

Press release

Data Governance Act: The Belgian Brain Council (BBC) launches the first data altruism organization for brain and mental health data to facilitate research and the creation of a Belgian Brain Plan

The European Data Governance Act (DGA) comes into force on 24 September 2023. This regulation encourages the voluntary sharing of data for altruistic purposes, such as scientific research or the improvement of public services, via data altruism organizations.

In this context, the Belgian Brain Council (BBC), which brings together 26 patient associations and 28 scientific societies, is launching the creation of the first data altruism organization for brain and mental health data. It will be responsible for managing the Brain Data Hub, a secure IT platform for collecting and sharing data. The BBC intends to act as an ethical and trusted intermediary for patients wishing to make their health data available for scientific research and the creation of a Belgian brain plan.



About the BBC

The BBC's initiative comes at a time when mental health and brain disorders are at the heart of European concerns. More than a third of the population is thought to be affected. In June 2023, the European Commission launched an initiative to promote a global approach to mental health, stressing the importance of better data availability.

In Belgium, the BBC has long been campaigning for the creation of a register and a brain plan along the lines of what has been put in place in the fight against cancer.

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“So far, the brain registry project has stalled. By creating a data altruism organization, the BBC is leveraging the new European regulation to move forward and enable patients and their families to play a part in improving research and health policy. Our initiative is attracting a great deal of interest beyond Belgium’s borders. We are in discussion with several foreign associations who would like to join our project”



- **Roland Pochet, Secretary General of the BBC.**

The BBC’s initiative is supported by the generous sponsorship of Eisai, Pfizer, Janssen – Johnson & Johnson, Lundbeck, Lilly, UCB, Bristol Myers Squibb, Teva and Ipsen.

For more information go to <https://www.braincouncil.be/>

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