



# 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  
and Innovation Action)

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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 PATIENTS benefit?

Through the framework of Observatories, H2O is set to empower patients to amplify their voice in their own care by giving them the tools to access more information about themselves and their health. With H2O, patients will be able to:

- **Track personal measures** about their condition and **identify any patterns** that might indicate personal manifestations or triggers for symptoms.
- Have **richer and more fruitful dialogue with their health care provider** resulting in more tailored and effective treatment decisions.
- Through **comparing with other patients** from H2O, better understand burden of disease and how their own experience and measures compare to those of others with the same condition, as well as assess the quality of care that the patient receives.
- Have an **integrated view of their own health information** at hand, enabling them to refer to it during a visit to any health care professional.
- At the same time, national and international patient organisations will be able to see aggregated information on their patients and use the evidence in providing **guidance and advocacy**.

### 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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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 Universität Wien - Austria For Diabetes

The Hyve

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Vall d'Hebron

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