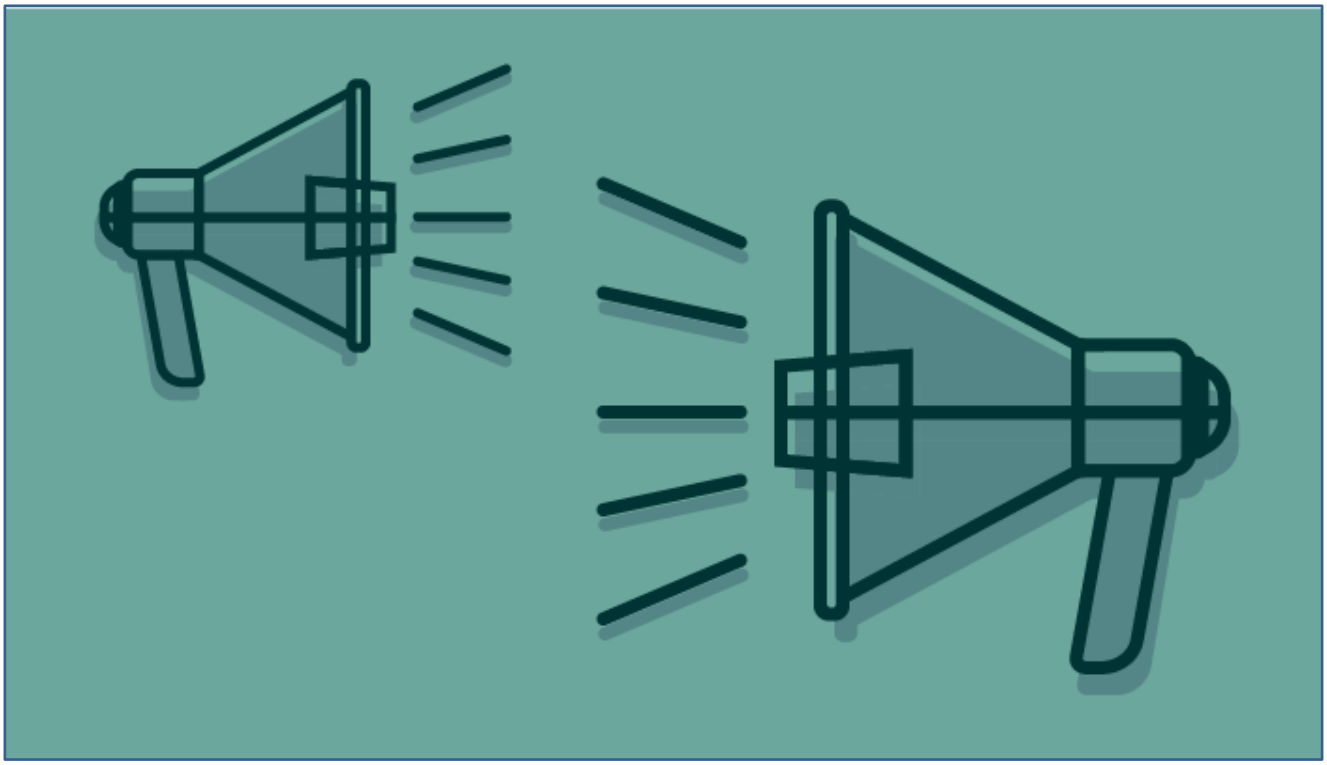
Overview of ethical issues across the HBP (OP9.9)



Project Number:	945539	Project Title:	HBP SGA3

Document Title:	Overview of ethical issues across the HBP (OP9.9)
Document Filename:	HBP_SGA3_Output_ Overview of ethical issues across the HBP (OP9.9).docx
Output Number:	SGA3 OP9.9 *(as per SGA3 Grant Agreement)*
Dissemination Level:	PU = Public
Due Date:	SGA3 M40 / 31 JUL 2023
Achieved Date:	SGA3 M36 / 30 APR 2023
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Abstract:	*An overview of the ethical issues across the HBP compiled in the context of the Ethics Rapporteur Programme and the Ethics Trilateral Meetings.*
Keywords:	*Ethical issues and challenges, RRI in HBP, Ethics Rapporteurs, Ethics Advisory Board*
Target Users/Readers:	EC, EC reviewers, HBP leadership, HBP ethics rapporteurs and researchers, Ethics Advisory Board

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1. Background

Trilateral meetings have been held between representatives of the Work Packages, the Ethics Director, and the Ethics Advisory Board since the Ramp-Up Phase of HBP. During these meetings, each HBP WP Ethics Rapporteur presents slides that cover the WP activities' scope, the identified ethical challenges, and future questions. The identification of ethical issues and challenges is preceded by internal work at each WP, several Ethics Rapporteur Programme meetings, capacity-building activities to identify ethical and dual use of concern issues and bilateral meetings between the Ethics Rapporteurs and the Ethics Advisory Board's "match-ups". The Ethics Rapporteur Programme's lead facilitated and coordinated these activities with the WP9 RRI-hub, particularly with the Dual Use Working Group and the Ethics Advisory Board.

As a result of the dialogues in the Trilateral meetings, a so-called "One-Pager of ethical issues and challenges" has been developed in each WP, which is an ongoing live document that is being updated on an annual basis and helps the WPs and HBP RRI-related activities to address and handle ethical issues and challenges across the project.

The following overview summarises in bullet points the identified ethical issues and challenges across the HBP presented by the Ethics Rapporteurs, which covers until SGA3 month 36 when it was finished.

2. Ethical Issues Across the HBP

WP1: The human multiscale brain connectome and its variability -from synapses to large-scale networks and function

- Relation between choice/construction of models and their function
- Drift of the use of models
- Lack of awareness on the drift
- Black-box effect

These issues relate to the distinction of responsibilities of the modeler and responsibilities of the user (and his awareness of it). Once a model is deployed and used by others, the responsibility shifts to the user to ensure that the model is used appropriately and its results are interpreted correctly. Users should be aware of the model's limitations and potential biases, and should not rely solely on the model's output without considering other relevant information. But it means that this information and limitations should be clearly available to the user.

WP2: Networks Underlying Brain Cognition and Consciousness

- Issues related to clinical impact:
  - Potential impact on understanding diagnosis and treatment of DOCs and Schizophrenia, both during resting state and after stimulation.
  - Regarding Digital twins technology and personalized models in general, it is noted that we are quite some way off from achieving prediction accuracy that will be applicable to the individual.

- Potential impact on understanding the mechanism of anaesthesia and how it differs from pathological states.

- Potential AI-related issues:
  - Potential for development of new AI architectures (i.e., bio-inspired and neurobiologically plausible models). This technology can raise ethical issues, but the current inputs from WP2 don't identify any specific issue.
  - Digital twins could be an example of AI-related and ethically relevant technology.
  - The anticipated prediction model(s) will be based on machine learning (ML) analyses of human assessments. The algorithm(s), once we have it/them, should never be applied blindly, in an AI setting, to make decisions about who should receive treatment or not, also to avoid erroneous algorithm outcomes, and ensure safe AI.
  - How to implement responsible use of ML in clinical practice is an open issue.
  - The possibility to produce Artificial sentience is ethically relevant. Even if not directly related to actual WP2 work, the discussion is ongoing about the need to more specifically assess it.
- Dual Use Of Concern-related issues:
  - All WP2 tasks are aware of dual-use and misuse risks.
  - A misuse (no tracking) of the data/models that WP2 is collecting and will be made publicly available on EBRAINS could lead to (really unlikely) some dual-use or misuse issues.
- Data protection-related issues:
  - All partners are compliant with GDPR rules.
  - There is a concern about full anonymization of the data without losing their potential for research.
  - A possibility might be that instead of sharing all the metadata WP2 researchers can provide a confidence interval around the true data (harder to identify the subject).

WP3: The Adaptive Networks for Cognitive Architectures: From Advanced Learning to Neurorobotics and Neuromorphic Applications

- Clear view by WP3 researchers that many tasks in WP3 are too fundamental to raise clear ethical challenges -based on the premise of no feasible applications in the SGA timeframe, and speculation further beyond that is problematic:
  - Raises questions as to how we can start to engage with ethical issues early enough in the research process to be useful in helping to address concerns as they arise without trying to start this discussion at a point where no meaningful anticipation can occur.
  - Also raises questions around possibility of dual use of concern issues, which requires prediction of the 'potential for use in ways which threaten the peace, health, safety, security and well-being of citizens' -difficult to ascertain if possible applications are unclear.
  - Any research at scale using digital platforms may inherently have some environmental implications through, for example, high-energy usage -use of neuromorphic platforms is positive, as these are more energy-efficient.
  - No specific data protection related issues have been identified.
  - However, it has been noted that some data used in WP3 has been sourced as a subset from Brain Atlas research in WP4.

- Sharing of data across HBP prevents duplication of data that is collected and stored.
- AI deliverable has highlighted that some researchers are not aware of the processes/mechanisms in place within the HBP to offer support in relation to ethical issues arising/areas of concern regarding their research.

WP4: EBRAINS Data Services

- **Human Intracerebral EEG Platform (HIP)**
  - All data included in the HIP will be part of the CHUV HIP Registry which has been legally and ethically validated by the CHUV.
  - Only pseudonymized and will be shared in the HIP and it will be constituted by 2 different datasets:
    - An iEEG/neuroimaging database stored in the Framework of the HBP / EBRAINS infrastructure.
    - A REDCapeCRF which contains all relevant demographics and clinical data will be located within each participating centre.
    - The HIP will comply with national and international law and agreements in areas such as intellectual property rights and the protection of privacy, ethical considerations and security regulations when designing rules and conditions for the access and the use the platform at any of the aforementioned spaces.
    - Only data obtained after appropriate informed consent shall be entered shared within the HIP platform.
    - Data providers submitting data to the HIP are responsible for compliance with their respective national legislation and EU regulations.
    - A HIP Charter is under preparation to define all the aspects related to data accessibility and authorship.

- HIP Dual Use and Misuse related issues: The risk of misuse of clinical data by using the HIP is minimal. The architecture of the HIP shall ensure that the platform does not constitute a backdoor to the data stored in the different hospitals and that users cannot launch queries which could isolate single patients. However, there are some aspects related to the research of brain function and more precisely linked to the use of EEG and neuroimaging files that have been identified:

- **Medical Informatics Platform (MIP)**
  - Data Collection And Anonymisation:
    - Only data obtained after appropriate informed consent shall be entered into the MIP (Local and Federated, hosted in hospital or in EBRAINS).
    - In any event, data owners from hospitals and research centres are the only stakeholders responsible for ethics compliance.
  - MIP architecture is based on Privacy by Design, using a two-independent-server structure:
    - MIP Local contains pseudonymized data for the sole use of the local clinicians and researchers.
    - MIP federated node only contains anonymized data (i.e., without any pseudo-identifier that could provide direct re-identification), and therefore, it is no longer considered to be personal and is thus outside the scope of GDPR application.

- MIP EBRAINS only contains anonymized data (i.e., without any pseudo-identifier that could provide direct re-identification), and therefore, it is no longer considered to be personal and is thus outside the scope of GDPR application.

- Data analysis:
  - All the analysis algorithms in the MIP are producing aggregated results and doesn't allow individual records retrieval below the predefined privacy threshold.
  - MIP algorithms are intended to be used for research only, and not for medical purpose.
- Dual-use related issues:
  - The risk of misuse of clinical data by using the MIP is minimal and remains the responsibility of the end-users.

WP5 (SC4): The Neurorobotics Platform (NRP)

- Data Protection:
  - On-line access to the platform might present a security issue.
  - Action: We are implementing an https proxy for encryption of data transferred between users' browser and our service.

- Misuse of the NRP:
  - The NRP software is open source and open access and relies on GNU General Public License, GPL. Under GPL terms we cannot restrict the use of the NRP for military purpose, nor we can prevent possible misuse of our software.
  - Action: Disclaimer added to our website and documentation webpage. Suggested policy action to address tension between RRI key open science and mitigation of risk of misuse. Suggested risk-benefit analysis.

WP6: EBRAINS Computing Services & ICEI -Interactive Computing E-Infrastructure for the HBP

- Data Protection:
  - ICEI resources will be used for the storage and processing of personal data according to the European General Data Protection Regulation (GDPR), e.g., data collected within the HBP or from external sources such as the Human Connectome Project or the UK Biobank.
  - Data protection issues are addressed in detail in ICEI Deliverable D6.1. Currently, a fundamental restriction for the processing of personal data within the Fenix Infrastructure is that pseudonymisation must be applied such that no information that would allow to (re-) identify a data subject enters the Fenix Infrastructure, and the procedure described in the Deliverable is followed.
  - The extent to which the Fenix Infrastructure can support the storing and processing of personal data varies between the Fenix sites due to different national, regional and institutional regulations. A set of security measures, providing a baseline of security for the storing and processing of personal data has been documented in the Fenix Security Measures Catalogue.
  - Fenix has the goal to further improve the security of its services in the future, to enable the storing and processing of personal data beyond what is offered today and

thereby meet corresponding requirements of HBP use cases. Fenix supports users working with personal data in meeting their legal obligations as Controllers under the GDPR, including, e.g., the necessary technical support for data encryption.

  - When using the NMPI service, the only personal data stored is the EBRAINS user identifiers to keep track of which jobs belong to which users, which requires access to the EBRAINS databases to link to a real person.
  - When using the Neuromorphic compute services via the Jupyter, the only link with the username is that used to log in to the service.
  - Users of Neuromorphic computing services are entirely responsible for their own data and scripts within the service. The scripts which they execute can encrypt and decrypt data as needed to ensure that any personal data processed is in keeping with their legal obligations under GDPR.

- Dual-use related issues
  - Risks identified: Abuse of supercomputing resources; Re-export of components to which control regulations apply; Export of confidential knowledge about technologies for which export control regulations apply.
  - The biggest risk is that supercomputing resources are abused for other purposes. Approaches to mitigate this and the other risks are based on standard practices of supercomputing centres (in particular, the signing of Usage Agreements) and are described in ICEI Deliverable D6.2.
  - Neuromorphic computing services are primarily designed to simulate (in the case of SpiNNaker) or emulate (in the case of BrainScaleS) spiking neural networks, and although there are no known examples of such networks being used outside of civilian applications, there are clear possibilities for the technology to be used for such purposes in the future; it is difficult to remove the risk entirely without removing all access to the services.
  - To mitigate risk, access to the neuromorphic systems are controlled through the signing of the EBRAINS user agreement which states that the services are not to be used for dual-use-of-concern applications. Direct access to the services at the individual sites is also controlled through local access mechanisms which are linked to employment contracts.
  - SpiNNaker hardware which has been sold or loaned in done under a strict academic license to date, but as the hardware was developed outside of the HBP, there is no requirement that the boards will be restricted in this way in the future as the EPSRC contract under which they were developed has no such restriction.
- Non-EU-Countries:
  - Fenix being a distributed infrastructure, personal data may possibly be exported from EU countries to Switzerland, or imported from Switzerland to EU countries.
  - The SpiNNaker neuromorphic service is hosted in the UK, and so personal data could be exported from EU countries to the UK, or imported from the UK to EU countries.
  - EC has recognised that Switzerland and the UK provides an adequate level of protection.
- Environmental impact:
  - Supercomputers are known to consume large amounts of energy, thus contributing to CO2 emissions.
  - HPC centres have a strong interest in energy-efficiency of their systems (also for economic reasons) and follow holistic approaches including changes to the system architecture, cooling, waste heat reuse etc.

- The centres also employ sophisticated scheduling systems to make sure that the supercomputers, which run 24/7 and thus permanently consume energy, are always filled with user jobs to the maximum extent possible, to avoid resources being idle.
- Access to the systems is generally controlled by scientific and technical peer review mechanisms to ensure scientific excellence and technical feasibility of the projects that use the resources.
- Neuromorphic computing is designed to simulate or emulate large neural networks whilst using less energy than standard computing. The large SpiNNaker machine consumes a maximum of 100KW of power, and individual boards are turned on and off as needed, so the power use is often less than this in practice. BrainScaleS is an analogue neuromorphic system and as such uses orders of magnitude less power in general, and also emulates networks faster than real-time meaning further power reductions in practice. Both of the large scale systems are packed in to machine rooms meaning that some cooling is also required.

WP7: Management and Coordination

- Main areas of contribution with a link to ELSI:
  - Research Integrity now part of WP7.

Within SGA3, Research Integrity and the role of the Ombudsperson have been transferred to WP7 under the governance Task (T7.2). This led to the complete writing of the SOP surrounding, the activity of the Ombudsperson and her relationship with the core Project.

The SOP have been approved by the DIR and are now fully implemented. Additionally, a comprehensive guideline to research integrity with a user-centric approach is being developed to better explain the responsibilities and rights of each staff member working as part of the HBP grant.

The main challenge, ethically speaking is to ensure that, notwithstanding the fact that T7.2 reports to WP7 Leadership, Research Integrity claims received by T7.2 on the dedicated email address are confidential. This has been discussed and approved with WP7 Leadership.

  - Preparing for the transition to EBRAINS.

An important challenge faced by WP7 was the transition from EPFL to EBRAINS in 2021 and everything it entailed in regard to transferring EPFL staff, assets and resources.

◊ Privacy and personal data (mostly HR-related)

◊ Structuring EBRAINS AISBL in regards to data protection

⇒ The privacy and personal data challenge have been addressed by working in close relationship with the EPFL and their dedicated services.

⇒ EBRAINS has recruited a Legal Advisor and Certified Data Protection Officer to develop and implement all the necessary measures to match the requirements around EBRAINS activities.

  - In addition, EBRAINS has contracted, for the transition period, both an external legal advisor and an external company to ensure that all the basic requirements were properly addressed. Governance:
    - Working on Conflicts of Interests.

All members of the main governing bodies have been required to fill in a Register of Interest approximately once a year, since an SOP was established on this topic. Many within the HBP have viewed or reduced this to a compliance filling exercise, and only begrudgingly provided minimum information after several reminders.

As the HBP moves towards its end, a pressing question has been how to effectively manage this issue and to encourage a culture of transparency, accountability, and disclosure. Conflicts of loyalty and benefits of interests need to be additionally considered.

The Governance task in WP7 (T7.2) worked concretely with the EAB, resulting in revised processes, guidelines, and tools to support individuals in actively reflecting on their interests, recognising possible conflicts, and acting responsibly should a situation arise. A broader "Policy on Transparency and Management of Interests" and a new annual "Declaration of Interests Form" have been developed and came into force during 2022.

Chairpersons of each HBP Governing Body now review their members' Declarations and so are empowered with information on interests which could potentially lead to conflicts. Insights revealed some members had problems identifying relevant info to be provided, indicating the form could be improved. Three members of the SB did not fill in the information required despite repeated requests.

- The Governance Handbook.

The Governance handbook has been entirely revisited as Deliverable D7.3, with a user-centric approach. The process led to a full review of the existing documents and to the update of the different ToR and SOPs of the bodies, committees and main working groups.

- Gender and Equal Opportunities.

Within WP7, there has not been any gender issues connected to the activities of the Work Package itself and none are foreseen. While WP7 is led by male WP Leader and co-leader, 5 of the 6 Tasks are led by female staff, which shows a fair balance among the 8 leadership positions across WP7.

Governing bodies are composed of individuals from across the Project and their coordination is centralised in WP7. WP7 does not however have any power over the appointment of the members of the Governing Bodies. There has been a gender imbalance in the governing bodies and leadership positions since the start of the HBP. The gender task produced a quantitative analysis and promoted awareness for gender balance in the leadership position. The results were visible in SGA3, were there was a significant increase of women in management and leadership positions with respect to SGA2. There is still room for improvement, but it is going into the right direction and the measures implemented and promoted should progressively deliver further results.

- WP7 is sincerely committed to supporting progress around diversity and equal opportunities. Two members of WP7 are represented in the DEOC, one of whom is the current Chair of the committee. Coordination tools and monitoring

PLUS is a tool which has some features open to all EBRAINS users, but it still runs in the humanbrainproject.eu domain. WP7 has been actively asking users to create user profiles in PLUS and no ethical concerns were raised. PLUS stores personal data which users knowingly choose to share with the Project for statistical purposes or with all EBRAINS users for community building. The Terms of use of PLUS need to be documented, this is ongoing. The Terms of Use will cover technical, legal, ethical and access issues. A DPIA is required. The DPIA will comply with the provisions of the GDPR and will be in line with EBRAINS Privacy statement.

The concerns around Emdesk have been addressed and all questions answered.

- Risks are identified and monitored, ethics and responsible research principles are fairly well managed and the new DPO will add a layer of structure and processes to anticipate and, if needed, to mitigate any arising issue.
- WP7 is involved in the Data Governance Working Group (until summer 2022), the Rapporteur Programme, the Dual Use Working Group and very much involved in the DEOC and in the Responsible Research and Innovation Task Force. Through its Task T7.2, WP7 also has regular exchanges with the EAB and with the Ethics management teams.

WP8: Communication, Outreach and Innovation

Ethical and social issues ongoing:

- Gender balance, diversity & equality in HBP events.

For all organised events, it is aimed to achieve a balanced representation of all genders. Every Call for Expression of Interest launched by the HBP Education Programme Office (EPO) includes recommendations for the composition of speakers, and programme committees are strongly encouraged to invite a balanced roster of speakers. In addition, the EPO considers gender balance in the selection of programme committee members. Upon availability of funds, the EPO also offers financial support for participants coming from lower-income European countries. Here, preference is given to the under-represented gender upon equal qualification. Gender is monitored for all speakers and participants of organised education and outreach events.

In addition, inclusion of diverse audiences (for example in terms of career level or geographical distribution) is aimed at. Measures include invitation of young researchers as speakers, organisation of virtual & hybrid events to lower access barriers for (young) researchers with limited monetary funds.

- Ongoing support of education and awareness building on ethical, societal, diversity & equality aspects of research.

The HBP Education Programme aims to include education on ethical, societal, diversity- & equality-related aspects in as many education events as possible. In this regard, the Outreach and Education team is collaborating closely with WP9 teams to organise talks & workshops at various HBP Education events, such as HBP Student Conferences, HBP Young Researchers Events or HBP Tea & Slides webinars.

- Guidelines for good science public relations.

Regarding media relations, WP8 adheres to the principles of good research public relations and scientific communications that are outlined in the Guidelines for good science PR (https://www.wissenschaft-im-dialog.de/fileadmin/user_upload/Ueber_uns/Gut_Siggen/Dokumente/Guidelines_for_good_science_PR_final.pdf)

- Partnering project applications.

The application form has a dedicated ethical compliance check section. Applicants must complete an online form (https://nettskjema.no/a/123442#/page/1) that is reviewed by WP9. Applications that have not completed the online form and that would have not been cleared by WP9 cannot be considered for selection by the Science and Infrastructure Board of the HBP.

- Ethic control in TRL assessment.

The consideration of ethical aspects in the development of HBP technologies and services is required by the HBP Technology Readiness Level (TRL) Guide (https://sos-ch-dk-2.exo.io/public-website-production/filer_public/34/8f/348f734a-9401-4ad6-a0ec-c8eeb3cca358/hbp_trl_assessment_guide_public.pdf). For TRL1, ethical aspects must be checked.

- Exploitation of project results.

The HBP Innovation team regularly collects the Exploitation plans elaborated by the different research groups. All present and future actions initiated or planned by the groups for the transition to the market are included in those documents. The plans are not assessed by the Innovation team from an ethical perspective. Eventual dangers on the commercialisation of technologies (i.e. a commercialisation undertaken by the groups or any other industrial partner or collaborator) should be identified by a committee specialised in Responsible Research and Innovation (RRI). However, the HBP Innovation team does require a reflection on ethical issues associated with the technology

development from the groups through the TRL assessment checklist. In fact, recognizing to have achieved a level 1 of maturity implies that the group has already identified those issues.

- Collaboration with external companies.

The steps taken by the different HBP groups towards the commercialisation of their tools, and their associated technology transferring decisions, are areas that must be scrutinised from an ethical perspective. In this sense, the HBP Innovation team will inform the Ethics committee, in the light of the information received in the Exploitation plans elaborated by the HBP researchers, of any ethical risks detected from the (present or planned) collaboration of research groups with industrial actors. This may have special relevance when the questioned external collaboration is undertaken by the private firms that recently joined the project, as partners, through the SGA3 HBP Open Calls for industry engagement. In the same line, dialogues initiated by the Innovation team to improve industrial engagement, like the ongoing conversations with medium-large organisations and the organisation of workshops with start-ups, should also address these ethical aspects.

Dual use of concern-related issues:

The utilisation of HBP technologies in controversial areas of economy, or with a questionable humanitarian purpose, is a question that deserves a participatory debate and evaluation within the Dual Use Working Group and other HBP-EBRAINS committees. In this respect, the HBP Innovation team is committed to provide these groups or committees with identified material that, with reservations, could eventually lead to harmful uses.

The Ethics Rapporteurs represent WP8 in the Dual Use Working Group to discuss more in depth the potential issues with the other members and take the necessary measures.

Data-protection related issues:

- Personal data collection

Personal data is collected in the context of events organised by WP8, in the Innovation CRM database and in the contact list of journalists maintained by the PR team. To avoid the risk of collecting data without respecting GDPR regulations, great attention is paid by all WP8 members to collect information in a compliant way. The HBP Data Protection Officer is contacted on a regular basis to check that GDPR regulation are followed accordingly (e.g. online forms; storage of data, opt-out options for mailing lists).

In addition, the various databases used to perform the daily management of WP8 activities are collected annually via the Data Management Plan. This exercise is a helpful reminder of the GDR regulations and how to apply them.

- Website cookies

'Cookie Pro' was recently implemented on both the Human Brain Project and EBRAINS websites. This software allows website visitors to block certain types of cookies (information - which does not usually directly identify users - will not be stored on their browser.) The new 'Cookie Pro' tool ensures that both websites are GDPR compliant according to EU law. The privacy policy text on the EBRAINS website is up to date and the privacy policy text on the Human Brain Project website is undergoing a final review.

- Internal newsletter

The internal newsletter mailing list is comprised of EBRAINS users that have been identified / accredited as working for HBP SGA3 at one of the HBP Consortium Partners. Going forward, WP8 needs to make sure that internal newsletters are not sent to users who have deactivated their EBRAINS account. A regular liaison between Task 8.3 and the EBRAINS Support Team takes place in order to update the internal newsletter mailing list and clear out deactivated accounts.

WP9: Responsible Research and Innovation

- Continued difficulties with hierarchies in collaboration between disciplines in the project

    - There is a tendency to add ethical and societal issues as an afterthought in the science work and communication about the project.
- Dual use of concern & Misuse related challenges
    - Risk of being understood as “ethics washing” and other misunderstandings of the goals of responsible research and innovation.
    - We are creating ‘safe spaces’ for discussing any potential concerns and have open and inclusive decision-making and sharing of information. However, these spaces and information shared can be misused for certain agendas, views, etc. It remains a challenge how to engage everyone in a balanced way in a free and honest exchange of views, and avoid misuse of trust, honesty and information shared.
- Data protection-related challenges:
    - Challenge of ensuring that the personal data that we collect in the course of work are stored securely and not for longer than necessary.
    - It is sometimes difficult to identify who the data controller is when we do events with other groups.

Future Questions for RRI in EBRAINS

- Resources for RRI work in EBRAINS
    - WP9 has been involved in the development of the EBRAINS Ethics and Society Vision but there are hardly any resources available to continue RRI work in EBRAINS beyond SGA3. The challenge remains how it will be implemented and where the resources for implementation will come from. A follow-on question for national nodes is how to ensure that resources are available for ethics and society work at the nodes.
- Patient involvement in EBRAINS
    - In line with RRI principles, WP9 have engaged with a broad cross-section of the public including patient representatives through the stakeholder and community-building work. The question of patient engagement should be considered going forward in terms of the purposes for which patients should be involved in research activities in EBRAINS. A follow on question is to what extent should a European Research Infrastructure engage more broadly with patients.