# REPORT – “50 MANDATES” INITIATIVE

The "50 Mandates" initiative signifies a strategic advancement in the execution of the European Brain Data Hub (EBDH), with the objective of establishing patient-centric data governance in accordance with the European Data Governance Law and overarching EU health data strategies.

Through this initiative, the Belgian Brain Council effectively engaged patients and patient associations to actively partake in a model of altruistic health data sharing, grounded in informed consent, transparency, and complete respect for individual rights. The initiative illustrates the feasibility of involving citizens in data-driven research ecosystems while maintaining trust and ethical integrity.

## KEY RESULTS AND IMPACT

- Over 50 mandates and informed consents have been collected, successfully fulfilling the campaign's initial objective.
- Engagement of multiple patient organizations throughout Belgium.
- Representation of a diverse array of neurological and mental health disorders.
- Implementation of a replicable awareness model for patient recruitment and engagement.
- Contribution to the advancement of a dynamic European data-sharing framework

This initiative demonstrates that patients are willing to engage in research when appropriate governance, transparency, and protective measures are established.

## PARTICIPATING PATIENT ASSOCIATIONS

The initiative was executed in partnership with a varied network of patient organizations, ensuring:

- APEPA is a prominent Belgian association dedicated to supporting individuals with autism and their families by offering guidance, advocating for their rights, and fostering community support.
- Belgian League Against Headaches: a national organization committed to enhancing awareness, refining diagnosis, and providing support for patients afflicted by migraines and chronic headaches.
- Whiplash Association: an organization dedicated to supporting individuals impacted by cervical trauma and chronic pain resulting from cervical injuries, frequently linked to enduring neurological symptoms.

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- Hersenletsel Liga: a Flemish organization committed to assisting individuals with acquired brain injuries while advocating for their social inclusion and rehabilitation.
- Neurodiversity Belgium: an organization advocating for the recognition and inclusion of neurodivergent individuals, particularly those with autism, ADHD, and related conditions.
- Stroke & Go: A patient-centered initiative designed to assist individuals in their recovery from a stroke, focusing on rehabilitation, awareness, and reintegration into the community.
- Werkgroep Hersentumoren: a support group committed to assisting patients with brain tumors by providing information, peer support, and advocacy initiatives.
- Fleurs Sauvages: A program dedicated to assisting women experiencing mental health challenges, particularly those with autism, ADHD, anxiety disorders, and eating disorders, with a focus on empowerment and social inclusion.

These partnerships have been instrumental in enhancing communication, supporting participants, and promoting inclusion across diverse patient communities.

## REPRESENTED PATHOLOGIES

The participants in this initiative represent a broad spectrum of neurological and mental health disorders, including:

- Autism Spectrum Disorder (including comorbid ADHD and intellectual disability)
- ADHD
- Migraine and chronic headache disorders
- Stroke (CVA)
- Multiple Sclerosis
- Acquired and traumatic brain injury
- Whiplash-associated disorders
- Depression
- Addiction
- Anxiety
- Troubles du Comportement Alimentaire (TCA)
- Agoraphobia
- Neurodevelopmental disorders
- Fibromyalgia
- Cancer-associated psychological conditions

This diversity highlights the transversal applicability of the EBDH model across multiple brain-related disorders, reinforcing its relevance at both clinical and policy levels.

## STRATEGIC SIGNIFICANCE

The "50 Mandates" initiative directly contributes to:

- the execution of EU data governance frameworks
- advancing patient empowerment and active engagement
- advancements in the study of neurological and mental health disorders
- the advancement of trust-based data ecosystems at the European level

By establishing connections among patient communities, healthcare systems, and research infrastructures, this initiative facilitates the shift towards a more inclusive, data-driven, and patient-centered healthcare system.

## CONCLUSION

The success of this initiative illustrates that patients are not only willing but also enthusiastic about actively participating in data-driven research and innovation when engaged within a framework founded on trust, transparency, and respect.

Throughout the "50 Mandates" initiative, numerous participants articulated a profound desire to be heard, recognized, and actively engaged. Several reported instances in which their symptoms were not fully comprehended or considered, or where they faced challenges in obtaining clear answers due to a lack of knowledge regarding specific neurological or rare diseases. This initiative afforded them a platform where their experiences were acknowledged and esteemed.

Simultaneously, participants conveyed a sense of pride and ownership regarding their illness, coupled with a desire to convert their personal challenges into something significant. Many underscored their motivation to assist others in circumventing similar hardships, enhance the understanding of their condition, and support future generations of patients.

This is evident in remarks such as:

*“I felt that no one really listened or understood what I was going through. Here, I felt heard.”*

*“There are still so many unknowns about my condition — contributing to this project feels like a way to move things forward.”*

*“If sharing my data can help someone else get answers faster than I did, then it is worth it.”*

Importantly, this engagement reflects a broader shift from a model in which patients may feel passively observed or insufficiently supported, towards a model where they become active contributors to research, with a clear sense of purpose and impact.

The “50 Mandates” initiative highlights that when patients are placed at the centre of the process, they feel empowered, valued, and motivated to contribute to a more inclusive and effective health ecosystem.

The Belgian Brain Council warmly thanks its sponsors for their essential support, which has made this initiative possible and has enabled patients’ voices to be meaningfully integrated into the future of brain health research.