



# Directions for using federated data in clinical practice

The Human Brain Project (HBP) is an ambitious research and technology development project with social, ethical and legal implications. This newsletter provides recommendations to the HBP on expanding the HBP user community to researchers and clinicians federating brain related data through the Medical Informatics Platform one of the six computing infrastructures being developed as a part of the HBP.

**A BIG DATA REVOLUTION** is underway in neurological healthcare that promises to advance the way we understand and diagnose the human brain and its diseases. One of the promising tools to classify, manage and analyse vast amounts of medical data about the human brain is the Medical Informatics Platform (MIP) being developed by the Human Brain Project. The MIP is a computing infrastructure which aims at federating medical data from hospitals and research centres in Europe. It is not, per se, a physical database as none of the available data is copied to a central server. Instead, it allows advanced computing algorithms to access data stored at hospitals and clinics, run analysis and aggregate results to provide users with statistical analyses. This federation means the aggregated results come from different sources ensuring confidentiality and representative results.

The MIP is currently deployed in four hospitals and four other health centres are in the process of joining it. However, to expand the network of hospitals and centres in the MIP federation, the team behind the MIP and the Danish Board of Technology Foundation (DBT) invited neuroscientists and clinicians from Danish

hospitals for a workshop<sup>1</sup> to discuss future perspectives and barriers for joining the MIP.

The MIP, released in 2016, enables researchers and clinicians to make queries for single, integrated views of all resources in the connected datasets without the data leaving the hospital where it has been collected. Virtual databases, like the MIP, have many advantages compared to physical databases, such as enabling researchers and clinicians to run analysis over several distinct datasets comparing them against one another while protecting personal data. A user can, for example, make a query about the distribution of cognitive dysfunctions measured by neuropsychological tests or the user can send a query for a correlation analysis between behavioural and neuroimaging data.

The participants at the workshop agreed that 'big data' is the way forward in the health sector, but also that – due to the very sensitive nature of the data - it is not as straightforward compared to the digital transition undergone by other sectors.

<sup>1</sup>Workshop 'Federating data to understand the human brain and its diseases' held October 2017 in Copenhagen, Denmark.

## POLICY OPTIONS AND RECOMMENDATIONS:

- Clarify who, among Danish healthcare actors, is capable of making the decision about joining the MIP and engage clinicians as early in the process as possible.
- Develop precise standard procedures on how to collect clinical data and which datasets should be included in the MIP in order to ensure a high quality of data.
- Establishment of national working groups consisting of representatives from hospitals including clinicians, neuroscientists and technicians.
- Develop clear-cut information material targeted the users and change the terminology from 'sharing data analysis' or 'sharing data aggregates'.
- Send a data governance support person physically to the hospitals when introducing the MIP.



## Human Brain Project

Privacy, informed consent and other ethical issues related to individual freedom were discussed at the workshop.

To ensure that the Human Brain Project lives up to privacy protection, the project has addressed data protection and related issues intensively and integrated public and expert recommendations deeply in its data governance policies. However, the participants at the workshop also requested legal support on national level.

### **STRUCTURED DATA AND THE DIGITAL TRANSITION**

Although the 'big data' stage for the MIP is not yet reality, the participants at the workshop saw many other advantages of using a centralized platform to organise medical data, such as brain images. Among the immediate benefits of the MIP, according to the participants, is that the MIP offers a tool to not only analyse others' data, but also to organise and categorise their own data in a structured way. As stressed by Professor Gitte Moos Knudsen, who participated in the workshop:

*"The moment you start to organize your own research data in a structured way, you will immediately see a beneficial effect on the data quality."*

This underlines a central point emphasised during the workshop, namely that the MIP may serve as a classification tool for structuring and storing data at hospitals and clinics. In fact, one major concern by the participants was the risk of 'big data' contributing to lower quality of data by increasing the variance in the data due to the lack of consensus about how to organise and share it. According to the participants more precise procedures for collecting medical data would allow more transparen-

cy on the quality of the data, which would also make federated data more useful in clinical practises and research.

The MIP is already targeting the issues with data selection through the DGDS (Data Governance and Data Selection) working group where harmonization and standardization is a key point. However, from the discussions at the workshop it was clear that clinicians need to be deeply involved in this process. Standard procedures could be implemented across Europe, although the participants stressed that the MIP procedures might clash with existing data collection protocols at the hospitals and clinics. However, the participants also agreed that many hospitals and clinics may benefit by implementing standards and more precise data collection procedures, and in this way serve as a quality check on clinical practise. In addition, it was mentioned that a tool to structure the data might in some cases reduce the administration costs at the institutions.

### **LONG TERM BENEFITS OF THE MIP**

The clinicians at the workshop saw many advantages of the MIP and other virtual medical databases and emphasised particularly the value of a second opinion before deciding on a medical treatment of a patient. Moreover, they emphasised the need for tools to address the increasing number of requests from medical companies wanting to buy data analysis from the clinics. In this respect they saw the MIP as a potentially useful tool to share models and analyses with companies while living up to the legal requirements of data protection. However, although they saw many advantages of the MIP they expressed ethical concerns about sharing analyses with commercial actors.

The neuroscientists who participated the workshop saw the MIP as a great alternative to submitting research data to an external archive somewhere, which requires stripping of critical information. In addition, they saw a potential in exploring large datasets and e.g. correlating neuroimaging with behavioral data.

### **RESOURCES CHALLENGES OF JOINING THE MIP**

The participants largely agreed that there us a huge potential in joining a computing infrastructure like the MIP. Despite this, one major challenge for joining in is the human resources required to implement the system in the hospitals. The neuroscientists and clinicians at the workshop felt neither qualified nor responsible to technically implement the MIP in their institution. Generally, there was an urge for more central leadership about deciding whether the MIP is something Danish hospitals should invest in and if so, how to do it practically, ethically and legally. Moreover, when the decision of joining the MIP has been taken, it was stressed by the participants, that local support by some kind of MIP personnel would be needed. This person should provide support to overcome some of the initial barriers of solving technical and practical issues at the hospitals and educating the IT personnel as well as the clinicians about the system.

### **FOLLOW UP: HOW TO JOIN**

The MIP promises to break down the traditional barriers between patient care, brain science, and clinical research, to minimise the delays involved in diagnosis of brain diseases and provide more precise treatments. The participants all expressed an interest in these kinds of tools, but were wondering about the technical requirements for hospitals to



## Human Brain Project

participate and which data and tools are available.

The topic of this first workshop was to highlight potential benefits and barriers for Danish hospitals to join the MIP; the MIP team now has to follow up on the needs expressed by the participants in order to provide them with sufficient information to help in their decision and future implementation.

Among other things it was unclear to the participants how the data enters the MIP, what volumes of data is necessary to ensure anonymization, what data is already available, and what data is needed.

According to the participants, it would be easier to make a qualified decision on whether to invest in the MIP if it was clear what data and analysing tools the MIP offers and which resources are required to join the MIP. The success of the MIP was, according to the participants, dependent on effective knowledge sharing between the MIP and clinicians and more focus on explaining how to join rather than explaining the value of the MIP. The participants also requested information material targeted to decision-makers in order for them to judge which resources are needed for full implementation, and whether it is worth investing in. In some countries, such as Denmark, this decision might be a political decision, and using the MIP would need political support.

### **FROM THE CULTURE OF "MY PATIENTS, MY DATA"**

Together with privacy protection and patient consent issues, one of the major concerns raised by the participants relates to the fact that researchers and clinicians do not have a culture of sharing patient data. 'My patients, my data' is squarely said to be the approach medical doctors have to data collected for medical or research purposes. The reason for

this is often that they have applied for their own funding to research, they plan to publish on their data or they want to protect the data of their patients or research participants from misuse.

Federated data may be welcomed by many medical doctors since only analyses of aggregated data are shared, but this needs to be clear to the users and decision makers. When communicating about the platform, the participants recommended that one should avoid using the terminology "sharing data" since the MIP shares databased analytics and not data. This is important because sharing patient data is a no go for ethical and legal reasons, but also because researchers and clinicians want to have control of how "their" data are used.

### **EXPANDING THE REACH TO IMPROVE PRECISION MEDICINE**

The workshop was the first of its kind, where the MIP team met for a whole day with representatives from hospitals across one nation to discuss their views on joining the MIP. One key observation made during the workshop was the demand for the tools offered by the MIP in clinical practise as well as in the research communities, but that people are waiting for someone centrally to make the decision about how data from patients and research participants can be used ethically and legally.

To improve precision medicine within the field of brain disorders the participants saw a need for centralized platform at national or regional level. According to the participants the MIP could serve as a platform for data centralization. However, to initiate a common discussion on whether or not they should invest energy and money in the MIP, the participants recommended the establishment of a working group consisting of re-

presentatives from Danish hospitals including clinicians, neuroscientists and technicians. The working group would be responsible for deciding whether the MIP is relevant in the Danish context and if so, draw a roadmap for implementing it at relevant Danish hospitals and clinics. There is a large unexploited potential for expanding the number of hospitals and centres federating data with the MIP. However, successful implementation of the MIP across Europe requires not just the technology and data governance becoming sufficiently in place. Clear-cut information material to the users and decision makers is also needed and should be translated into their contexts. This requires insights into country specific organisational and legal aspects as well as insights into the reality of potential users. In other words, more focus on people and processes, rather than technology is needed in the next phase of the MIP -where the user community and the volume of data are expected to grow big.

### **PUBLIC ENGAGEMENT AND DIALOGUE**

The Danish Board of Technology Foundation (DBT) is part of the Human Brain Project subproject 'Ethics and Society'. DBT organises dialogue meetings between researchers from HBP, external stakeholders and the public. The themes for debate in 2017 include data governance and informed consent policies as well as perspectives and barriers for successful recruitment of users to the Medical Informatics Platform (MIP).



*This newsletter is written and edited by DBT Director Lars Klüver and DBT Project Manager Karen Riisgaard, with input from MIP Project Leader Ferath Kherif and MIP Ethics and Communication Officer Florent Gailard. While every caution has been taken to represent the views of the participants quoted in this newsletter accurately, the final representation remains the responsibility of the author(s). The views and opinions expressed in this newsletter may not be taken as those of the Human Brain Project or any of its sub-projects.*

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