



# H2O: Strengthening the patient voice in health care

## Facts & figures

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IMI2 – Call 18

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945345

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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.

## 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).



## Why is H2O important?

H2O is creating an innovative governance and infrastructure 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 and used in the interest of society.

### How will Researchers benefit?

H2O opens a new window of opportunity for clinical research by providing the necessary infrastructure and data governance system to conduct cross-country analysis and facilitate the creation of European networks for observational and randomised studies using real world evidence. This innovative framework will facilitate the consolidation of health data -now fragmented- in Europe, thus fostering a more competitive research environment.

H2O will enable researchers to:

- **Run research studies** using the infrastructure and/or data, e.g. cross-country analyses to provide insights into burden of disease and disease evolution as well as identify potential trends for further studies.
- **Assess the impact of new therapies** on the population and **identify optimal treatments** for different types of patients by distilling relevant **insights** from patient-reported and other standardised patient outcomes data.
- Facilitate the use of these European Observatories networks for **observational and randomised studies** to assess changes in clinical practice using the real world data.

## 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.

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MEDICAL UNIVERSITY OF VIENNA

teawit RESEARCH

Takeda

Medtronic

EPF European Patients Forum

KAROLINSKA UNIVERSITY HOSPITAL

KING'S HEALTH PARTNERS

An Academic Health Science Centre for London

Mensuring better health for all

Lilly

KNL Nederlandse Comprehensive Cancer Organisation

KU LEUVEN

Pfizer

iHD The European Institute for Innovation through Health Data

UniSR Universiteit van Tilburg voor de Zorg

The Hyve

CHARITÉ

SANOFI

Vall d'Hebron

Erasmus MC