a first draft of the Evers, *et al* article for comments from a dozen leading experts in philosophy, neuroscience, computer science and engineering. This has launched a collective and fruitful dialogue on the nature and status of simulation in scientific practice, and especially in neuroscience.

Kathinka Evers and Arleen Salles have also published a book related to WP12.2 research: *La Vida Social del Cerebro*, Eds. Salles, A. & Evers, K., Ediciones Fontamara, Mexico, 2014.

WP12.2 and WP12.6 co-organised the first two SP12 conferences in Paris at the Institut Pasteur. These conferences are part of a cycle of public academic meetings, and bring together scientists from ICT, medicine and neuroscience, as well as the social sciences, philosophy and ethics. The first Conference, held on 27 February 2014 was entitled, "How can neurotechnology - notably brain simulation as developed in the HBP - help assess, understand and access consciousness?" It featured lectures by Steven Laureys (Coma Science Group, Liège) and Dr Jacobo Sitt (Unicog, INSERM U992CEA/Saclay). The second Conference on 26 June 2014 was entitled, "The Epistemology of Simulation: How can *in silico* simulation help understand and reproduce complex processes such as higher brain functions?" featured lectures by Henry Markram (EPFL), Alain Destexhe (CNRS), Hervé Le Treut (CNRS) and Julie Jebeile (IHPST Paris 1- CNRS).

WP12.2 also initiated and developed a series of cross-SP collaborations, with participants in SP3 (Jacobo Sitt), SP4 (Alain Destexhe, Idan Segev), SP6 (Henry Markram, Jeannette Hellgren Kotaleski), and SP8 (Richard Frackowiak).



## 3.3 WP12.2: Main Problems

N/A

## 3.4 WP12.2: The Next Six Months

The third SP12 conference, originally planned on September 2014, was cancelled; another similar conference focusing on conceptual and ethical issues related to the transformation of medicine and psychiatry will be scheduled in 2015.

WP12.2 will focus on conceptual and philosophical topics relevant to the future psychiatry and brain medicine. We have already planned to extend our collaboration with SP8. This work will hopefully result in new publications in high-impact, peer-reviewed journals. At the same time, we will carry on the analyses on simulation and brain-mind relationships.



## 4. WP12.3 The Public, Dialogue and Engagement

### 4.1 WP12.3: Overall Goals

The goal of WP12.3 is to help the HBP create a constructive dialogue with stakeholders and with the general public while engaging with views external to the HBP, identifying emerging controversies, and formulating recommendations for HBP research. WP12.3 is divided into three Tasks, each corresponding to a different public audience and level of dialogue. T12.3.1 will invite large ( $n \geq 100$ ) groups from the general public to identify and discuss their expectations and the issues arising from HBP research. T12.3.2 will gather communities of respondents and introduce them to HBP research, allowing them enough time to form a deep understanding and to express sensible recommendations. T12.3.3 will create a dialogue between HBP participants and outside experts and stakeholders.

### 4.2 WP12.3: Main Achievements

WP12.3 achieved Milestone MS221 (M6, Public dialogue activities fully specified; first stakeholders' forum) on time. In the first 12 months, IP and FT worked in parallel on the three Tasks in WP12.3. We have developed plans for the content and form of the online deliberations (three rounds), stakeholder involvement activities (three rounds), and the citizen convention (one event at the end of the Ramp-Up Phase). IP and FT have aligned the topics of the online deliberation and the stakeholder activities with the "Foresight Lab" (WP12.1) agenda:

- 1) Data collection and treatment in the HBP
- 2) Future Neuroscience
- 3) Future ICT and robotics

In T12.3.3, FT held a first stakeholder forum on 7 May 2014. The forum comprised a twofold webinar on 'Multi-level data federation and data protection' and 'Disease signatures and personalised medicine,' and facilitated a constructive dialogue between SP8 researchers and external high-level specialists in different relevant fields (law, ethics, social sciences). Together, the participants engaged in a first exploration of the concepts of privacy, informed consent and anonymisation from a legal and ethical perspective, and made tentative connections to the build-up of the architecture for the medical informatics platform of SP8. Furthermore, they reflected on possible challenges and implications of developing new disease signatures for categories like 'disability', 'normality' and 'biological determinism.'

In T12.3.1, IP has closely followed the first outcomes of the qualitative interviews with the senior staff in WP12.4, and of the webinar hosted by T12.3.3 and WP12.1, to develop a roadmap for the first online consultation. The consultation will focus on the general public's expectations toward future medicine and future psychiatry, and will try to assess to what extent the expected outcomes of the HBP meet these expectations. We have chosen a precise tool (developed by House of Common Knowledge, a French research institute) and protocol to fit the intended deliberative framework, and have worked closely with Partners throughout SP12 to define this consultation's content.

Throughout the period, we have developed the WP12.3 activities in close collaboration with Partners in 12.1, and 12.4 (KCL, DMU), and researchers from SP8.

Regarding personnel changes, Lise Bitsch has joined FT as Project Manager, while Nanna Engberg and Anders Jacobi have left FT.





## 4.3 WP12.3: Main Problems

FT is not experiencing any major problems. Due to personnel changes, the first seminar was delayed; however, FT will still finish its first round of stakeholder activities in 2014. The original work plan for the Ramp-Up Phase had the stakeholder activities organised as: webinar, seminar, and workshop. The legal landscape of privacy and data protection is constantly changing, and we are considering the format of the workshop (to be held in 2015) that will generate concrete recommendations relating to data security and privacy. We want to set up forums for SP8 researchers and external experts to discuss which solutions to the problems identified in the webinar and seminar in May and October 2014. Recommendations for future action will also be covered in our newsletter to the European Commission. We are also considering changing the format of the one-day seminar to a two-day workshop for our next round of stakeholder activities (Future Neuroscience).

IP is not experiencing any major problems. The development of materials for the first online deliberation is taking more time than expected, since it must build on previous work in the other SP12 Tasks and WPs. Therefore, the first deliberation planned for M12 will not take place before M15. This will not affect the delivery of MS222, planned for M18.

## 4.4 WP12.3: The Next Six Months

FT hosted a seminar on 9 2014 in Copenhagen with SP8 and other Partners in SP12 (IP, KCL, DMU). We will develop a workshop (to take place in 2015) on the changes in the legal landscape on privacy and data protection, involving SP8 researchers and external experts, dedicated to solutions to problems identified and discussed in the webinar and seminar in May and October 2014. We will produce our first newsletter to the European Commission, reporting on the outcome of the first round of stakeholder activities, including recommendations for future actions.

In parallel, FT will hold a webinar and a two-day seminar on "Future Neuroscience," and plan a follow-up to its seminar on data federation and personalised disease from October 2014. FT will begin planning the set-up and organisation of the European Citizen Convention (MS223) to be held before M30. IP will finalise the preparation of the first online deliberation, and conduct the fieldwork in M15 or M16 at the latest. Before M18, the outcomes of the first online deliberation on future medicine will be circulated among the SP12 and then be communicated to the HBP community. In parallel, during M13-M18, we will start preliminary work for the second online deliberation on future neuroscience.





## 5. WP12.4 Researcher Awareness

### 5.1 WP12.4: Overall Goals

WP12.4 Researcher Awareness aims to foster ethical and social reflection among the Consortium's researchers, clinicians and technology developers—especially those early in their careers. The WP's objectives are to explore with these groups their perceptions of:

- Ethics
- The role of the HBP in society,
- Responsible innovation

In this way, WP12.4 seeks to help these groups become alert to ethical and social issues, and be willing to raise them in appropriate forums.

### 5.2 WP12.4: Main Achievements

Between M3 and M9, WP12.4 conducted, analysed and reported on qualitative interviews with senior staff to determine the major ethical and social issues facing the Consortium. We circulated a consultation document during M8 to SP12, and presented a summary of the final report during the SP12 internal meeting at the end of M9. In order to conduct the interviews, WP12.4 collaborated with all other SPs. During the resulting conversations, WP12.4 developed a detailed understanding of the work undertaken across the HBP. A number of possible ethical and social issues concerning senior staff were revealed in conjunction with their views of the Project. These insights are of crucial importance to the HBP as a whole, because they can be used to highlight potential 'show-stoppers' - issues that could jeopardise important aspects of HBP research, or possibly the Project as a whole. The findings will be discussed in detail in the forthcoming report.

In M6, WP12.4 contributed to D12.6.1 - the Ethics and Society Research Plan. In M5 and M9, WP6 contributed to meetings with SP12 colleagues.

### 5.3 WP12.4: Main Problems

The main problem experienced by WP12.4 was arranging interviews with SP leaders in a way that accommodated their diaries. This delayed completion of the full set of recordings and transcripts until three months after the planned deadline in M6. The knock-on effect was to delay the production of the final report by two months, because a thorough analysis could only be finalised when most of the data were available. This has also affected the delivery of Milestone 225, which is likely to be delayed by one month. These delays were exacerbated by unforeseen pressures on staff time, which have now been addressed via negotiation with P11.

### 5.4 WP12.4: The Next Six Months

The process intended to deliver Milestone 225 commenced during M12 with the development and piloting (within SP12) of a survey that will ultimately be aimed at all HBP researchers. During M13, the survey was implemented by making it available to all HBP researchers in an appropriately secure manner. We are still waiting for the emailing list of the whole Consortium to be available. Offers have been received from the HBP management team to assist, and these will be followed up.



The resulting data will be reviewed to determine whether the expected results are being achieved. If not, problems will be addressed in consultation with SP12. During this period, a process for archiving qualitative interviews with SP leaders will also be developed, which will require evaluating the analysis and writing research papers.

WP12.4 is actively seeking collaborators, such as Christopher Coenen at the Karlsruhe Institute of Technology, to help expand researcher awareness and the scope of its research within the HBP.



## 6. WP12.5 Ethics, Governance and Regulation

### 6.1 WP12.5: Overall Goals

The primary goal of WP12.5 is to support HBP decision-making on issues with significant social and/or ethical implications, and to help ensure that the Project fully complies with European and national legal and regulatory requirements.

WP12.5 coordinates the HBP's participation in planned ethical reviews and communicates with the EC Project Officer regarding them. Currently, a full ethical review has been called following the M8 screening review. Another ethics review is planned in M30.

WP12.5 also coordinates operations of two ethical advisory committees, ELSA and REC. The Ethics, Legal and Social Aspects Committee (ELSA) will advise HBP management (ExCo) on issues of policy and strategy, forming Working groups to address specific ethics, legal, philosophical and social issues while maintaining an agile responsiveness and alertness to potential, unexpected ethical, legal and social issues that may arise during the lifetime of the Project, or that may have the potential to exist in the future. The Research Ethics Committee (REC) will review ethical applications and will assist and advise HBP researchers and HBP management regarding procedural and practical ethical inquiries in current or planned projects.

WP12.5 provides *ex officio* members to each committee, and maintains a small secretariat to support their operations. WP12.5 will arrange for the recruitment and appointment of new members if and when needed, and assist with report writing. The WP will also facilitate the assignment of working groups, make meeting schedules and agendas, maintain an ethics data registry, and communicate the official Project position on specific procedural ethics issues in the HBP research program. The latter activity will include maintaining a website on ethics procedures to support research ethics approval processes.

### 6.2 WP12.5: Main Achievements

WP12.5 achieved the Milestones related to establishing two HBP ethical committees—the Ethics, Legal and Social Aspects (ELSA) and the Research Ethics Committee (REC)—in a timely manner. To appoint members to the two committees, a Selection Committee (SC) was first established with nominees from the External Advisory Board and the Presidents' Advisory Board. The SC's efforts were then coordinated to review ethics committee candidates and provide a list of nominees. This nominee list, which includes 12 ELSA and 6 REC members from a broad range of European nations, was presented to the EC in M4. The EC waived a previously written procedure that had ELSA appointing REC members before the M6 meeting. The EC approved the 12 members to ELSA but advised that an additional member familiar with data protection and privacy be added. After recruitment efforts, this was achieved and approved in M5, leaving ELSA with 13 members. The six REC members were approved by the EC. In M5, the HBP Board of Directors approved the committee appointments and the EU was informed.

The ELSA and REC committees held inaugural meetings (both individual and joint) in M6, at Institut Pasteur in Paris. SP12 and the WP12.5 Secretariat provided support for accommodation, travel, and meeting preparation and coordination. The REC held a second internal meeting and a joint meeting with SP12 members in M9. The Secretariat maintains an updated repository for ethical applications and decisions. T12.5.2 (REC) has received 31 permits from HBP Partners who are performing or planning to perform research on animals or humans. Eight applications for ethical review were reviewed and assessed from Competitive Call researchers.



ELSA members participated in the 7 May 2014 webinar on “Future Medicine in the Human Brain Project,” organised by WP12.3 and WP12.1. ELSA members also attended the 26 June 2014 SP12 symposium on Simulation.

WP12.5 gathered and reported information for the Ethical Review in M8. The “screening” review led to a full review, which is ongoing.

As SP12 Project Manager, Benjamin Simmenauer has been instrumental in arranging SP12 interactions with committees. Administrator Shamim Patel has provided essential support by making travel and accommodation arrangements for both committees, and by corresponding with research groups on the data registry.

## 6.3 WP12.5: Main Problems

Milestones MS228 (Selection committee formulates proposal for ELSA and REC membership, planned for M3) and MS229 (Board of Directors approves committees; EU informed, planned for M4) were each achieved after a one-month delay, in M4 and M5 respectively. This delay was due to the greater time needed to convene the Selection Committee. However, plans to launch both the ELSA and the REC were implemented on schedule in M6, and both committees are operating according to plan.

Work on the EC Ethics Review began in M8 with requests for “preliminary” ethics-related information, which was followed in M9 with a request for delivery of all materials to the EC. In M11, the EC reviewers requested additional information and decided to initiate a “full” review, which is ongoing.

The web-based registry has been created, but its user-friendliness needs to be improved before the ELSA and REC committees are confidently on board, and before the data obtained on ethical applications by Linnéuniversitetet can be safely stored and accessed.

## 6.4 WP12.5: The Next Six Months

WP12.5 will continue to coordinate the operations of the ELSA and REC committees. The Secretariat will continue to update and make accessible the repository of local research ethics applications and formal decisions made by local, national or regional ethics bodies. WP12.5 aims to continue to prepare the committees to act in their deontological as well as pragmatic roles, for example to be alert to issues that arise and to changes in ethics governance and regulation locally, nationally, in HBP, and in the EU; and aims to respond to previously unanticipated issues that may arise.

WP12.5 emphasises “linkages” to promote communication among stakeholders and the committees, and to share understanding within and outside the HBP community. ELSA and REC will have the opportunity to connect with various SPs, the ExCo, SP12 and the REC. It will also have the opportunity to participate in forums held by other WPs in SP12. The REC will meet via teleconference in M15. ELSA was scheduled to meet in M12.



## 7. WP12.6 Scientific Coordination

### 7.1 Scientific Coordination: Internal Meetings

Date	Description	Location	Participants
8-9 Oct 2013	Internal SP12 workshop at the HBP Summit	EPFL, Lausanne	Torsten Wiesel, Jean-Pierre Changeux (IP), Kathinka Evers (UU), Kevin Grimes (KI), Nikolas Rose (KCL), Bernd Carsten Stahl (DMU), Yadin Dudai (WIS), Nanna Engberg (FT), Lars Klüver (FT), Christine Mitchell (HVDU), Abdul Mohammed (LNU), Richard Walker (EPFL), Benjamin Simmenauer (IP), Christopher Ebell (EPFL), Annika Hjelm (EPFL)
3 Dec 2013	WP12.1, WP12.3 and WP12.4 workshop	King's College, London	Nikolas Rose (KCL), Claire Marris (KCL), Catherine Jefferson (KCL), Nanna Engberg (FT), Anders Jacobi (FT), Benjamin Simmenauer (IP), Bernd Stahl (DMU) Mark Shaw (DMU)
27-28 Feb 2014	SP12 internal meeting	Institut Pasteur, Paris	Kathinka Evers (UU), Nikolas Rose (KCL), Abdul Mohammed (LNU), Richard Walker (EPFL), Kevin Grimes (KI), Christine Aicardi (KCL), Michele Farisco (UU), Mark Shaw (DMU), Karl Sallin (UU), Anders Jacobi (FT), Nanna Engberg (FT), Ida Deleuran (FT), Michael Reinsborough (KCL), Paola Bello (KCL), Tara Mahfoud (KCL), Benjamin Simmenauer (IP)
26-27 Jun 2014	SP12 internal meeting	Institut Pasteur, Paris	Jean-Pierre Changeux (IP), Kathinka Evers (UU), Nikolas Rose (KCL), Yadin Dudai (WIS), Abdul Mohammed (LNU), Bernd Carsten Stahl (DMU) Shamim Patel (LNU), Richard Walker (EPFL), Kevin Grimes (KI), Christine Aicardi (KCL), Michele Farisco (UU), Mark Shaw (DMU), Karl Sallin (UU), Anders Jacobi (FT), Lise Bitsch (FT), Ida Deleuran (FT), Michael Reinsborough (KCL), Paola Bello (KCL), Tara Mahfoud (KCL), Benjamin Simmenauer (IP), Christine Mitchell (HVDU), Arleen Salles (UU), Marcus Christen (ELSA), Martina Schmalholz (UHEI)

Table 1: Meetings between SP12 staff



## 7.2 Scientific Coordination: HBP Meetings

Date	Description	Location	Participants
9 Oct 2013	Cross-meeting SP8 with SP12	EPFL, Lausanne	Richard Frackowiak, Jean-Pierre Changeux (IP), Kathinka Evers (UU), Nikolas Rose (KCL), Richard Walker (EPFL) and several other members of SP8 and SP12
10 Oct 2013	Meeting of SP12 representatives with the EPFL team for developing the HBP portal on SP12 web tools' requirements, and implementation roadmap	EPFL, Lausanne	Jeff Muller (EPFL), Richard Walker (EPFL), Kevin Grimes (KI), Benjamin Simmenauer (IP)
27 Feb 2014	First SP12 conference on neurotechnological assessments of consciousness in collaboration with members of SP3	Institut Pasteur, Paris	Invited speakers: Steven Laureys (Coma Science Group, Liege) and Jacobo Sitt (SP3, INSERM / CEA) PLUS Kathinka Evers (UU), Nikolas Rose (KCL), Abdul Mohammed (LNU), Richard Walker (EPFL), Kevin Grimes (KI), Christine Aicardi (KCL), Michele Farisco (UU), Mark Shaw (DMU), Karl Sallin (UU), Anders Jacobi (FT), Nanna Engberg (FT), Ida Deleuran (FT), Michael Reinsborough (KCL), Paola Bello (KCL), Tara Mahfoud (KCL), Benjamin Simmenauer (IP)
26 Mar 2014	ELSA and REC inaugural meetings	Institut Pasteur, Paris	Abdul Mohammed (LNU), Barbara Sahakian (UCAM), Benjamin Simmenauer (IP), Christine Mitchell (HVDU), Jean-Pierre Changeux (IP), Kevin Grimes (KI), Shamim Patel (LNU) + Members of ELSA: Berit Bringedal, Marcus Christen, Hironori Matsuzaki, Fiorella Operto, Joëlle Proust, Alberto Rábano, Ignacio Torres Alemán, Jean-Dominique Vassalli, Nikola Biller-Andorno, Stefano Rodotà Members of REC: Karin Blumer, Miguel Medina, Melita Šalković-Petrišić, Henrik Walter, Jürg Kesselring
26 Jun 2014	Second SP12 conference on simulation in collaboration with members of SP6	Institut Pasteur, Paris	Speakers: Henry Markram (EPFL), Alain Destexhe (CNRS), Julie Jebeile (CNRS), Hervé LeTretut (CNRS) + Jean-Pierre Changeux (IP), Kathinka Evers (UU), Nikolas Rose (KCL), Yadin Dudai (WIS), Abdul Mohammed (LNU), Shamim Patel (LNU), Richard Walker (EPFL), Kevin Grimes (KI), Christine Aicardi (KCL), Michele Farisco (UU), Mark Shaw (DMU), Karl Sallin (UU), Anders Jacobi (FT), Lise Bitsch (FT), Ida Deleuran (FT), Michael Reinsborough (KCL), Paola Bello (KCL), Tara Mahfoud (KCL), Benjamin Simmenauer (IP), Christine Mitchell (HVDU), Arleen Salles (UU), Marcus Christen (ELSA)
27 Jun 2014	REC & SP12 meeting	Institut Pasteur, Paris	REC: Henrik Walter, Karin Blumer, Margaret Buckingham, Miguel Medina, Melita Šalković-Petrišić SP12: Jean-Pierre Changeux (IP), Kathinka Evers (UU), Nikolas Rose (KCL), Yadin Dudai (WIS), Abdul Mohammed (LNU), Bernd Carsten Stahl (DMU) Shamim Patel (LNU), Richard Walker (EPFL), Kevin Grimes (KI), Christine Aicardi (KCL), Michele Farisco (UU), Mark Shaw (DMU), Karl Sallin (UU), Anders Jacobi (FT), Lise Bitsch (FT), Ida Deleuran (FT), Michael Reinsborough (KCL), Paola Bello (KCL), Tara Mahfoud (KCL), Benjamin Simmenauer (IP), Christine Mitchell (HVDU), Arleen Salles (UU) SP13: Martina Schmalholz (UHEI)

Table 2: Cross-SP meetings





## 7.3 Scientific Coordination: External Meetings

Date	Description	Location	Participants
7 May 2014	Webinar on Future medicine in the Human Brain Project Multi-level patient data federation and the development of personalised medicine for brain diseases	Online meeting hosted by FT	Invited speakers: Dennis-Kenji Kipker, Member of the European Academy for Freedom of Information and Data Protection (EAD) Dirk Lanzerath, General Secretary of the European Network of Research Ethics Committees (EUREC) Paul Quinn, Researcher at Law Science Technology & Society, Vrije Universiteit Brussel Caspar Bowden, Independent privacy researcher, surveillance technology/law/policy, and former Chief Privacy Adviser at Microsoft Gregor Wolbring, Associate Professor, University of Calgary, Faculty of Medicine, Dept. of Community Health Sciences, Stream Community Rehabilitation and Disability Studies Emilio Mordini, Managing Director and President of the Centre for Science, Society and Citizenship (CSSC) Barbara Prainsack, Professor, King's College London, Department of Social Science, Health & Medicine Doug Brown, Director of Research and Development, Alzheimer's Society Attendance: members of SP8 and SP12 (list on demand)

Table 3: External Meetings





## 7.4 Scientific Coordination: Monitoring and Quality Control

WP12.6 defined a series of Key Performance Indicators (KPIs) in the Ethics and Society Research Plan (D12.6.1, submitted in M7). During the preparation of his report, WP12.6 asked all SP12 participants to update the values for the KPIs relevant to their activities. WP12.6 organises one 'general' internal meeting with all of SP12 every six months to supervise the progress of work in the different SP12 Work Packages, and make sure that the research done in SP12 is complementary. WP12.6 held three general meetings in M1 (EPFL, Lausanne), M5 (IP, Paris), and M9 (IP, Paris). These 1.5-day meetings follow a common threefold structure:

- 1) Individual WP and Task progress reports by WP leaders and staff
- 2) Round-table discussion on coordination among SP12 participants
- 3) Sub-group workshops

The first internal meeting in M1 focused on the approval of the selection criteria for ELSA and REC membership, and on the clarification of the SP12 roadmap during the Ramp-Up Phase. The meeting in M5 was mostly devoted to the presentation of the Work Package research programs, which have been approved by the Subproject Leader (Kathinka Evers) and specified in the Ethics and Society Research Plan (D12.6.1, submitted in M7). During the meeting in M9, the main WP progress reports included a first summary of the outcomes of the HBP leaders' survey by DMU, a presentation of the main findings from the webinar on Future Medicine held in M8 with SP8 by FT and KCL, and an oral summary of the ongoing conceptual and philosophical research by WP12.2 team.

Besides these plenary sessions, we organised one-day workshops (informal work sessions) involving subgroups in SP12 on a less-regular basis. One workshop was held in M3 (KCL, P32) and made it possible to align the roadmaps for WP12.1, WP12.2, WP12.3 and WP12.4 (details in D12.6.1).

We also hold regular Skype conversations involving representatives of the SP12 Work Packages to coordinate research activities, and discuss the latest outcomes. Finally, we received extremely useful support from Richard Walker (EPFL), HBP spokesman and principal science writer, in all matters regarding the scientific coordination of SP12.

## 7.5 Scientific Coordination: Additional Comments

WP12.6 and WP12.2 co-organised the first two SP12 conferences (in M5 and M9) in Paris at the Institut Pasteur, as part of a cycle of public academic meetings. These conferences brought together scientists from the three main HBP research areas (ICT, medicine and neuroscience) and researchers in the social sciences, philosophy and ethics. We refer the reader to section 7.1 for more details on these events.

## 7.6 Scientific Coordination: The Next Six Months

In M18, WP12.6 will organise another SP12 general meeting in Lisbon at the Gulbenkian Foundation in connection with a neuroscience-philosophy conference on 10-11 April, which both SP12 Co-Directors will attend. Finally, given the high efficiency of the informal workshop format, we plan to hold another in M14 at KCL in London.



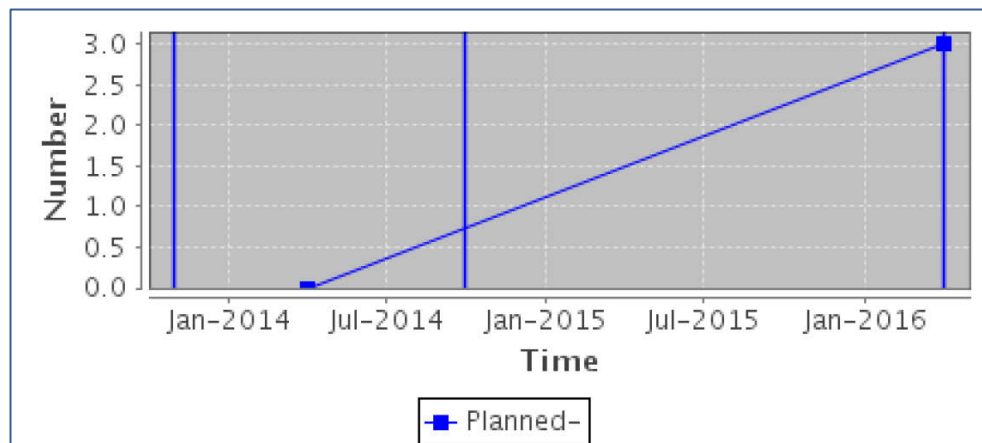
## Annex A: Milestones

No.	Milestone Name	WP	Month Due	Month Achieved	See Page
MS227	Selection committee for ELSA and REC chosen; selection criteria defined; invitation for nominations.	12.5	1	1	
MS228	Selection committee formulates proposal for ELSA and REC membership.	12.5	3	4	
MS229	Board of Directors approves committees; EU informed.	12.5	4	5	
MS213	Activities of Foresight Lab fully specified.	12.1	6	6	
MS218	Activities on philosophical and conceptual issues fully specified.	12.2	6	6	
MS221	Public dialogue activities fully specified; first stakeholders' forum.	12.3	6	6	
MS224	Researcher awareness activities fully specified.	12.4	6	6	
MS230	ELSA and REC start operations.	12.5	6	6	
MS214	Membership, scope, and methods of analysis for the Foresight Lab defined.	12.1	12	12	
MS225	First survey of the attitudes of researchers to the ethics and social consequences of their research begun.	12.4	12	Not yet achieved	

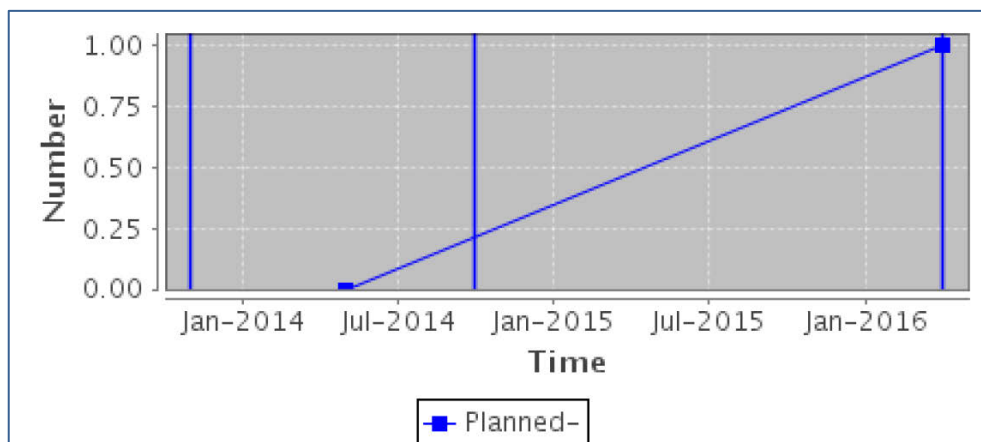


## Annex B: Subproject Scientific Key Performance Indicators (SKPIs)

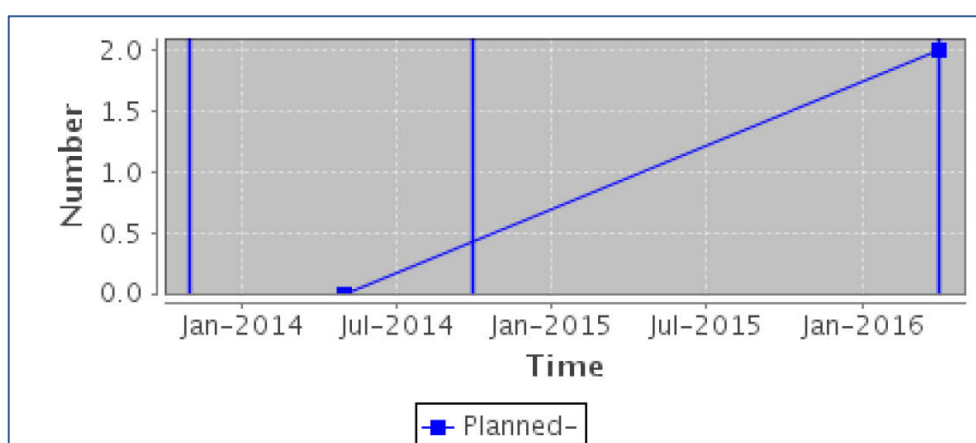
- Number of Citations of the Foresight Reports in HBP internal reports and publications
- Responsible: [nikolas.rose@kcl.ac.uk](mailto:nikolas.rose@kcl.ac.uk)



- Number of scientific publications citing the Foresight Reports
- Responsible: [nikolas.rose@kcl.ac.uk](mailto:nikolas.rose@kcl.ac.uk)

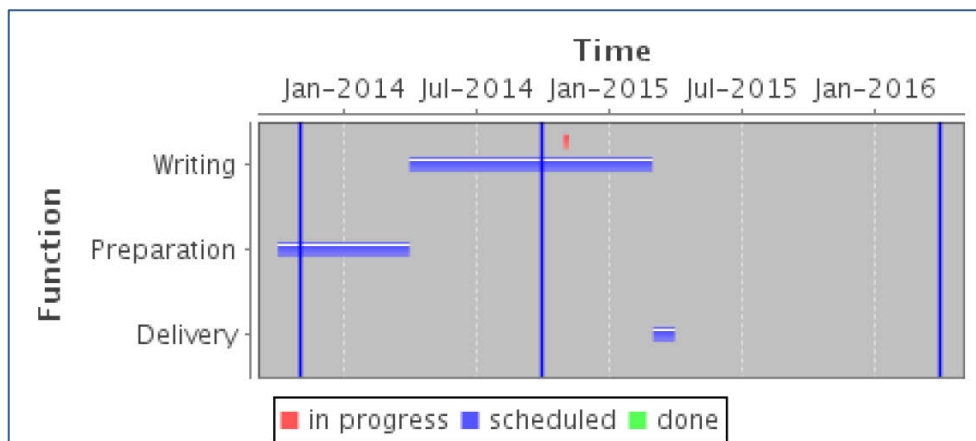


- Number of media articles citing reports from Foresight Reports
- Responsible: [nikolas.rose@kcl.ac.uk](mailto:nikolas.rose@kcl.ac.uk)

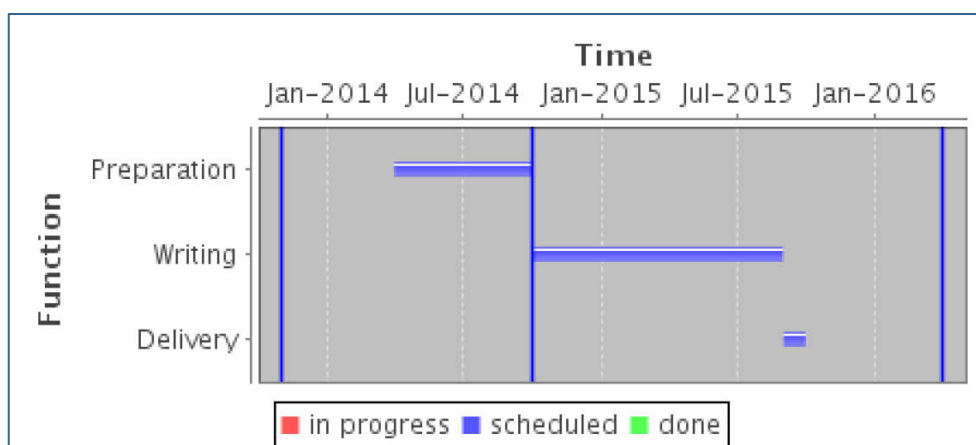




- 1st Foresight Report (Future Medicine)
  - Preparation. Planned: 2013/10/01 - 2014/03/31
  - Writing. Planned: 2014/03/31 - 2015/02/28
  - Delivery. Planned: 2015/03/01 - 2015/03/31
- Responsible: [nikolas.rose@kcl.ac.uk](mailto:nikolas.rose@kcl.ac.uk)

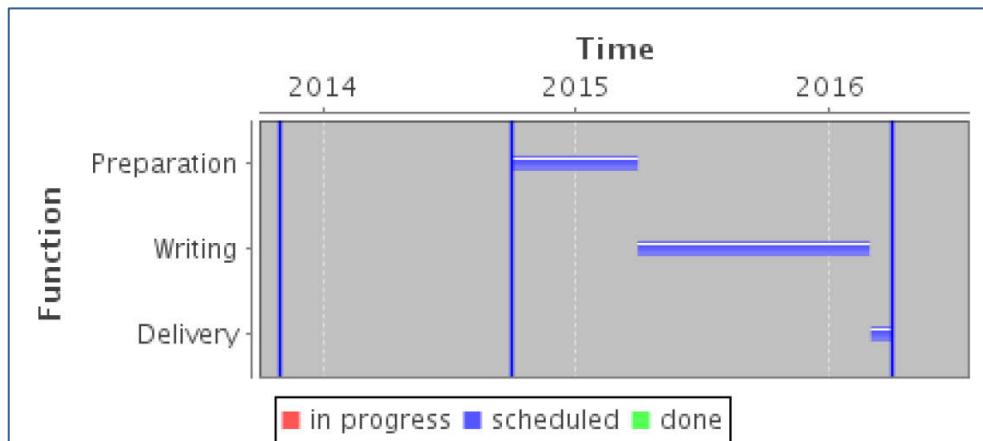


- 2nd Foresight Report (Future Neuroscience)
  - Preparation. Planned: 2014/03/31 - 2014/09/30
  - Writing. Planned: 2014/09/30 - 2015/08/31
  - Delivery. Planned: 2015/09/01 - 2015/09/30
- Responsible: [nikolas.rose@kcl.ac.uk](mailto:nikolas.rose@kcl.ac.uk)





- 3rd Foresight Report (Future Computing/Robotics)
  - Preparation. Planned: 2014/09/30 - 2015/03/31
  - Writing. Planned: 2015/03/31 - 2016/02/28
  - Delivery. Planned: 2016/03/01 - 2016/03/31
- Responsible: [nikolas.rose@kcl.ac.uk](mailto:nikolas.rose@kcl.ac.uk)

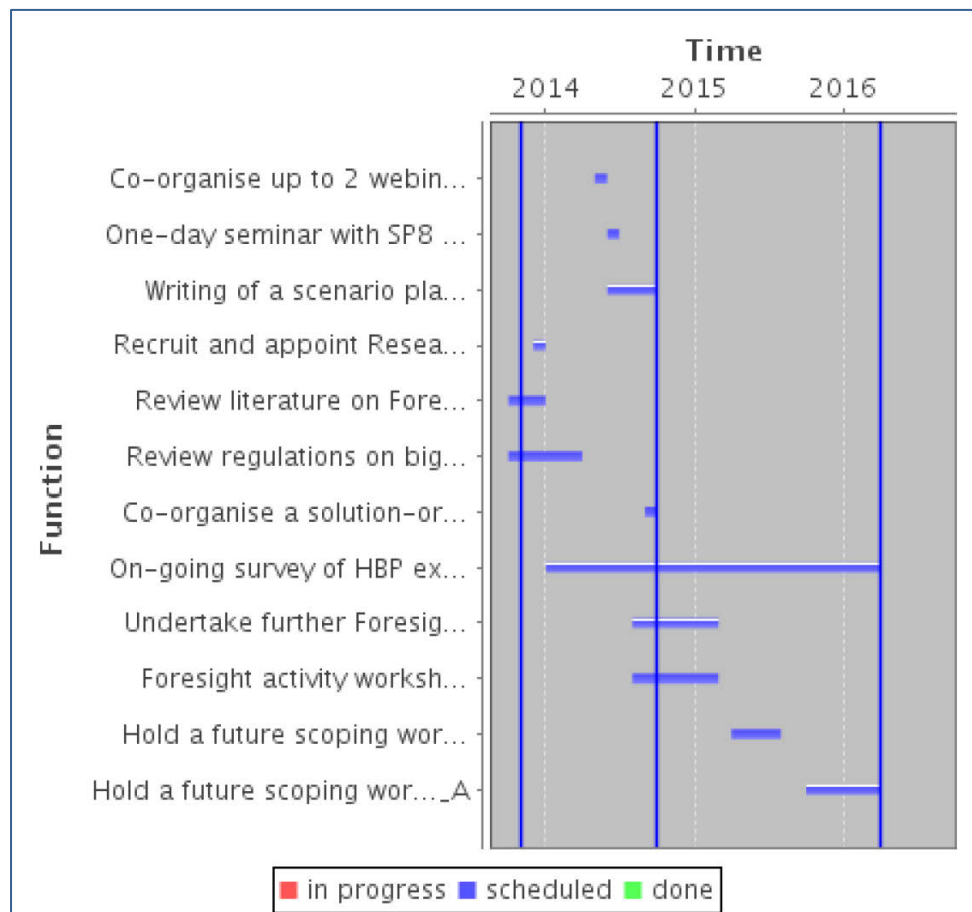


Implementation steps related to T12.1.1:

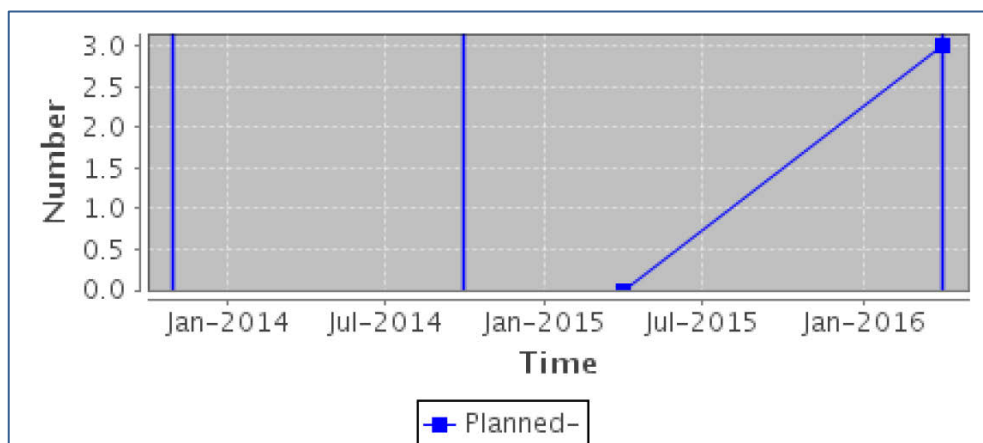
- Co-organise up to 2 webinars with SP8 researchers and other stakeholders in Future Medicine. Planned: 2014/05/01 - 2014/05/31
- One-day seminar with SP8 researchers and non-HBP stakeholders in the domain of Future Medicine. Planned: 2014/06/01 - 2014/06/30
- Writing of a scenario planning (potential HBP impact on future medicine) draft report. Planned: 2014/06/01 - 2014/09/30
- Recruit and appoint Research Officers and Project Officer by Month 3. Planned: 2013/12/01 - 2013/12/31
- Review literature on Foresight and anticipatory governance with focus on methods used. Planned: 2013/10/01 - 2013/12/31
- Review regulations on big data and medical data sharing in preparation for webinars and workshop. Planned: 2013/10/01 - 2014/03/31
- Co-organise a solution-oriented task force meeting (1-2 days) focussed on Future Medicine. Planned: 2014/09/01 - 2014/09/30
- On-going survey of HBP expectations, promises, fears, hopes, and outcomes, through media monitoring. Planned: 2014/01/01 - 2016/03/31
- Undertake further Foresight work with special focus on Future Medicine. Planned: 2014/08/01 - 2015/02/28
- Foresight activity workshop with key stakeholders to explore their perceptions (Future Medicine). Planned: 2014/08/01 - 2015/02/28
- Hold a futurescoping workshop with key stakeholders in the domain of Future Neuroscience. Planned: 2015/04/01 - 2015/07/31
- Hold a futurescoping workshop with key stakeholders in the domain of Future Computing/Robotics. Planned: 2015/10/01 - 2016/03/31



- Responsible: [nikolas.rose@kcl.ac.uk](mailto:nikolas.rose@kcl.ac.uk)

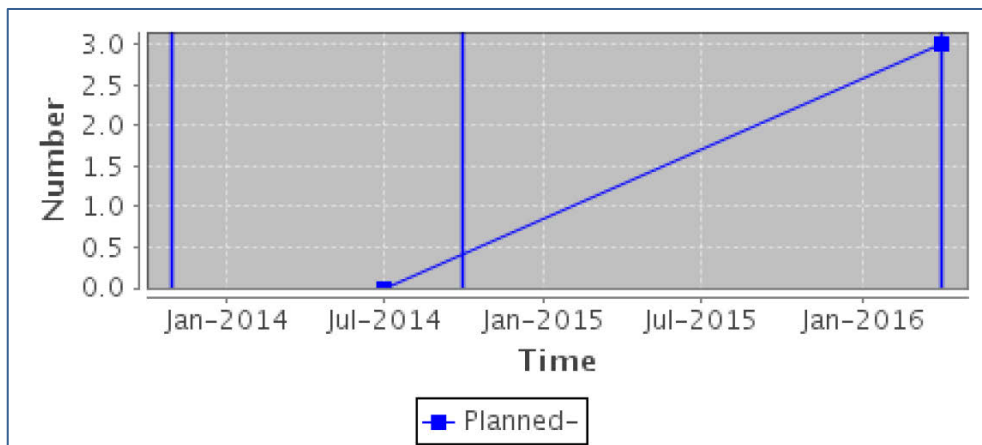


- Number of Citations of report "Relationship between brain, body and environm. for brain simulation"
- Responsible: [yadin.dudai@weizmann.ac.il](mailto:yadin.dudai@weizmann.ac.il)

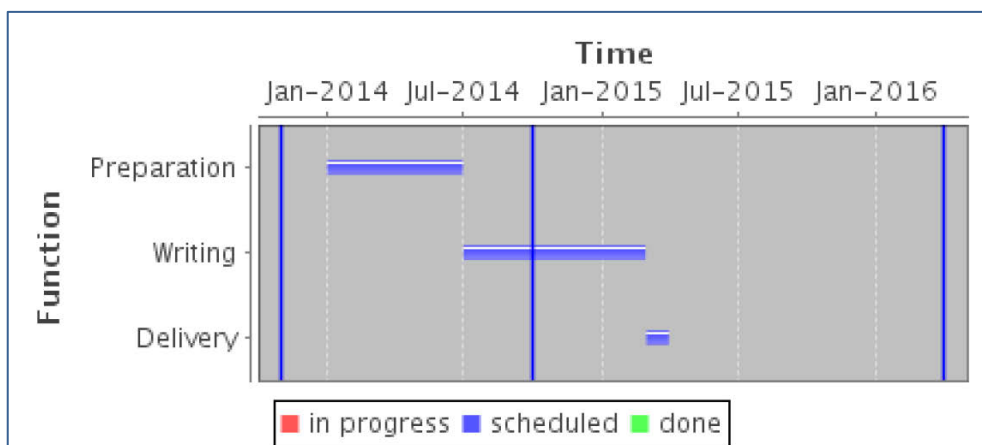




- Number of Papers accepted in conference & high-impact journals (directly referring to HBP research)
- Responsible: [yadin.dudai@weizmann.ac.il](mailto:yadin.dudai@weizmann.ac.il)



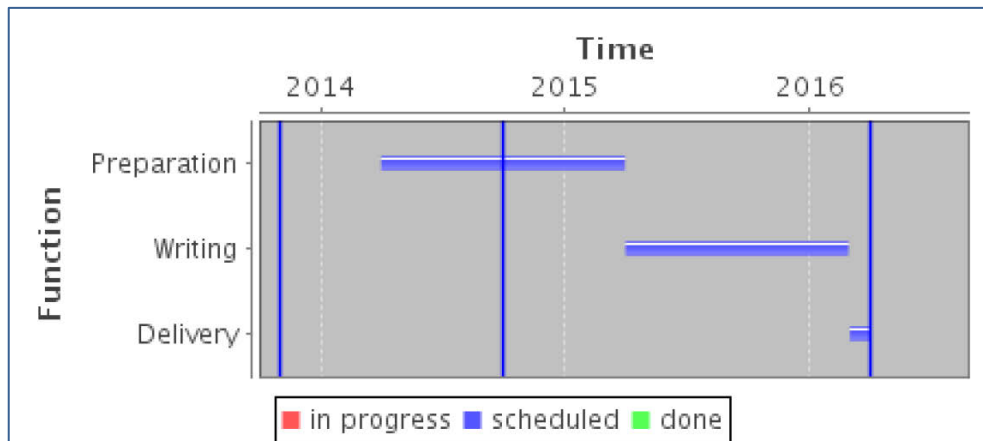
- MS219 Report on how far brain simulation can explain mechanisms of the mind
  - Preparation. Planned: 2014/01/01 - 2014/06/30
  - Writing. Planned: 2014/07/01 - 2015/02/28
  - Delivery. Planned: 2015/03/01 - 2015/03/31
- Responsible: [yadin.dudai@weizmann.ac.il](mailto:yadin.dudai@weizmann.ac.il)





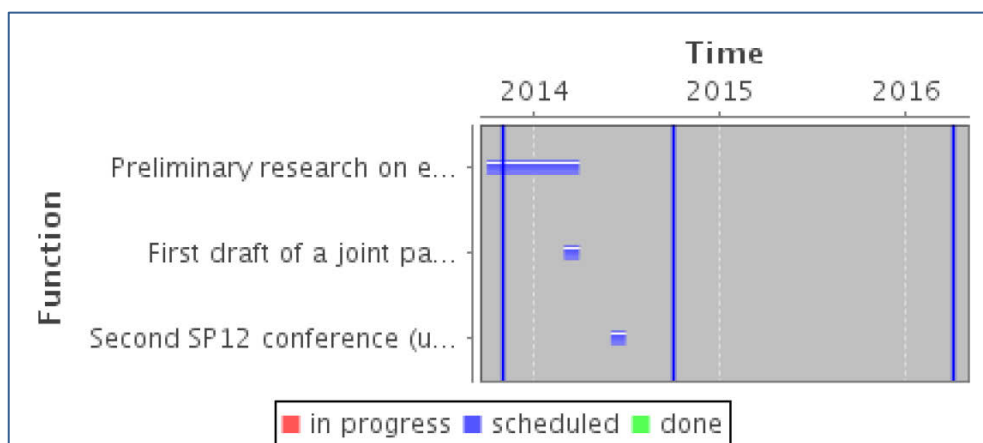


- MS220 Report on the relationship between brain, body and environment for brain simulation  
Preparation. Planned: 2014/04/01 - 2015/03/31
  - Writing. Planned: 2015/04/01 - 2016/02/28
  - Delivery. Planned: 2016/03/01 - 2016/03/31
- Responsible: [kathinka.evers@crb.uu.se](mailto:kathinka.evers@crb.uu.se)



## Implementation steps related to T12.2.1

- Preliminary research on epistemology of simulation and the HBP notion of a brain simulation.  
Planned: 2013/10/01 - 2014/03/31
- First draft of a joint paper by K. Ewers, Y. Dudai, and members of the SP6 on "Brain simulation".  
Planned: 2014/03/01 - 2014/03/31
- Second SP12 conference (under the lead of T12.6.1) on simulation in 06/2014 with SP6 members.  
Planned: 2014/06/01 - 2014/06/30
- Responsible: [yadin.dudai@weizmann.ac.il](mailto:yadin.dudai@weizmann.ac.il)

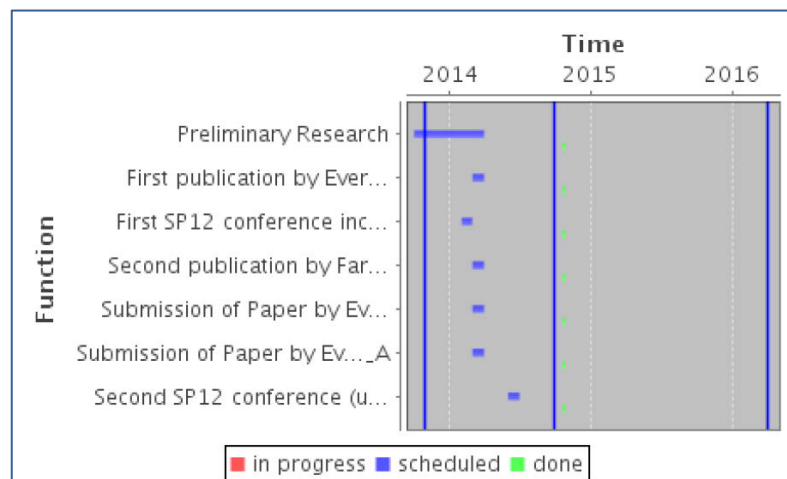


## Implementation steps related to T12.2.2

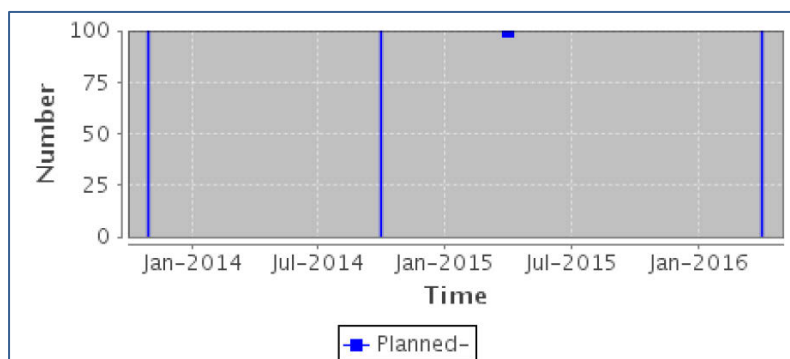
- Preliminary Research. Planned: 2013/10/01 - 2014/03/31
- First publication by Evers K. & Sigman M. (SP3). Planned: 2014/03/01 - 2014/03/31
- First SP12 conference including members of SP3. Planned: 2014/02/01 - 2014/02/28
- Second publication by Farisco M., Evers K., and Petrini C. Planned: 2014/03/01 - 2014/03/31



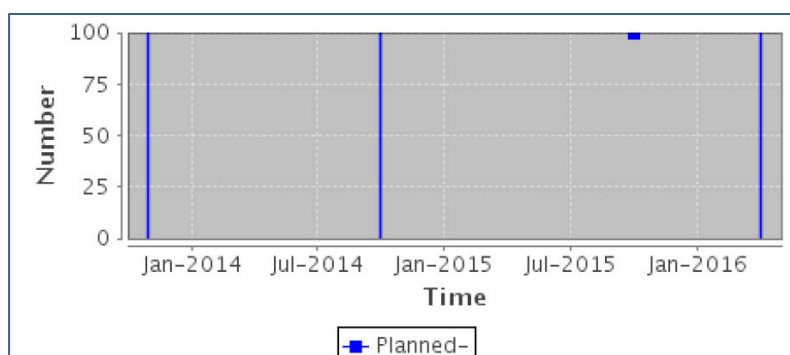
- Submission of Paper by Evers K. and Farisco M. Planned: 2014/03/01 - 2014/03/31
- Submission of Paper by Evers K. and Changeux J.P. Planned: 2014/03/01 - 2014/03/31
- Second SP12 conference (under the lead of T12.6.1) on simulation in 06/2014 with SP6 members. Planned: 2014/06/01 - 2014/06/30
- Responsible: [kathinka.evers@crb.uu.se](mailto:kathinka.evers@crb.uu.se)



- Number of participants in 1st HBP online consultation (on Future Medicine)
- Responsible: [changeux@noos.fr](mailto:changeux@noos.fr)

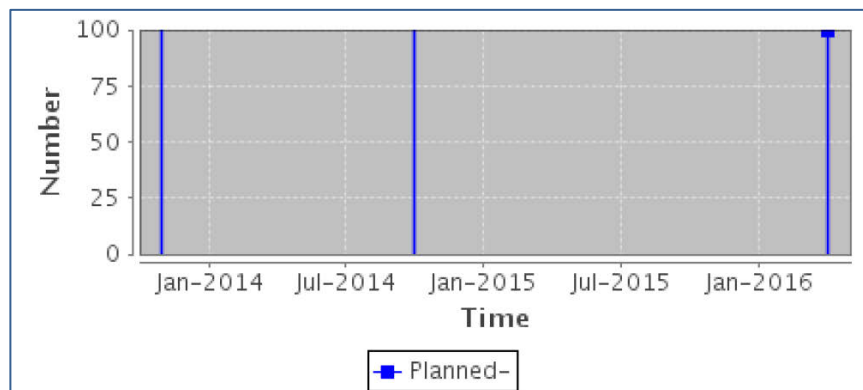


- Number of participants in 2nd HBP online consultation (on Future Neuroscience)
- Responsible: [changeux@noos.fr](mailto:changeux@noos.fr)



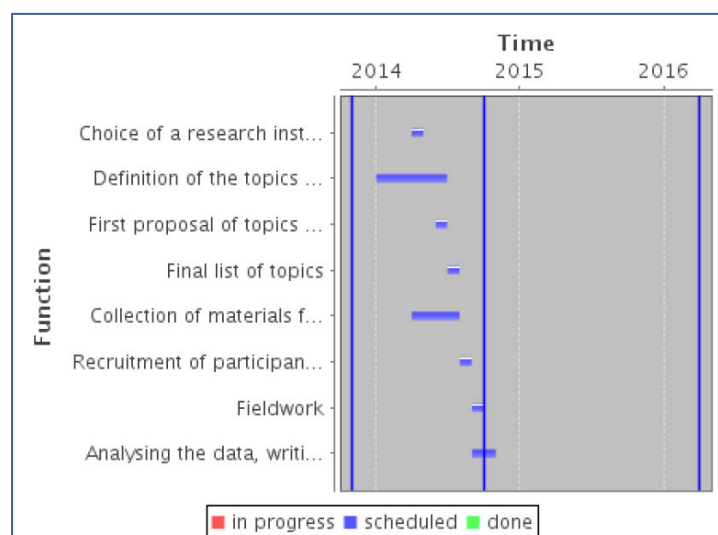


- Number of participants in 3rd HBP online consultation (on Future ICT and Robotics)
- Responsible: [changeux@noos.fr](mailto:changeux@noos.fr)



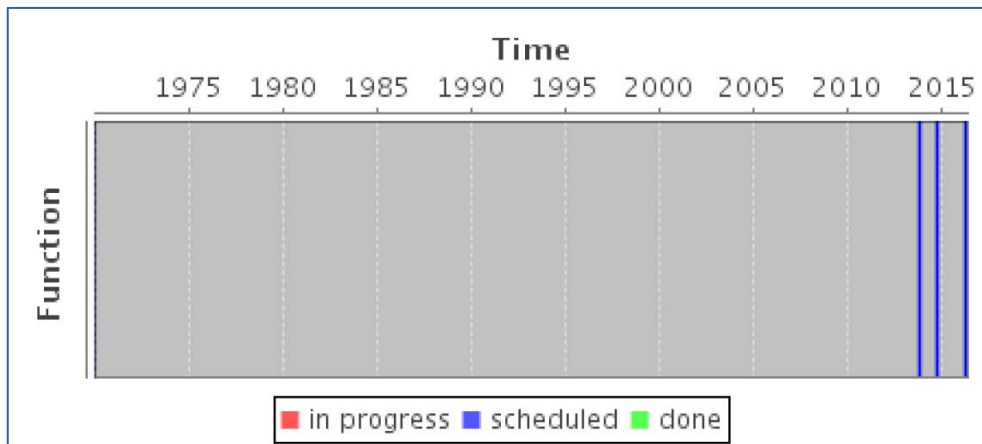
## Actions related to T12.3.1 - 1st HBP online consultation (on Future Medicine)

- Choice of a research institute for the online platform and recruitment of participants; subcontract. Planned: 2014/04/01 - 2014/04/30
- Definition of the topics for the first online consultation. Planned: 2014/01/01 - 2014/06/30
- First proposal of topics to be circulated throughout SP12 for review and suggestion. Planned: 2014/06/01 - 2014/06/30
- Final list of topics. Planned: 2014/07/01 - 2014/07/31
- Collection of materials for the survey (in close cooperation with SP12 & HBP management. Planned: 2014/04/01 - 2014/07/31
- Recruitment of participants for the first consultation. Planned: 2014/08/01 - 2014/08/31
- Fieldwork. Planned: 2014/09/01 - 2014/09/30
- Analysing the data, writing of the report. Planned: 2014/09/01 - 2014/10/31
- Responsible: [changeux@noos.fr](mailto:changeux@noos.fr)

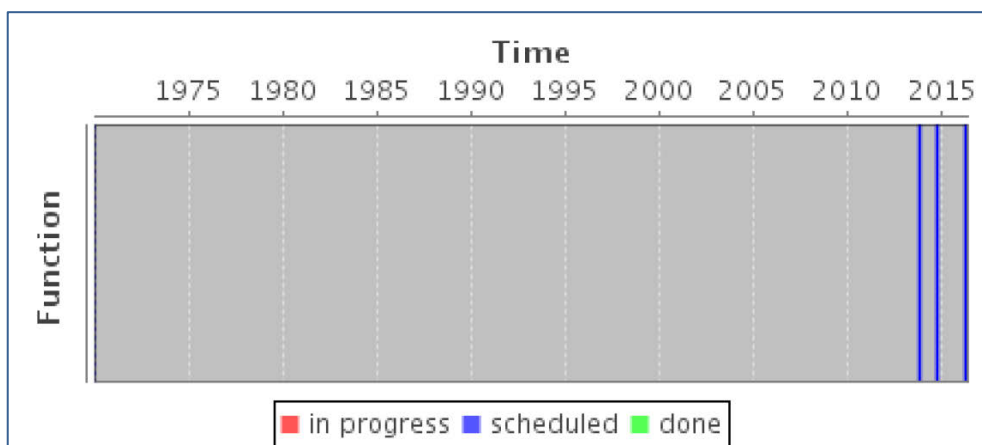




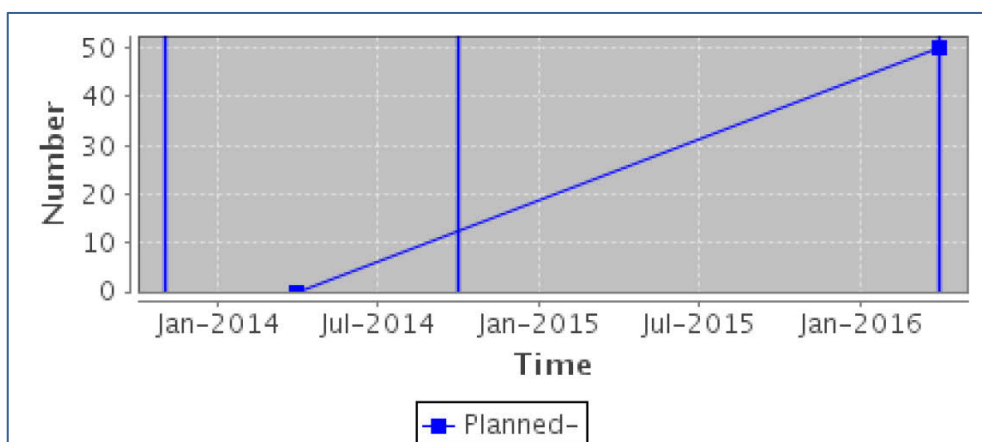
- Actions related to T12.3.1 - 2nd HBP online consultation (on Future Neuroscience)
- Responsible: [changeux@noos.fr](mailto:changeux@noos.fr)



- Actions related to T12.3.1 - 3rd HBP online consultation (on Future ICT and Robotics)
- Responsible: [changeux@noos.fr](mailto:changeux@noos.fr)



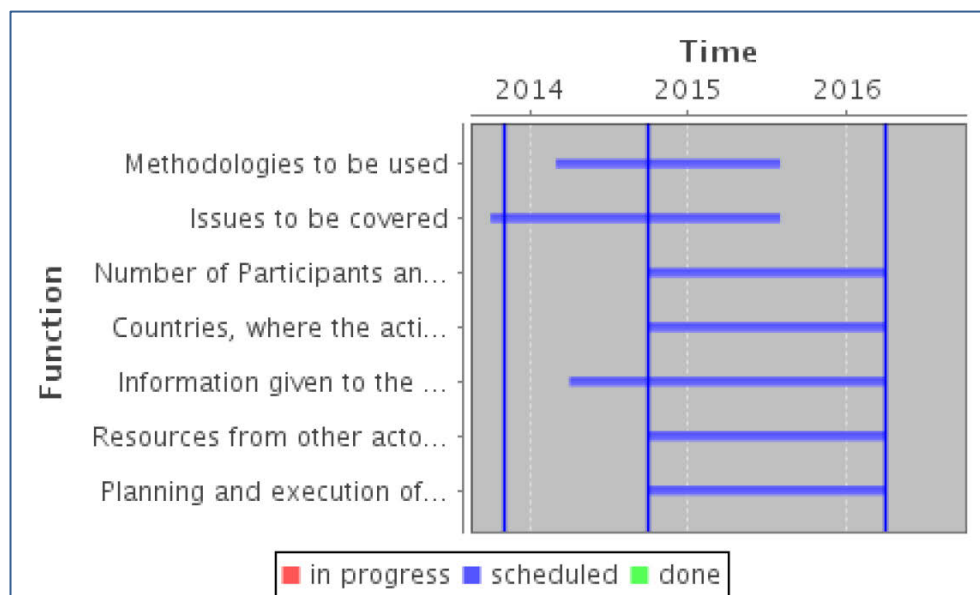
- Number of participants in the first Citizens' Convention
- Responsible: [lk@tekno.dk](mailto:lk@tekno.dk)





## Implementation of T12.3.2 - on Future Medicine

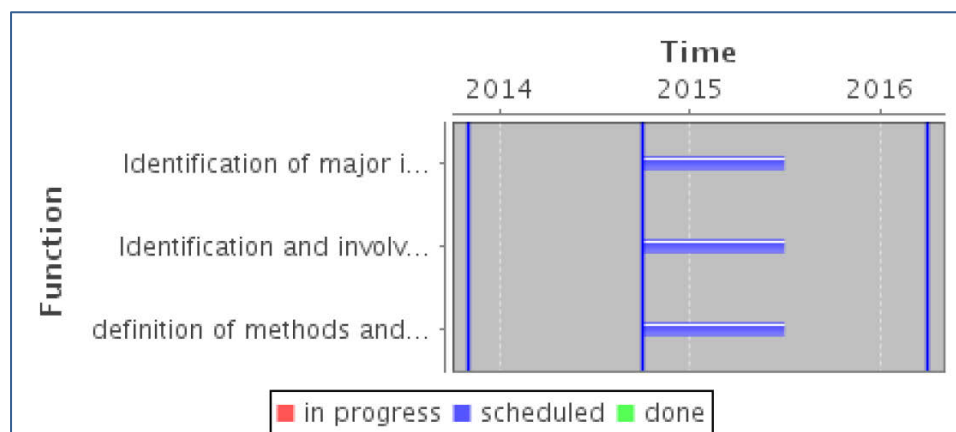
- Methodologies to be used. Planned: 2014/03/01 - 2015/07/31
- Issues to be covered. Planned: 2013/10/01 - 2015/07/31
- Number of Participants and their characteristics. Planned: 2014/10/01 - 2016/03/31
- Countries, where the activities will take place. Planned: 2014/10/01 - 2016/03/31
- Information given to the participants before and during the activities. Planned: 2014/04/01 - 2016/03/31
- Resources from other actors inside and outside the HBP to be included. Planned: 2014/10/01 - 2016/03/31
- Planning and execution of the first European Citizen's Convention. Planned: 2014/10/01 - 2016/03/31
- Responsible: [lk@tekno.dk](mailto:lk@tekno.dk)





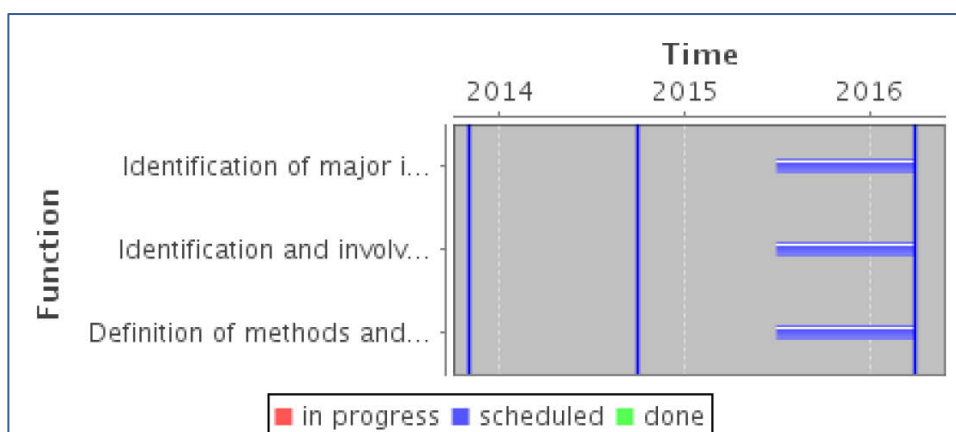
## Implementation of T12.3.2 - on Future Neuroscience

- Identification of major issues through desk research and dialog with SP8 representatives, HBP manage. Planned: 2014/09/30 - 2015/06/30
- Identification and involvement of relevant stakeholders and experts. Planned: 2014/09/30 - 2015/06/30
- Definition of methods and detailed process with agenda for the 3 planned activities. Planned: 2014/09/30 - 2015/06/30
- Responsible: [lk@tekno.dk](mailto:lk@tekno.dk)



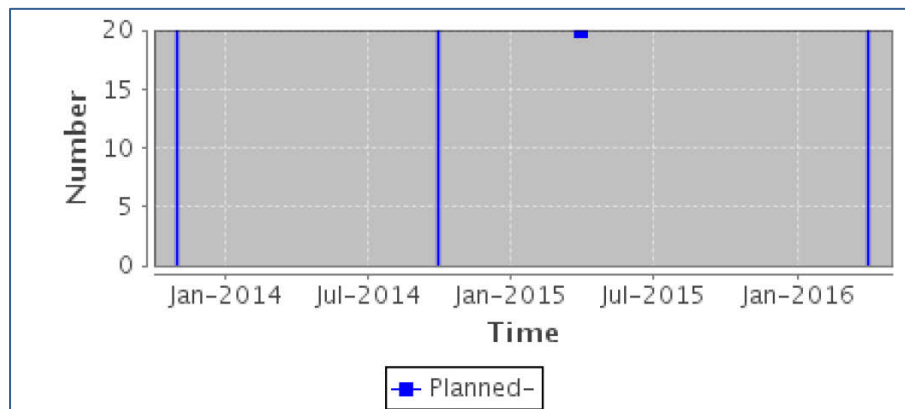
## Implementation of T12.3.2 - on Future ICT and Robotics

- Identification of major issues through desk research and dialog with SP8 representatives, HBP manage. Planned: 2015/06/30 - 2016/03/31
- Identification and involvement of relevant stakeholders and experts. Planned: 2015/06/30 - 2016/03/31
- Definition of methods and detailed process with agenda for the 3 planned activities. Planned: 2015/06/30 - 2016/03/31
- Responsible: [lk@tekno.dk](mailto:lk@tekno.dk)

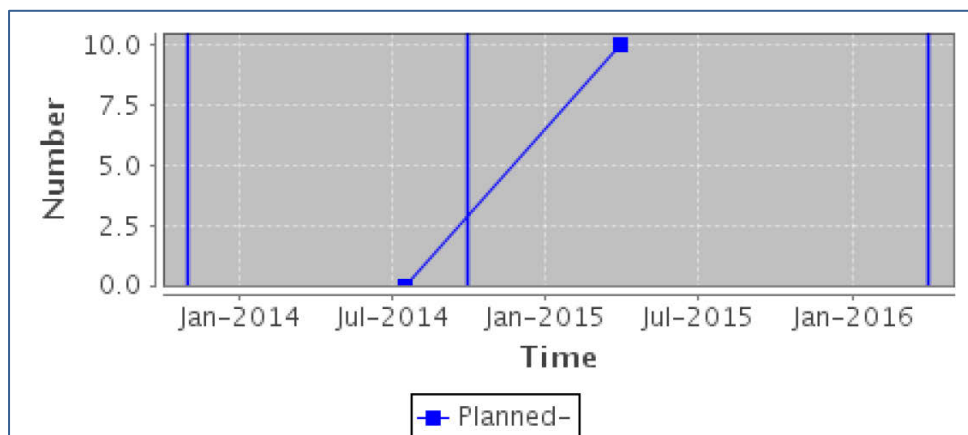




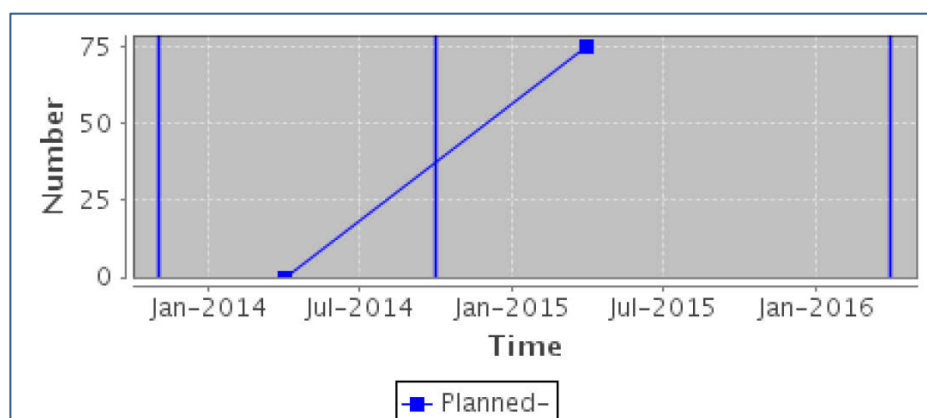
- Number of external stakeholders involved in 1st Stakeholders' Forum: webinars, seminars, workshops
- Responsible: [lk@tekno.dk](mailto:lk@tekno.dk)



- Number of HBP researchers involved in 1st Stakeholders' Forum: webinars, seminars, workshops
- Responsible: [lk@tekno.dk](mailto:lk@tekno.dk)



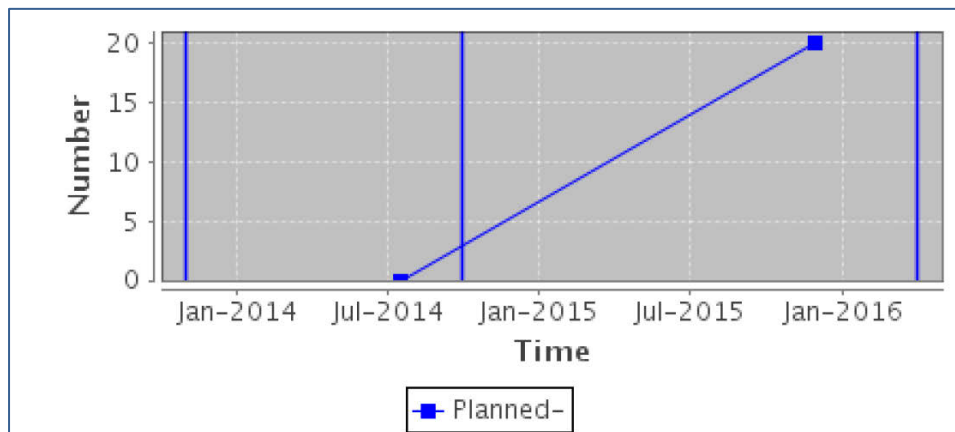
- Percentage of HBP researchers involved in the first stakeholders' forum, deeming the input useful for future
- Responsible: [lk@tekno.dk](mailto:lk@tekno.dk)



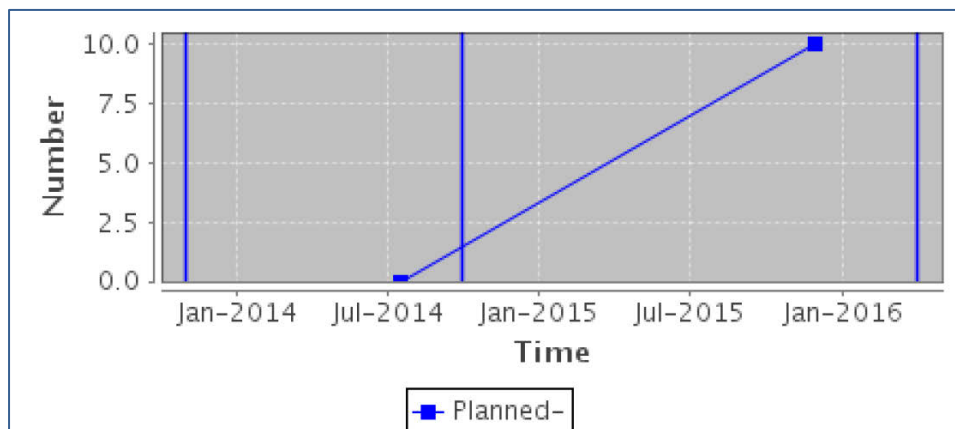




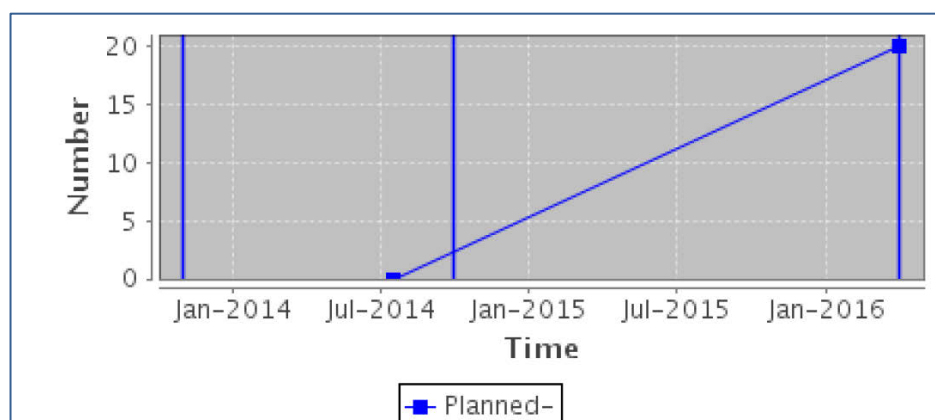
- Number of external stakeholders involved in 2nd Stakeholders' Forum: webinars, seminars, workshops
- Responsible: [lk@tekno.dk](mailto:lk@tekno.dk)



- Number of HBP researchers involved in 2nd stakeholders' forum: webinars, seminars and workshops
- Responsible: [lk@tekno.dk](mailto:lk@tekno.dk)

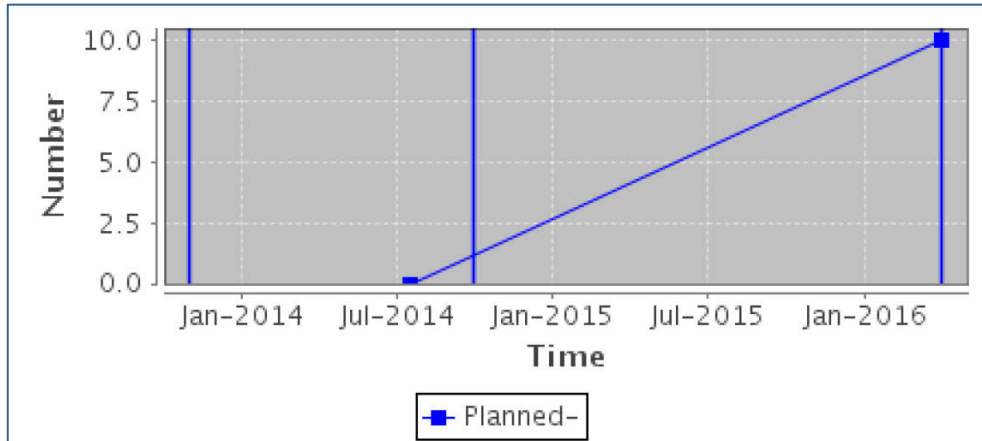


- Number of external stakeholders involved in 3rd Stakeholders' Forum: webinars, seminars, workshops
- Responsible: [lk@tekno.dk](mailto:lk@tekno.dk)



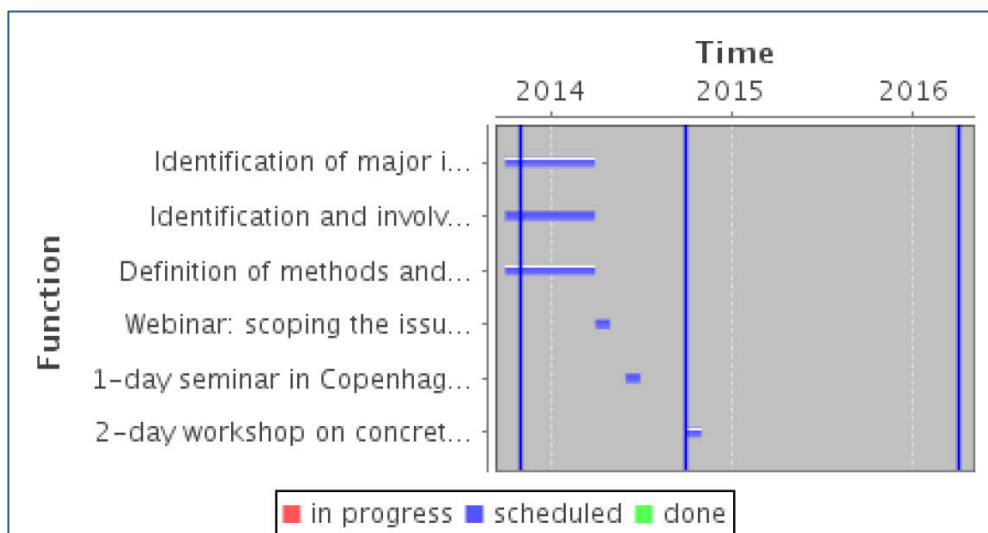


- Number of HBP researchers involved in 3rd stakeholders' forum: webinars, seminars and workshops
- Responsible: [lk@tekno.dk](mailto:lk@tekno.dk)



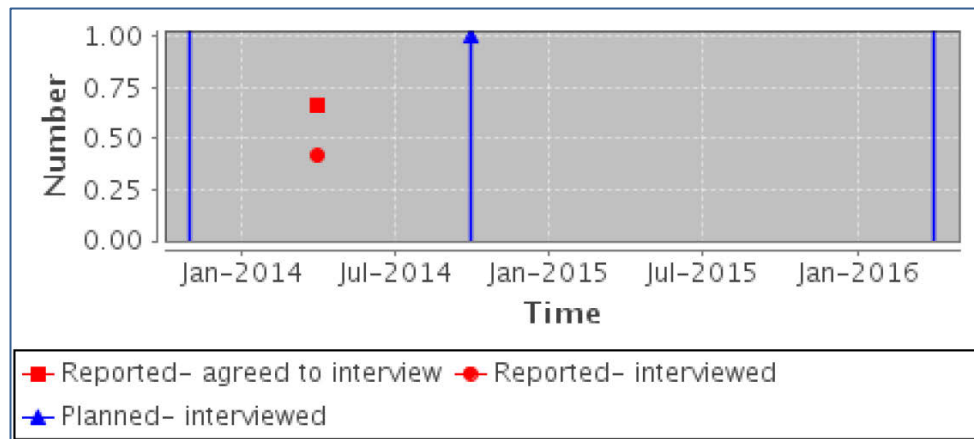
## Implementation of T12.3.3

- Identification of major issues through desk research and dialog with SP8 representatives, HBP manage. Planned: 2013/10/01 - 2014/03/31
- Identification and involvement of relevant stakeholders and experts. Planned: 2013/10/01 - 2014/03/31
- Definition of methods and detailed process with agenda for the 3 planned activities. Planned: 2013/10/01 - 2014/03/31
- Webinar: scoping the issues, questions, challenges and concerns. Planned: 2014/04/01 - 2014/04/30
- 1-day seminar in Copenhagen (30 participants). Planned: 2014/06/01 - 2014/06/30
- 2-day workshop on concrete recommendations for actions in HBP research using medical data. Planned: 2014/10/01 - 2014/10/31
- Responsible: [lk@tekno.dk](mailto:lk@tekno.dk)

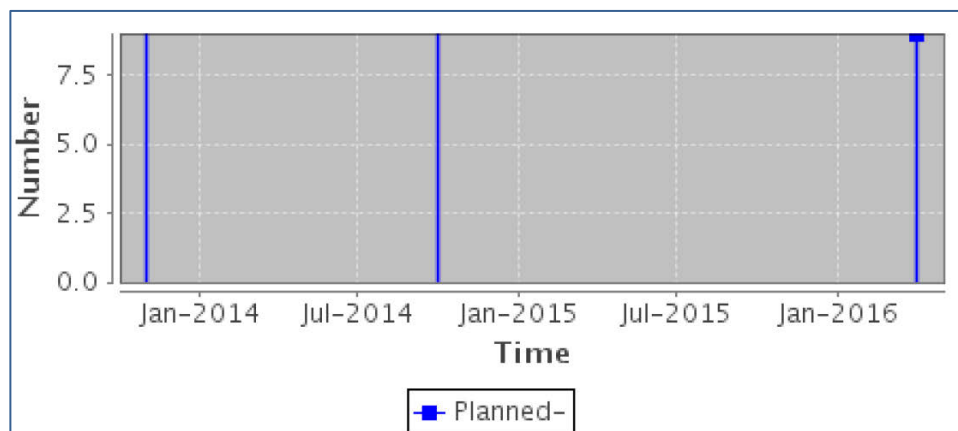




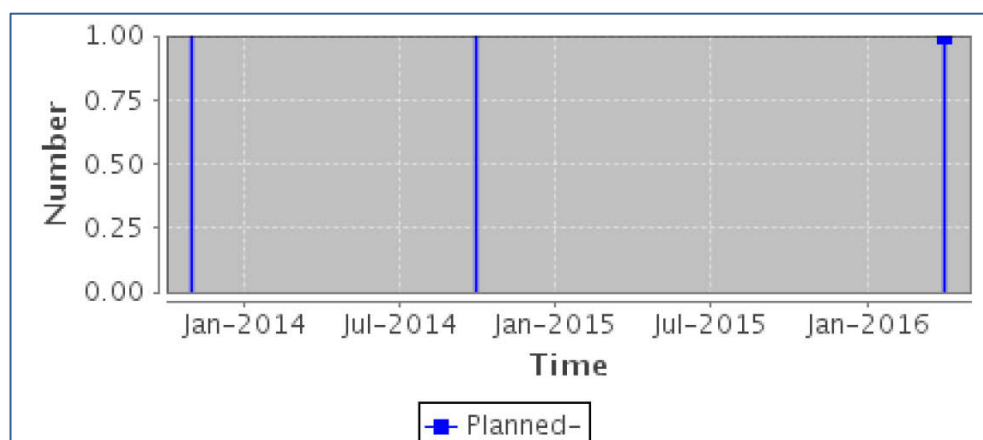
- Number of qualitative interviews with management
- Responsible: [bstahl@dmu.ac.uk](mailto:bstahl@dmu.ac.uk)



- Number of interviews (during the in-depth investigation programme)
- Responsible: [bstahl@dmu.ac.uk](mailto:bstahl@dmu.ac.uk)



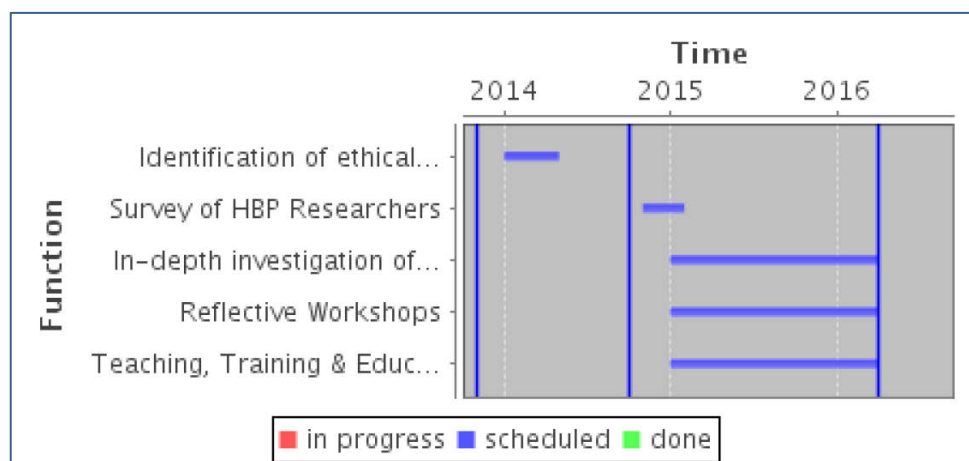
- Number of reflective workshops
- Responsible: [bstahl@dmu.ac.uk](mailto:bstahl@dmu.ac.uk)



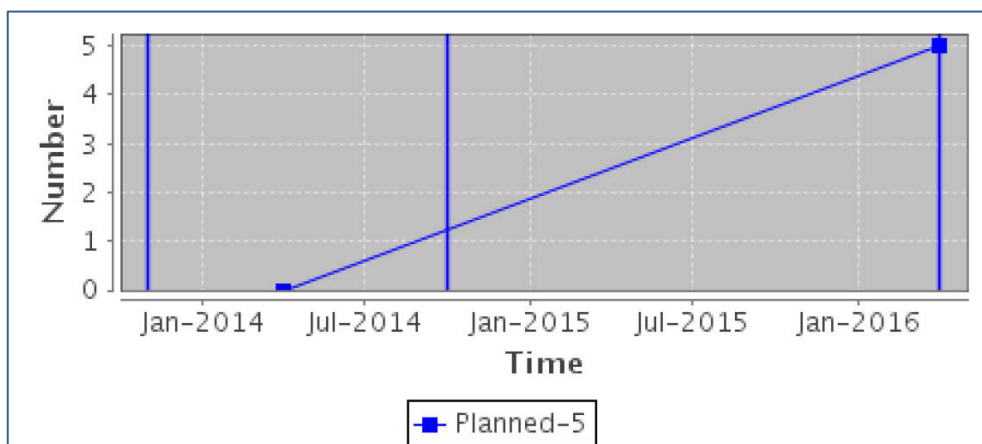


## Implementation of T12.4.1

- Identification of ethical and social issues by management. Planned: 2013/12/31 - 2014/04/30
- Survey of HBP Researchers. Planned: 2014/10/31 - 2015/01/31
- In-depth investigation of issues using focus groups and interviews. Planned: 2014/12/31 - 2016/03/31
- Reflective Workshops. Planned: 2014/12/31 - 2016/03/31
- Teaching, Training & Education. Planned: 2014/12/31 - 2016/03/31
- Responsible: [bstahl@dmu.ac.uk](mailto:bstahl@dmu.ac.uk)

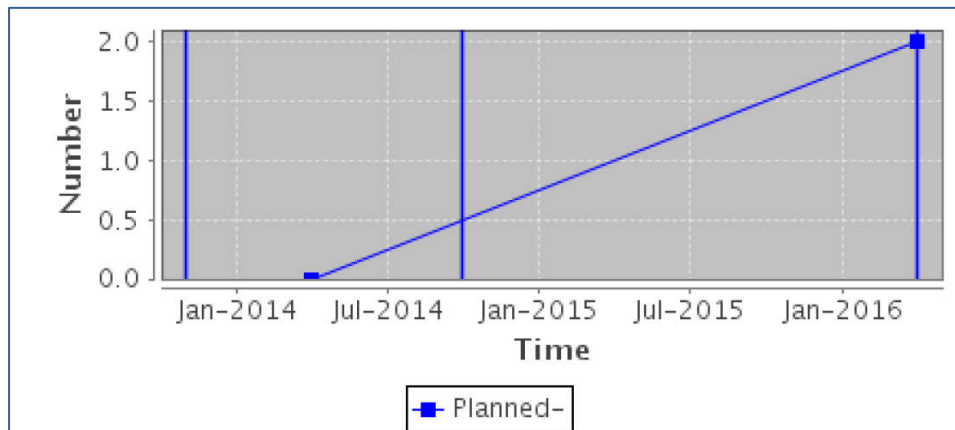


- Number of ELSA meetings
- Responsible: [kevin.grimes@ki.se](mailto:kevin.grimes@ki.se)

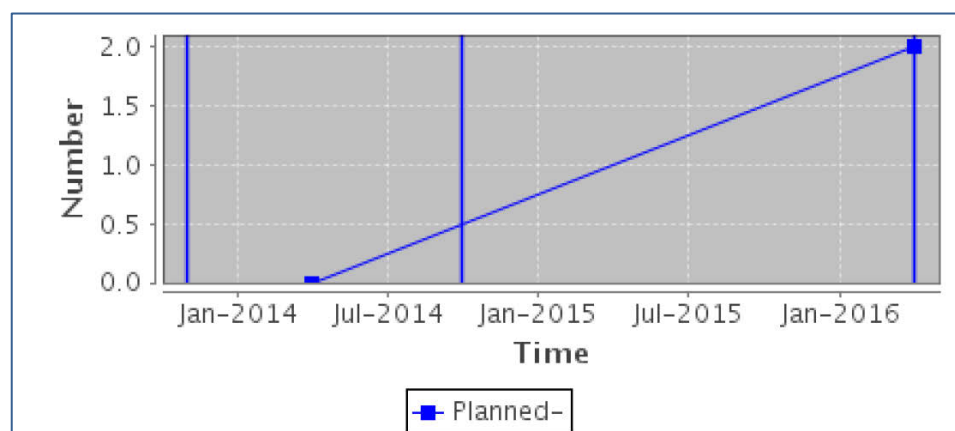




- Number of working groups appointed to examine issues
- Responsible: [kevin.grimes@ki.se](mailto:kevin.grimes@ki.se)

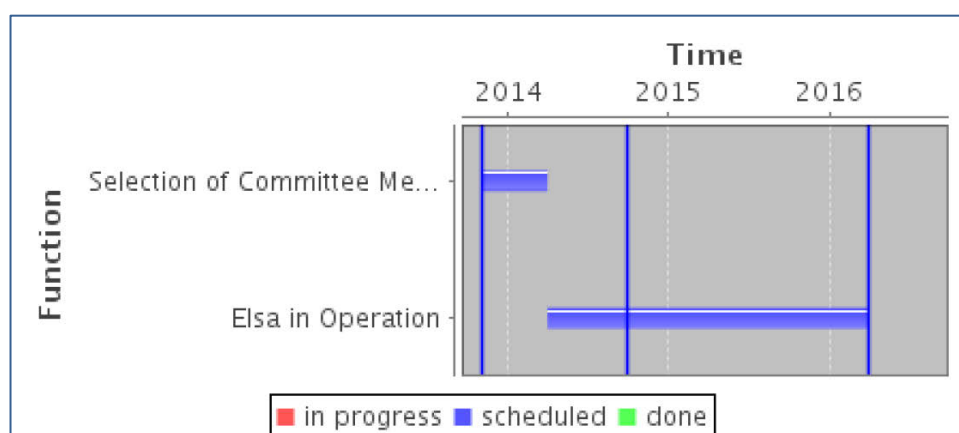


- Number of approved Ethical Reviews conducted by the Commission
- Responsible: [kevin.grimes@ki.se](mailto:kevin.grimes@ki.se)



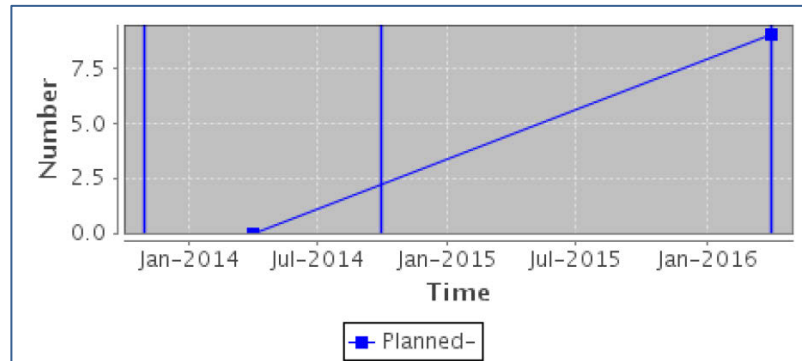
## Implementation of T12.5.1

- Selection of Committee Members and set-up of ELSA. Planned: 2013/10/31 - 2014/03/31
- Elsa in Operation. Planned: 2014/03/31 - 2016/03/31
- Responsible: [kevin.grimes@ki.se](mailto:kevin.grimes@ki.se)

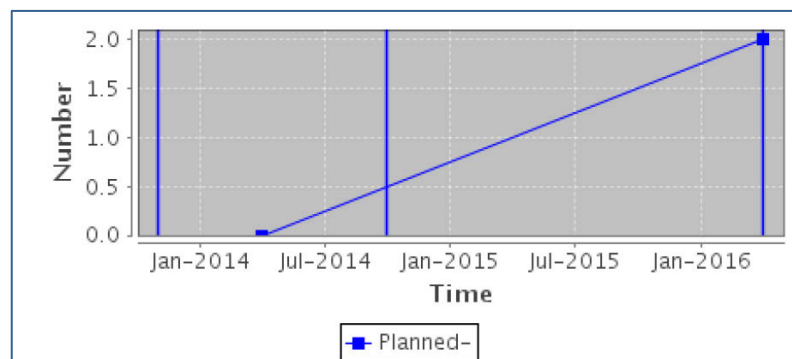




- Number of REC meetings
- Responsible: [abdul.mohammed@lnu.se](mailto:abdul.mohammed@lnu.se)

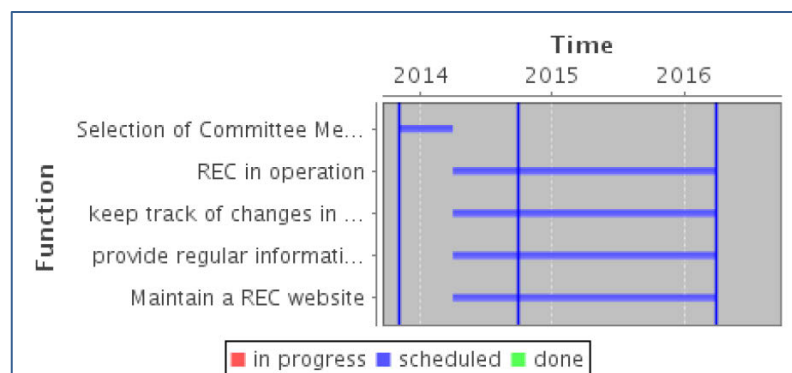


- Number of approved Ethical reviews conducted by the Commission
- Responsible: [abdul.mohammed@lnu.se](mailto:abdul.mohammed@lnu.se)



## Implementation of T12.5.2

- Selection of Committee Members and set-up of REC. Planned: 2013/10/31 - 2014/03/31
- REC in operation. Planned: 2014/03/31 - 2016/03/31
- Keep track of changes in national and European regulations. Planned: 2014/03/31 - 2016/03/31
- Provide regular information on changes to REC members and HBP researchers. Planned: 2014/03/31 - 2016/03/31
- Maintain a REC website. Planned: 2014/03/31 - 2016/03/31
- Responsible: [abdul.mohammed@lnu.se](mailto:abdul.mohammed@lnu.se)





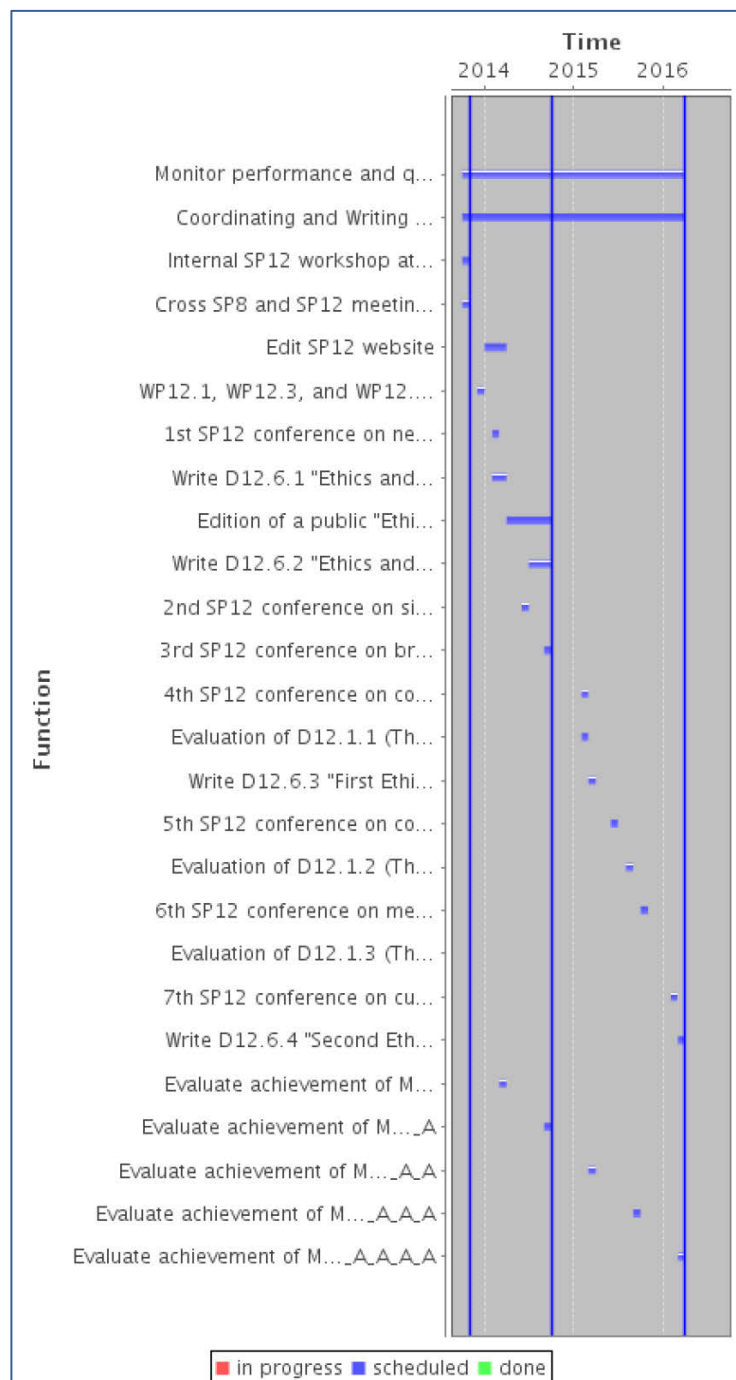
## Actions related to T12.6.1:

- Monitor performance and quality of the WPs. Planned: 2013/10/01 - 2016/03/31
- Coordinating and Writing of the Deliverables. Planned: 2013/10/01 - 2016/03/31
- Internal SP12 workshop at HBP summit 2013. Planned: 2013/10/01 - 2013/10/31
- Cross SP8 and SP12 meeting. Planned: 2013/10/01 - 2013/10/31
- Edit SP12 website. Planned: 2013/12/31 - 2014/03/31
- WP12.1, WP12.3, and WP12.4 workshop at King's College, London. Planned: 2013/12/01 - 2013/12/31
- 1st SP12 conference on neurotechnical assessments of consciousness in collaboration with SP3 members. Planned: 2014/02/01 - 2014/02/28
- Write D12.6.1 "Ethics and Society research plan". Planned: 2014/01/31 - 2014/03/31
- Edition of a public "Ethics and Society in HBP" website for public information and communication. Planned: 2014/03/31 - 2014/09/30
- Write D12.6.2 "Ethics and Society progress report". Planned: 2014/06/30 - 2014/09/30
- 2nd SP12 conference on simulation in collaboration with members of SP6. Planned: 2014/06/01 - 2014/06/30
- 3rd SP12 conference on brain diseases and disorders with members of SP8 on HBP summit 2014. Planned: 2014/09/01 - 2014/09/30
- 4th SP12 conference on consciousness and self-consciousness in collaboration with SP3 members. Planned: 2015/02/01 - 2015/02/28
- Evaluation of D12.1.1 (The HBP Foresight Lab - First report on Future Medicine). Planned: 2015/02/01 - 2015/02/28
- Write D12.6.3 "First Ethics and Society Report". Planned: 2015/03/01 - 2015/03/31
- 5th SP12 conference on cognitive enhancement with members of SP3. Planned: 2015/06/01 - 2015/06/30
- Evaluation of D12.1.2 (The HBP Foresight Lab - First report on Future Neuroscience). Planned: 2015/08/01 - 2015/08/31
- 6th SP12 conference on memory manipulation with SP3 members. Planned: 2015/10/01 - 2015/10/31
- Evaluation of D12.1.3 (The HBP Foresight Lab - First report on Future ICT and Robotics)). Planned: 2016/02/01 - 2016/02/01
- 7th SP12 conference on cultural circuits in the brain and simulation with members of SP6. Planned: 2016/02/01 - 2016/02/28
- Write D12.6.4 "Second Ethics and Society Report". Planned: 2016/03/01 - 2016/03/31
- Evaluate achievement of Milestones in month 6 (MS213, MS218, MS221, MS224). Planned: 2014/03/01 - 2014/03/31
- Evaluate achievement of Milestones in month 12 (MS214, MS225). Planned: 2014/09/01 - 2014/09/30
- Evaluate achievement of Milestones in month 18 (MS215, MS219, MS222). Planned: 2015/03/01 - 2015/03/31





- Evaluate achievement of Milestones in month 24 (MS216). Planned: 2015/09/01 - 2015/09/30
- Evaluate achievement of Milestones in month 30 (MS217, MS220, MS223, MS226). Planned: 2016/03/01 - 2016/03/31
- Responsible: [benjamin.simmenauer@hck-solutions.com](mailto:benjamin.simmenauer@hck-solutions.com)





## Annex C: References

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<sup>1</sup> Rose, N. (2014). "The Human Brain Project: social and ethical challenges." Neuron 82(6): 1212-1215.  
<http://www.sciencedirect.com/science/article/pii/S0896627314004917>

<sup>2</sup> Dudai, Y., Evers, K., To simulate or not to simulate: What are the questions?, accepted for publication in Neuron, 2014.

<sup>3</sup> Rose, N. (2014). "The Human Brain Project: social and ethical challenges." Neuron 82(6): 1212-1215.  
<http://www.sciencedirect.com/science/article/pii/S0896627314004917>