Belgian Brain Plan

Minutes of the on line meeting of Oct. 27, 2022

Attended by Dr. Nick Marly (N.M.), Pr. Dirk Van Roost (DVR), Lia Le Roy (LLR), Laurence Ris and Roland Pochet (R.P.)

N. M. is advisor at the Cabinet of Minister of Public Health and Social Affairs Frank Vandenbroucke, working on the domains of eHealth, mHealth and Health Data. N.M. has a Master of Science in Mathematics, in Electrical Engineering and a Ph.D. in Applied Sciences (1982 – 1995) from UGent

The first part was the presentation of the Belgian Brain Council and its motivation for the advancement of a Belgian Brain Plan (see the 6 slides joined). *Notice that N.M. informed us that the content of slide 5 about the answer given by Health Minister to Kathleen Depoorter was prepared/written by N.M.*

Dr. Marly presented what is currently in use in Belgium for health data collection in insisting on the existence (since several years now) of a DPI (Dossier Permanent Informatisé intégré) or EPD (geintegreerd elektronisch patientendossier) which is well standardized and allow data capture and is implemented in *every* Belgian hospital (RP comment: Is it really the case?). This was also argumented by DVR who highlighted that the notes are stored in free form and partially coded for billing purposes, for example. Hospital- or practice-specific codes are used here, which are then converted into NIHDI codes. *Comment: we maybe should have a template of a DPI.* DVR also suggested that a central registry could be fed by these codes, provided that they are used in a general and uniform way for 1) the exact designation of the disorder (cf. ICD-11 or SNOMED), 2) the degree of severity of the disorder (there are clinically and scientifically accepted scales, specific for a number of disorders), 3) the nature of the treatment, 4) the frequency of the treatment sessions. Points 1, 3 and 4 are already used by health insurance companies. These codes could be the entry in a central register, with the particular advantage of requiring little or no additional administrative work on the part of the care provider, a sensitive point, which was also stressed by N. M.

At the closure of the meeting N.M. insisted on the global aspect of the registry, meaning that this should not be restricted to brain health/disorders and that we should now come with concrete propositions.

The meeting closed at 12:00

Post comments by R.P.

The dialogue was established and of very good quality. It is also evident that several actions about health data collection are currently running and we are not going to reinvent the wheel. The slot I see is that DPI is available for hospitals (only?) and there is a large gap/lack of data collection (e.i. in brain diseases/disorders) from patients and M.D. that do not go (or barely) to hospitals. I suggest that we might then find how we could concretely (business plan…) help filling this gap.

To nurture our thoughts and propose concrete measures to N.M. I advice us to read the plan d'action santé 2019-2021 in particular "Les règles d'application au Coffre-fort de l'e-santé et répartition des taches entre les sources authentiques" (Pages 147-147) including point 0.6 "Terminologie" (page 146). I also would like to highlight that the Unit of Medical Informatics & Statistics from UGent is working in close collaboration with the Health Ministry and initiated a start-up i-HD (The European Institute for Innovation through Health Data) that is funded by several EU grants but also by Johnson & Johnson and Microsoft.

Here are statements made by i-HD

Trustworthy and ethical use of health data: we are all involved!

Patients are willing to share health data provided they trust that their data is secure.

Healthcare providers expect guarantees the external health systems they connect with are privacy compliant.

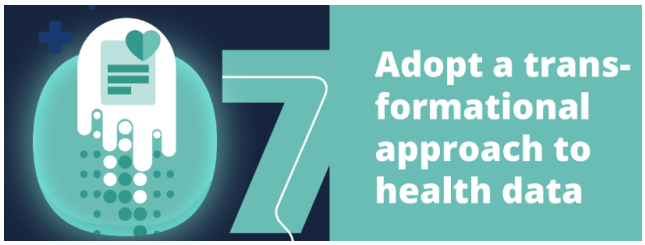
Health authorities want to safeguard and endorse the trustworthiness of digital health solutions.

Clinicians want to give and receive reassurance their data system meets the highest information governance and data privacy requirements.

Research want to reassure all data providers (citizens, participants in clinical studies, hospitals) of the robustness of the data security measures in their data systems.

Developers and vendors of data-driven ICT systems, medical devices and apps want to convince both users and commissioners of their trustworthy data handling.

And here is an extract from a report i-HD produced in 2020



All stakeholders should support and promote treating repositories of pooled anonymised health data as a societal good.

Investments should promote the uptake of federated data models to facilitate interoperability, connectivity and FAIR data access while upholding GDPR compliance.

Europe should now consolidate efforts on one or a small number of common data models so that data harmonisation methods, tools and skills can be scaled up to become a readily available and affordable resource.

Stakeholders should focus eHealth governance models, trust mechanisms and research infrastructures to contribute data to large-scale independent health data repositories that provide real-time continuity of data access for individuals, healthcare delivery and for population level analysis, with appropriate governance.

Synthetic data sandboxes should be developed to enable research into novel security approaches and the training of AI algorithms.

A transformation towards cross-organisational and independently run health data repositories will require radical change in ICT products and procurement, for which policy enablers must now be enacted.

Regional and national early adopters should be encouraged to collaborate across borders to develop best practices, lessons learned and accelerate the reuse of data and the development of benefits from it, sharing with other Member States and stimulating European competitiveness.

50% thought the most important call was adopting a transformational approach to health data.

82% thought if health data is to be a societal good it should be defined by a group formed of multiple stakeholders.

72% thought a list of data uses that would normally be supported and those that would not be supported should be developed by a group formed of multiple stakeholders.

73% thought that, to develop trust in data access and use, they would prefer to see a combination of written laws/ regulations and multi-stakeholder codes of conduct.