



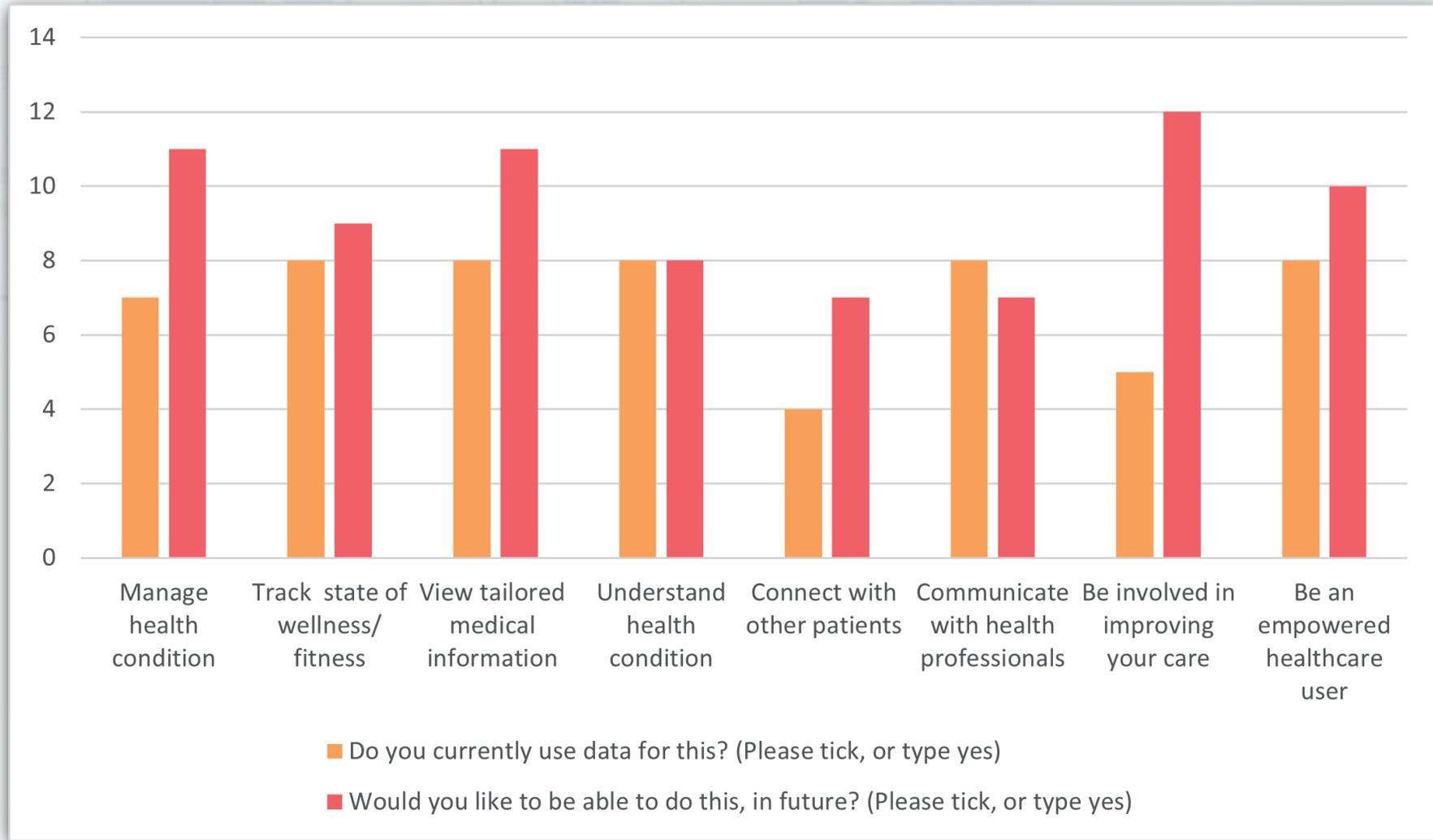
The European Institute For
Innovation Through Health Data

DIGITAL HEALTH: EMPOWERING PATIENTS, ENRICHING RESEARCH

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Why do patients want to make more use of their own health data?



How do patients use digital health today?

Learn about health conditions, treatment options

Track health state

Compare with others

Set personal goals

Track progress towards targets

Track bodily function

Adjust dosage to fit lifestyle

Monitor symptoms

Prevention and wellbeing

Assess impact of treatment

Better able to share decision making

Activity, sleep, diet

Document side effects

Contribute their own collected data to research

Know what to discuss with clinical team

Allow their clinical data to be used for research

What it covers



Why it is important



mHealth market



What is the EU doing about this? Targeting potential issues & barriers, such as





Your health connected



EUROPEAN INNOVATION AND KNOWLEDGE MHEALTH HUB

The European mHealth Hub

- mHealth enables a shift in health systems focus towards early diagnosis and detection of changes in risk of disease, promotion of health and prevention, and self-management of chronic diseases

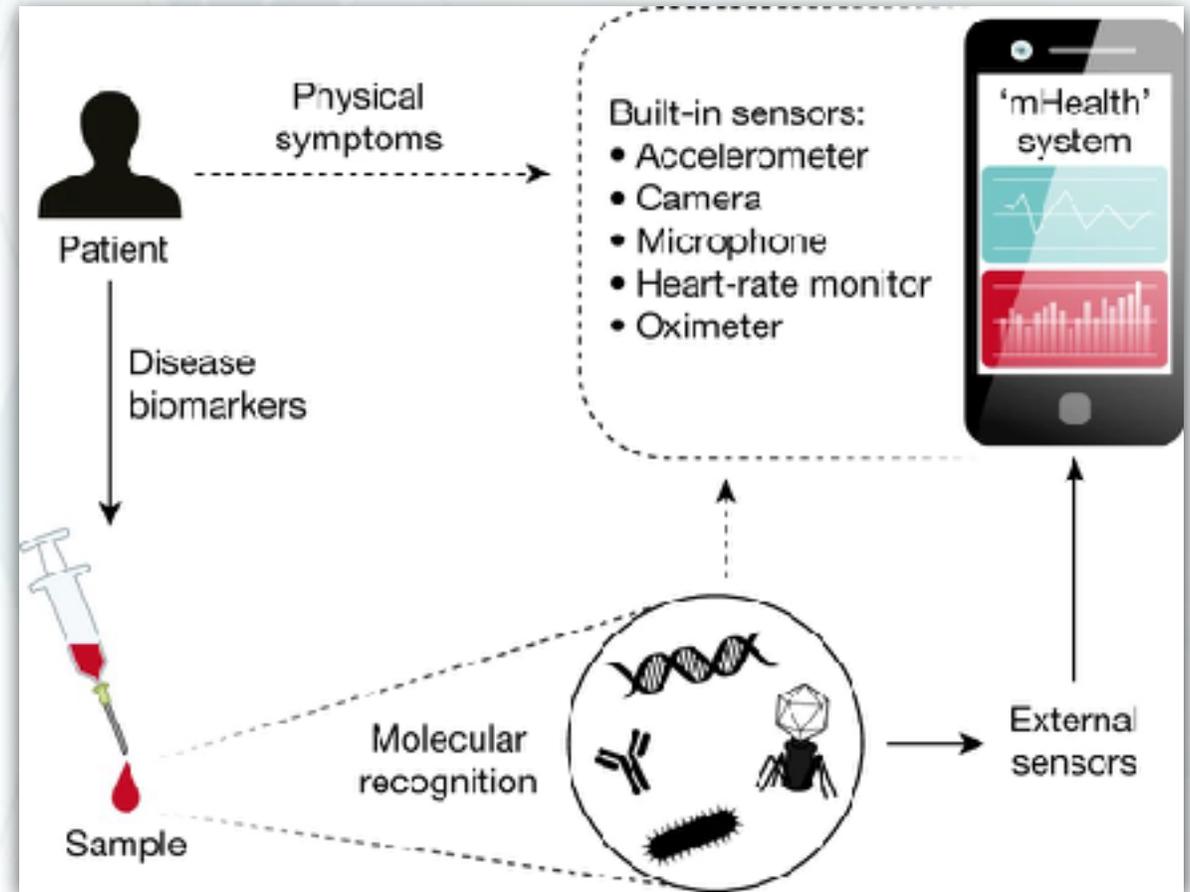


- The European mHealth Innovation and Knowledge Hub is being established
 - to collect and share national experiences on mHealth
 - to support countries and regions in setting up large-scale mHealth programmes

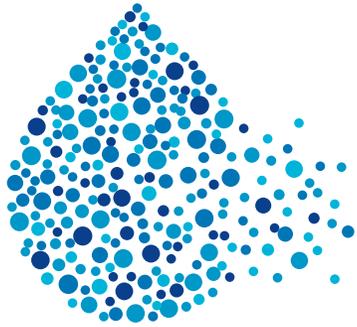
mHealth is effective

- Remote tele-monitoring of patients with heart failure reduces hospitalisation, improves cardiac function, reduces heart failure severity and improves patients' physical and emotional well-being, improves quality of life and reduces future hospitalisations
- In COVID-19, mHealth apps can estimate the probability of infection and help to prioritise diagnostic testing in individuals whose data suggests a moderate to high probability of infection

mHealth diagnostics for infectious diseases



Wood, C.S., Thomas, M.R., Budd, J. et al. Taking connected mobile-health diagnostics of infectious diseases to the field. *Nature* 566, 467–474 (2019). <https://doi.org/10.1038/s41586-019-0956-2>



H₂O

HEALTH OUTCOMES
OBSERVATORY



innovative
medicines
initiative

efpia



JDRF IMPROVING
LIVES.
CURING
TYPE 1
DIABETES.

Trial Nation
Clinical Trials Denmark

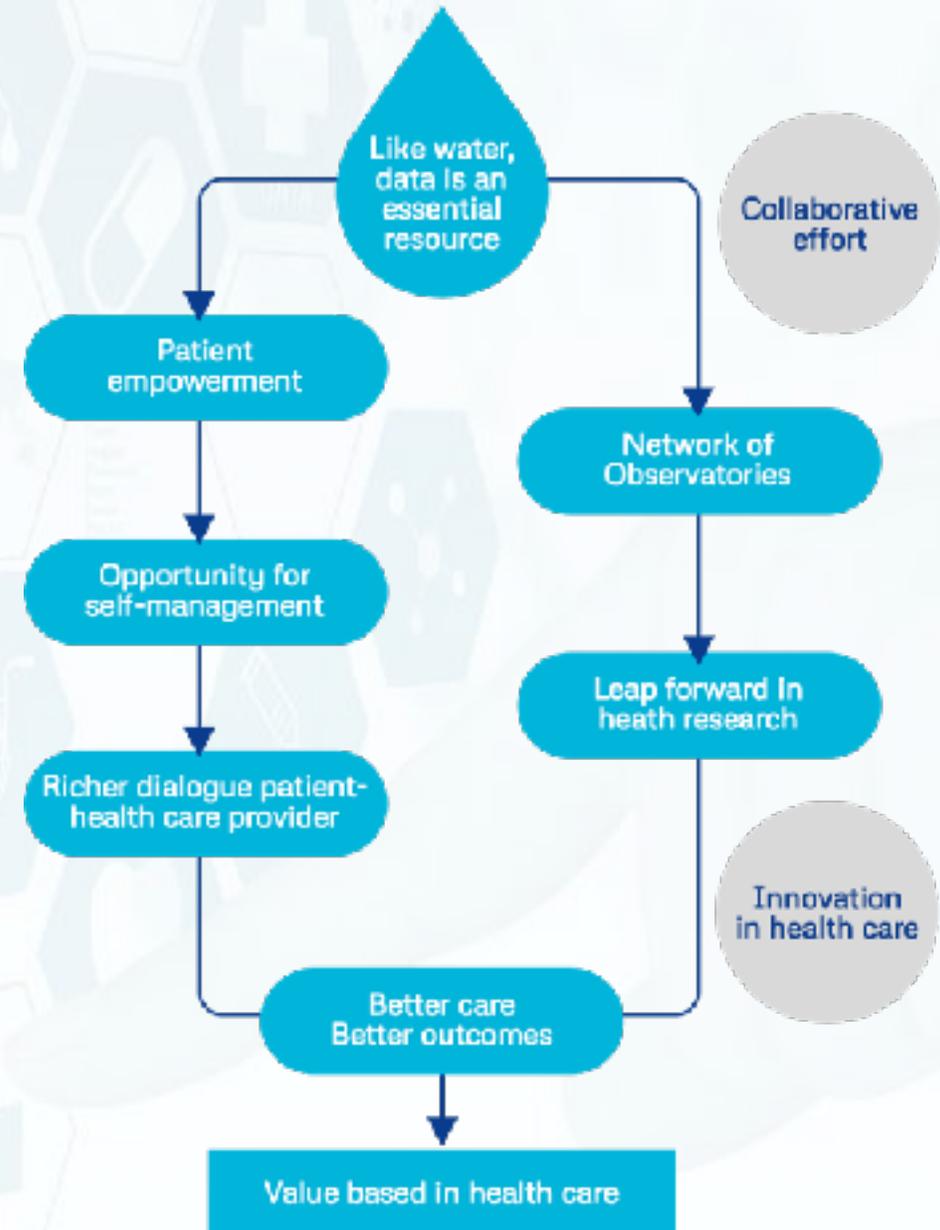
H2O: Strengthening the patient voice in health care

H2O is a **strategic partnership** between the **public and private sectors** to create a robust data governance and infrastructure model to **collect and incorporate patient outcomes at scale into healthcare decision making** at an individual and population level.

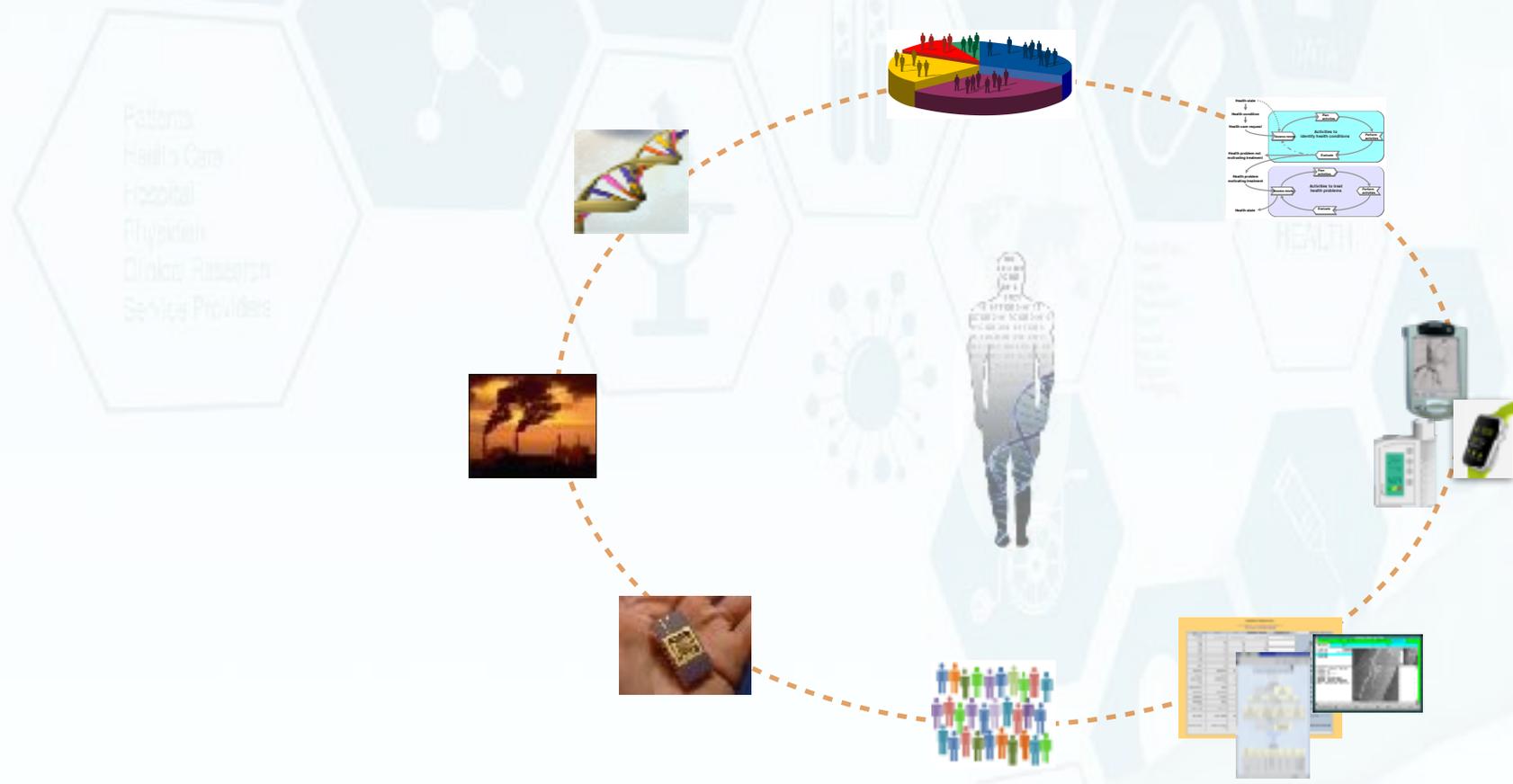
National Observatories (H2Os) are independent, not-for-profit, legal entities created for data collection, analysis and evidence sharing to inform clinical practice and healthcare decisions.

These H2Os 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.

The H2O approach gives patients ultimate control of their health data and ensures that only they exercise this control.



Many kinds of health data are useful for research



All this data brings opportunities for large scale research studies to uncover new knowledge about disease, insights into health needs and novel ways to improve health outcomes

The challenge with gaining public acceptance of health data reuse

Individual level health data

EHR systems, apps, sensors, genomics, Clinical Decision Support, AI guidance

Used for:

- Health status monitoring
- Continuity of care (including the patient and caregivers)
- Care pathway tracking, clinical workflow management
- Real-time feedback and guidance to patients and clinicians
- Personalised medicine
- Disease interception, prevention and wellness
- Healthcare provider reimbursement

Population level health data

EHR systems, regional & national eHealth infrastructures

Reused for:

- Healthcare provider performance and planning
- Quality and safety, care pathway optimisation
- Medical device and algorithm refinement
- Pharmacovigilance
- Public health surveillance
- Public health strategy
- Health services and resource planning

Big health data

national & international research infrastructures, federated query research platforms + cross-sectoral infrastructures & services

Reused for:

- Epidemiology
- Digital innovation: devices, sensors, apps
- AI development
- Personalised medicine and bio-marker research
- Diagnostics development
- Drug development
- Disease understanding and stratification

Decreasing public understanding of why and how data are used

Increasingly unfamiliar data users

Increasing distance of data results from the patient

Increasing time from data use to demonstrated value

Perceived lessening choice and greater cybersecurity risk = harder to trust

If we are to scale up health data research, by many organisations, across many countries

We all need trust

- Patients and the public
 - Health and care organisations, and systems
 - Research users - public and private
 - Society as a whole
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- **We need to find the right balance between protecting the individual and benefits for the individual - and society**
 - **This requires transparency with the public and engagement of the public**