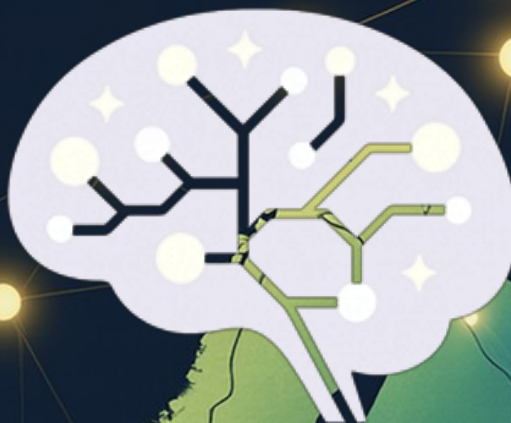


# ACTIVITY REPORT

## JANUARY-JUNE

### 2025



European Brain  
DataHub

**EBDH**

International non-profit  
association  
BCE 101 3.171.235

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Organisation altruiste  
en matière de données  
reconnue dans l'UE

# KEY ACHIEVEMENTS



## Recognition

Since 4 June 2025, the EBDH has been officially registered in the Belgian public register of recognised altruistic organisations. Its publication in the European register is therefore imminent, making it the second altruistic organisation to obtain this recognition at European level.

In preparation for this registration, the EBDH has created a website that complies with the requirements of the DGA and the RGPD, available in French and English, and a secure e-mail box.



## Validation

The test phase of the project made it possible to validate the legal architecture based on Data Altruism and the mandate to exercise rights. In this context, the EBDH mobilised its network in order to identify volunteer patients wishing to support the initiative, in particular through prior exchanges with Ms Cécile Grégoire of the ASBL Action Parkinson. Several patients also contacted the EBDH directly. A complete contractual kit was drawn up, and patient data was collected.



## Promotion

The EBDH has also carried out a number of networking, promotional and awareness-raising activities around Data Altruism and its concept. In particular, it took part in the Health Data Agency's second symposium, and organised a conference on 1<sup>st</sup> April 2025, which brought together more than fifty participants. The EBDH also presented the progress of its work at the 20<sup>th</sup> anniversary of the Belgian Brain Council, to an audience of over one hundred people. Finally, the project was given media exposure in an interview with RTBF.






























## Preparation










The EBDH prepared for the launch of the project by drawing up a model licence for the use of the data and seeking financial support for the development of the Platform. A team of students from Solvay (ULB) provided support for this.

Research has also been carried out into the added value of the data collected compared with that of 'competitors', and a meeting with a representative of UCB Belgium provided an opportunity to explore this issue in greater depth.

this question.

# Test Phase Protocol

Patient	Holder	Send to	Responses	Follow-up	Prior contact ?	Validation in principle?	Response definitive	Result Current
Patient 1		07.02.25	13.02.25	/	 Patient	Yes	13.02.25	
Patient 1		07.02.25	20.02.25	/	 Patient	Yes	28.03.25	
Patient 1		07.02.25	10.03.25	1	Patient initiative	Yes	10.03.25	
Patient 1		07.02.25	20.02.25	/	 Patient	Yes	12.03.25	
Patient 1		07.02.25	12.02.25 21.03.25 28.03.25 02.04.25	/	/	No	02.04.25	
Patient 1		27.03.25	23.03.25	/	 EBDH	Yes	06.04.25	
Patient 1		28.03.25	22.04.25	1	 Patient	Yes	07.05.25	
Patient 2		06.06.25	23.06.2025	/	/	Yes	/	
Patient 2		06.06.25	12.06.25	/	/	Yes	16.06.25	
Patient 3		15.06.25	30.06.25	1	/	In treatment	/	
Patient 3	Pharmacy X	15.06.25	/	1	/	Under treatment	/	
Patient 3	Pharmacy Y	15.06.25	/	1	/	Under treatment	/	

Patient	Holder	Send to	Responses	Follow-up	Prior contact ?	Validation in principle?	Response definitive	Result Current
Patient 3		15.06.25	/	1	/	Undergoing treatment	/	
Patient 3		15.06.25	17.06.25	/	/	Yes	/	
Patient 3		15.06.25	/	1	/	Undergoing treatment	/	
Patient 3	Neurologist	15.06.25	18.06.2025	/	/	Yes	/	
Patient 3		15.06.25	18.06.25	/	/	Yes	18.06.25	

## INNOVATIVE AND VALIDATED PROJECT

The Test Phase validated the conceptualised legal architecture. Thanks to Data Altruism and the mandate to exercise rights, it is now possible to receive - with the explicit consent of the Patient - rich, diversified health data that is as complete as possible, under unprecedented conditions. This data is intended to support general interest objectives in terms of public policy, healthcare and research into mental and brain health.

This test phase is currently being extended to anticipate any technical or human difficulties that may arise, to assess the quality of the data collected, and to prepare for the development of the *European Brain Data Hub's* IT platform. Two new patient volunteers have recently decided to contribute, and their mandates are currently being prepared.

However, there is still one stumbling block: Apple, the only company to definitively refuse to share the data requested by the patients recruited during the Test Phase. We are preparing the legal follow-up.





# European Brain DataHub

## ACKNOWLEDGMENT

We would like to express our sincere thanks to all those who have provided financial support for this project. Thanks to you, we have been able to demonstrate the value and feasibility of this project. The progress we have made bears witness to its real potential.

Today, we're ready to go even further. With renewed support, the launch of the EBDH platform can become a reality.

Thank you for your confidence and your contribution to this collective dynamic.

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Follow us on the networks

