



# H2O: Strengthening the patient voice in health care

## Facts & figures

**START DATE:**

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IMI2 – Call 18

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945345

**TYPE OF ACTION:**

RIA (Research  
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20.6 million €

## What is H2O?

The Health Outcomes Observatory (H2O) is a strategic alliance between the public and private sectors to create an **unprecedented, standardised data governance and infrastructure system across Europe** that incorporates **patients' experiences and preferences** in decisions affecting their individual health care and those of the entire patient community.

This will materialise in a network of Observatories that will allow an ethical and legal use of data to:

- Measure outcomes more effectively.
- Facilitate personalised treatments.
- Enhance health research prospects.
- Promote value-based approaches in health care systems.

## Our mission

H2O is set to **transform the use of patient-reported information in health care**, enrich the interaction between patients and health care providers and, as a result, drive better outcomes for patients. The project will **fill an important gap** as outcomes reported by patients are not usually incorporated in a comprehensive and systematic way into the decision-making process affecting their individual clinical care.

H2O plans to:

- Set up national Observatories, initially in 4 countries and focusing on 3 disease areas, before extending the concept across Europe and to other diseases.
- Adopt user friendly digital tools and processes for patients and providers to share relevant information.
- Empower patients with digital tools to better manage their health care.

WEB



## Why is H2O important?

H2O is creating an **innovative governance model to unleash the potential of health data** in Europe, whilst making sure that **patient's privacy rights are protected** and data, as an essential resource, is better safeguarded in the interest of society.

The network of Observatories will ensure that, with patients' consent, data is made available in an ethical way to those with a legitimate interest – patients, researchers, providers, health authorities, regulatory bodies or industry – to improve care and outcomes. H2O will help:

- Patients and their physicians to communicate better.
- Health authorities to make more informed decisions based on what really matters to patients.
- Researchers to advance knowledge and science in health care.

## Who participates in H2O?

The Consortium brings together 13 leading Academic institutions, SMEs and patients' organisations and 10 EFPIA companies. The project is led by Takeda Pharmaceutical and the Medical University of Vienna (MUW).

## What are the Observatories?

The national Observatories are **independent, not-for-profit, legal entities** created for **data collection, analysis and evidence sharing** to inform clinical practice and healthcare decisions.

These ethically and legally sound national Observatories are initially being created in **four countries** – the Netherlands, Austria, Germany and Spain – covering **three diseases** – cancer, diabetes and IBD (Inflammatory Bowel Disease) –.

They operate under a **governance model** that guarantees **data protection** under national and European jurisdictions. These independent entities (Observatories) guard data on behalf of patients, who keep control of their own data being used for individual and collective care, research or the evaluation of new technologies.

These entities connect to a **pan-European Observatory** to facilitate interoperability, guide reproducibility in other countries, and promote the benefit of measuring and using patient-centred outcomes at regional, national, European, and global levels.

## ACKNOWLEDGEMENT + DISCLAIMER

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