

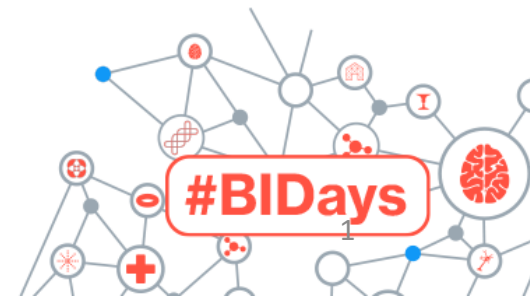
Brain Talk 9:25-9:35



Brain Talk

The European Brain Data Hub: Facilitating Data Sharing to Accelerate Brain Disorder Research and Inform Public Policy

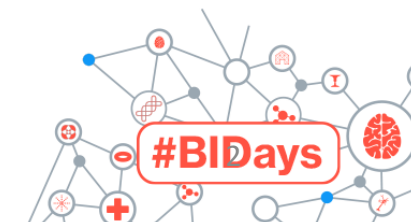
Roland Pochet 14 nov.2024





Published May 30, 2022

Entry into force on 24 September 2023

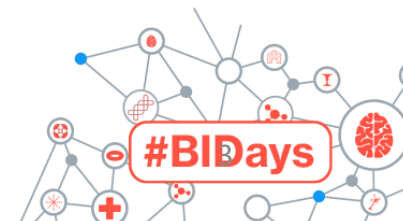




‘data altruism’ means the voluntary sharing of data on the basis of the consent of data subjects to process personal data pertaining to them (...) **for objectives of general interest (...)**



EU Recognised
Data Altruism
Organisation





Belgian Law



ROYAUME DE BELGIQUE

KONINKRIJK BELGIE

**SERVICE PUBLIC FEDERAL ECONOMIE,
P.M.E., CLASSES MOYENNES ET ENERGIE**

**FEDERALE OVERHEIDSDIENST
ECONOMIE, K.M.O., MIDDENSTAND EN
ENERGIE**

**Projet de loi mettant en œuvre le règlement (UE)
2022/868 du Parlement européen et du Conseil du 30
mai 2022 portant sur la gouvernance européenne des
données et modifiant le règlement (UE) 2018/1724**

**Ontwerp van wet tot uitvoering van verordening
(EU) 2022/868 van het Europees Parlement en de
Raad van 30 mei 2022 betreffende Europese
datagovernance en tot wijziging van Verordening
(EU) 2018/1724**

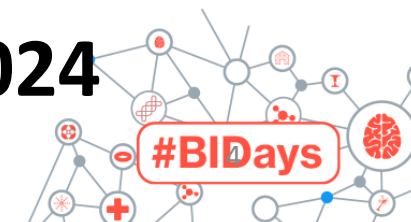
PHILIPPE, Roi des Belges,

FILIP, Koning der Belgen,

A tous, présents et à venir, Salut.

Aan allen die nu zijn en hierna wezen zullen, Onze
Groet.

Approved by the Belgian Federal Parliament on May 8 2024



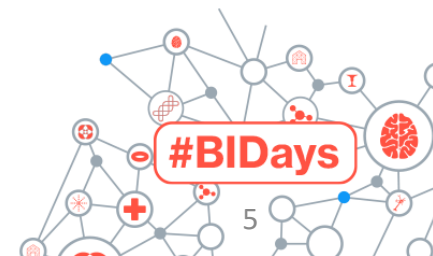


Implementation

**PATIENTS CANNOT SHARE THEIR DATA
BECAUSE THEY DO NOT HAVE THEM
EVEN IF :**

GDPR – Articles 15 and 20 provide for

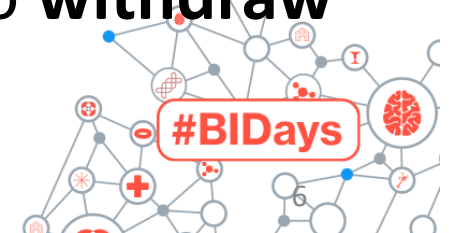
- **right of access and right to data portability**
- **That are difficult to implement by individuals**





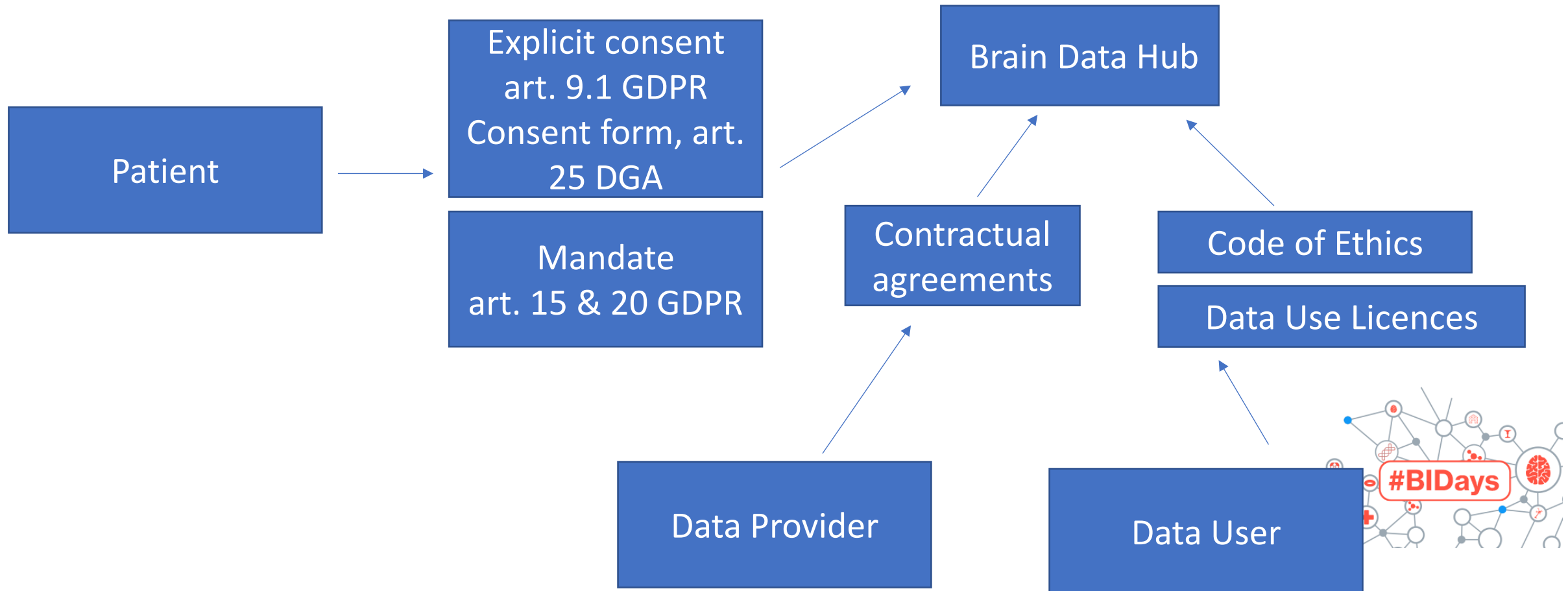
THE CONCEPT OF THE EUROPEAN BRAIN DATA HUB

- (1) An **international not-for-profit patient-centric data altruist organization** fullfilling all the conditions of the DGA, chapter IV
- (2) that will receive **in any european country a legally valid mandate** from patients **to collect their health data on their behalf** on the basis of art. 15 and 22 of the GDPR
- (3) In order to share their data on the basis of a **broad consent form** (art. 25, DGA) for improving research and public policy
- (4) Giving to patients tools to **monitor** the use of their data and to **withdraw** consent at any time



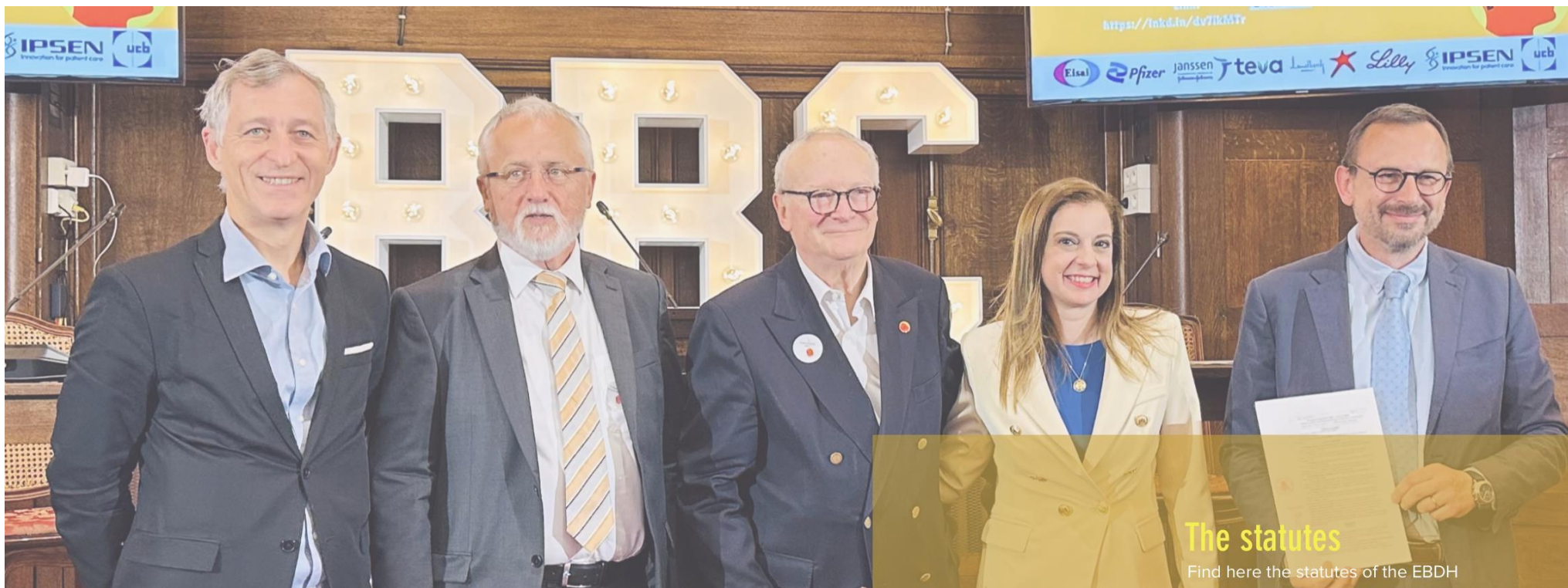


The model to be tested



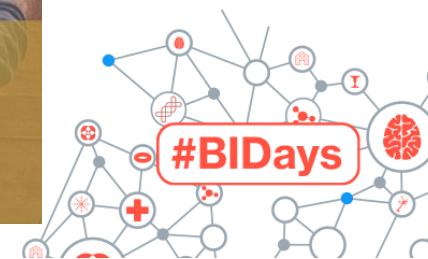


May 15, 2024 European Brain Data Hub AISBL Co-founders



The statutes
Find here the statutes of the EBDH

FR-Philip Gorwood DE-Thomas Mockrusch BE-Roland Pochet GR-Christina Dalla The Notaris





Conclusions

- **The EBDH complying with all the legal duties and having received the patients associations' consent is ready to start this innovative approach to data sharing**
- **The next steps depend today on fundraising. The 2025 phase III business plan has been drawn-up and is now in the hands of our partners.**

