



<b>Title:</b>	Terms of Reference: HBP SGA2 Data Governance Working Group
<b>Partner Responsible:</b>	DMU
<b>SP / WP / Task Involved:</b>	All SPs

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### Document Approval Status

Date	Comments
23/04/2018	Initial draft based on SGA1 document
05/09/2018	Submission to SIB
	Approval by the DIR

#### [1. Purpose](#)

#### [2. Membership](#)

#### [3. SGA2 Items of Concern](#)

##### [3.1 Data Policy Manual, D12.4.1, M01](#)

##### [3.2 First draft of Charter on Governance of data sharing and analysis, MS8.3.3 \(T8.3.1\), M06](#)

##### [3.3 Review of Data Management Plan and Data Policy Manual, MS7.5.5 \(T7.5.2\), M06](#)

##### [3.4 Data Governance Audit Committees](#)

##### [3.5 Data Management Plan, KnowledgeGraph, Data Curation](#)

##### [3.6 Data from outside the EU](#)



- [3. Links](#)
- [4. Quorum](#)
- [5. Decisions](#)
- [6. Reporting](#)
- [7. Servicing and Support](#)
- [8. Meeting Schedule](#)
- [9. Approval and revision](#)
- [10. Termination](#)

## 1. Purpose

The HBP Data Governance Working Group (DGWG) was created by decision of the SIB on 20.05.2016. Its purpose is to identify cross-cutting data governance issues that affect different parts of the HBP, clarify them and find possible solutions. The DGWG is strategically oriented rather than technically oriented, generating concepts which are subject to approval and implementation by other bodies at the level of the issue category or the institution.

In SGA1, the DGWG supported data governance and management infrastructure development across the HBP, produced the Data Policy Quick Guide (an essentials-only guide to Data Policy in the HBP), and undertook continued development of the Data Policy Manual, intended as a living document including policy background and other relevant materials. The DPM is expected to be modified and updated in response to project requirements and changing legislative needs. The work of the DGWG will continue the course of these efforts, and support the advancement of research in the Human Brain Project by supporting responsible data governance and data sharing.

Furthermore, the Regulation (EU) 2016/679 (EU GDPR) coming into force as of 25 May, 2018 and the accompanying rise in public awareness of data protection and privacy issues makes it highly appropriate to continue the work of the DGWG as a matter of high priority within the project.

The DGWG collaborates with other bodies in the HBP, notably the SIB, Directorate, the scientific and technical coordinators, the Medical Informatics Data Governance Steering Committee, and other relevant bodies such as the Ethics Support team and the independent Ethics Advisory Board.



## 2. Membership

In SGA2, membership of the Data Governance Working Group has been expanded to include representatives from each SP, who have been nominated by their SP in response to a request from the DGWG. This expansion has been made in order to facilitate cross-SP collaboration and more effective dissemination of data governance-related information across the HBP. The DGWG will also continue to include SP, WP, Task leaders, and coordinators with defined roles in the DGWG (e.g. authorship of the Data Policy Manual). Some SPs therefore have multiple members in the DGWG, and any potential Conflicts of Interest must be disclosed prior to joining the group. Membership of the DGWG will be reviewed periodically at the beginning of each funding period. The Data Governance Working Group will be chaired by nominated parties approved by the DIR and SIB.

### 2.1 Membership criteria

Membership of the Data Governance Working Group is contingent upon the following factors:

An individual must be a member of the Human Brain Project, and either

1. A data-governance related aspect is part of their role, or
2. They have been nominated by their subproject

Membership of the DGWG is not limited by seniority, role, or field of expertise. We value the contributions of multiple, diverse voices in creating innovative solutions to data governance issues.

### 2.2 Termination of Membership

An individual ceases to be a member of the Data Governance Working Group when they are no longer affiliated with the Human Brain Project, they choose to withdraw from the role, or a conflict of interest arises. Other reasons for termination of individual membership may be considered by the DGWG at the point of membership review at the beginning of each funding period.

### 2.3 Members

Role	Designated Individual
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Ethics Director	Bernd Stahl
SP1 representative	Douglas Armstrong
SP2 representative	Simon Eickhoff
SP2 representative	Bertrand Thirion
SP3 representative	Mavi Sánchez-Vives
SP4 representative	Sonja Grün
SP4 representative	Michael von Papen
SP5 Leader	Jan Bjaalie
SP6 representative	Katrien van Look
SP6 representative	Daniel Vare
SP6 representative	Suat Sevensan
SP7 representative	Colin McMurtrie
SP8 representative	Vasilis Vassalos
SP9 representative	David Lester
SP9 representative	Björn Kindler
SP10 representative	Fabrice Morin
SP11 representative	Annapoorni Sitaraman
SP11 representative	Martina Schmalholz
SP12 representative	Manuel Guerrero
SP12 Ethics Compliance	Will Knight
Chair, Ethics-related Data	Tyr Fothergill



Governance Task Leader	
Co-Chair, SP8 Ethics, Data Governance, and Outreach Officer	Florent Gaillard
Co-Chair, Technical coordinator	Jeff Muller
Scientific coordinator	Martin Telefont
Data Protection Officer	Katrine Ore
Data Protection Officer	Kevin McGillivray

### 3. SGA2 Items of Concern

#### 3.1 Data Policy Manual (DPM), D12.4.1, M01

Building on the work of the DGWG over the course of SGA1, the Data Policy Quick Guide has been submitted in place of the DPM and is also publicly available<sup>1</sup>. The SGA2 agreement includes the DPM as a deliverable, scheduled for submission on 05/09/2018, and intended to be developed in response to external reviewer comments, changes in legislation, and the needs of the project.

#### 3.2 First draft of Charter on Governance of data sharing and analysis, MS8.3.3 (T8.3.1), M06

The Data Governance Working Group is specifically named as a collaborator in the development of MS8.3.3. This Charter is intended as an appendix to the Data Policy Manual which specifically addresses the case of Data Governance in the Medical Informatics Platform. It will detail the ways in which medical data is managed and processed in the HBP within the wider framework of the Data Policy Manual. As such, its production will fall within the remit of T8.3.1 and an associated special cross-SP committee. The DGWG will be involved in the production of the Charter, but is not responsible for creating its content.

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<sup>1</sup>

[https://sos-ch-dk-2.exo.io/public-website-production/filer\\_public/25/2a/252ac9d0-d408-41fc-8fae-bab89dae5ee6/hbp\\_data\\_policy\\_quick\\_guide.pdf](https://sos-ch-dk-2.exo.io/public-website-production/filer_public/25/2a/252ac9d0-d408-41fc-8fae-bab89dae5ee6/hbp_data_policy_quick_guide.pdf)



### 3.3 Review of Data Management Plan and Data Policy Manual, MS7.5.5 (T7.5.2), M06

This is a short report detailing the implications of the Data Policy Manual (DPM) and Data Management Plan (DMP) on HPAC operations, especially the Federated Data Infrastructure.

### 3.4 Data Governance Audit Committees

Data governance policies must be audited in order to be reliable and effective. In keeping with SGA2, this will require the following:

- The DGWG are responsible for the Audit Committee Process, which defines:
  - The events and requests which trigger the formation of committees;
  - The criteria for selecting “audited services” which will be the subject of the audit;
  - The criteria for partner institutions responsible for audits of individual “audited services”; and
  - The process for assembling the audit reports of individual “audited services” into a **combined audit report**.
- The Audit Committee bears the responsibility for making themselves known to the DIR and for communicating audit failures and actions arising to appropriate parties.
- The Ethics Director, as a member of the DIR and the DGWG, is responsible for introducing the Audit Committee to the SB and SCSB.
- The DGWG are responsible for developing a process for assembling the **combined audit report**.
- The Ethics Director is responsible for initiating all audits based on the triggering conditions defined by the DGWG.
- The Ethics Director is also responsible for receiving one (or more) reports from Audit Committee members, and assembling the **combined audit report**.

### 3.5 Data Management Plan, KnowledgeGraph, Data Curation

The work of the DGWG takes place in parallel to continuing efforts in SP5 and all other platforms and subprojects to responsibly manage HBP data and make it available following the FAIR guidelines. It is expected that these lines of work will develop contingently, and shape each other in a responsive manner.

### 3.6 Data from outside the EU

Data collected outside the European Union must meet certain ethical standards to be used within the HBP, and the DGWG should work toward a system in which the relevant



information on non-EU data can be tracked and potentially evaluated for adequacy (should that prove possible) so that it can be incorporated and shared.

## 4. Links

The Data Governance Working Group works closely with other groups that focus on infrastructure and data, notably the Joint Infrastructure Coordination Meeting and the Medical Informatics Data Governance Steering Committee. The DGWG focuses specifically on data governance issues, and will coordinate with other groups where there is overlap to avoid duplication of efforts.

### 4.1 Joint Infrastructure Coordination Meeting

This meeting combines technical leaders and technical implementers from the HBP Platform subprojects based around Platform Integration Use Cases where technical integration issues between Platforms are reported and discussed and where further action items are set to resolve issues.

## 5. Quorum

For decision-making related to internal DGWG work, e.g. creation of documents, development of related milestones and deliverables, quorum of the Data Governance Working Group is achieved with 50% of all members +1, and a decision-making majority is achieved with more than half of members present.

## 6. Decisions

The DGWG does not make substantive decisions in that we do not actively make policy decisions. The decisions reached by the DGWG are solely with respect to our own work and the needs which must be addressed in the process of drafting our outputs, e.g. assignment of responsibilities concerning particular outputs. There are two reasons for this: such decisions should take place at the level of the institution; and we are not a legal entity and thus not qualified to do so. Individual partner institutions remain responsible for the way they process data. Until such a time as the HBP is established as a legal entity and all partnering organisations decide to pass responsibility to that legal entity, these lie with the institutions rather than the DGWG.



The DGWG may prepare policy and other documents, e.g. SOPs, Manuals, Plans, for approval and adoption by the decision making bodies of the HBP. Any decisions made by the DGWG will be applicable only with regard to the production of policy documents and development of related milestones and deliverables as described in the SGA2 DoA. Although the protocols, policies, workflows, processes, etc. developed by the DGWG, once approved and adopted, will be implemented (e.g. and become the by which Audit Committees judge adherence to HBP policy, for example) decisions on accepting and applying the products of our work are made by other bodies (e.g. the DIR, SIB, institutions) as relevant.

## 7. Reporting

The Data Governance Group ultimately reports to the Directorate, although the SIB may be involved depending upon the relevant issue and whether it is of a scientific or administrative nature. The SB and SCSB will be kept apprised of the outcomes of the work conducted by Audit Committees. Data Governance-related SP, WP, and Task leaders will be responsible for reporting on their respective portions of DGWG work as appropriate and required. This means that individuals with a role dedicated to data governance or including data governance as part of the role-associated duties are responsible for representing the topics and perspectives of their specific SP, WP, or Task in work of the DGWG, e.g. policy documents, workflows, etc. SP Representatives are expected primarily to represent to perspective of their SP, and only have reporting responsibilities when they agree to take on specific roles or tasks related to the DGWG, e.g. writing a specialist section in the DPM.

## 8. Servicing and Support

The group will be serviced by the Ethics Support team, representatives of which will act in the capacity of secretary and observer. Furthermore, for the purpose of ensuring coordination with the Ethics Compliance strand of Ethics Support, the team member responsible for Ethics Compliance will have membership of the DGWG.

## 9. Meeting Schedule

The group will meet every two weeks, with the frequency of meetings (particularly of ad-hoc groups formed to address specific items) to be determined by high-priority tasks and deliverables. Meeting times and frequency will be reviewed and changed depending upon project needs and workload requirements.





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## 10. Approval and revision

These terms of reference will be reviewed by the group and modified when significant amendments are required.

## 11. Termination

The Data Governance Working Group may be terminated when its tasks are fulfilled, associated deliverables are complete, and its input is no longer required (i.e. the ongoing maintenance of the Data Policy Manual and other living documents is arranged and assigned to specific parties). The termination of the DGWG will be proposed by an absolute majority of all DGWG members, and ultimately decided upon by the SIB and DIR.