

Health data drives innovation



ESCAIDE 2021

*Digital health opportunities for
Public Health: how far from reality?*

*Trustworthy
digital health data*

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President of i~HD*

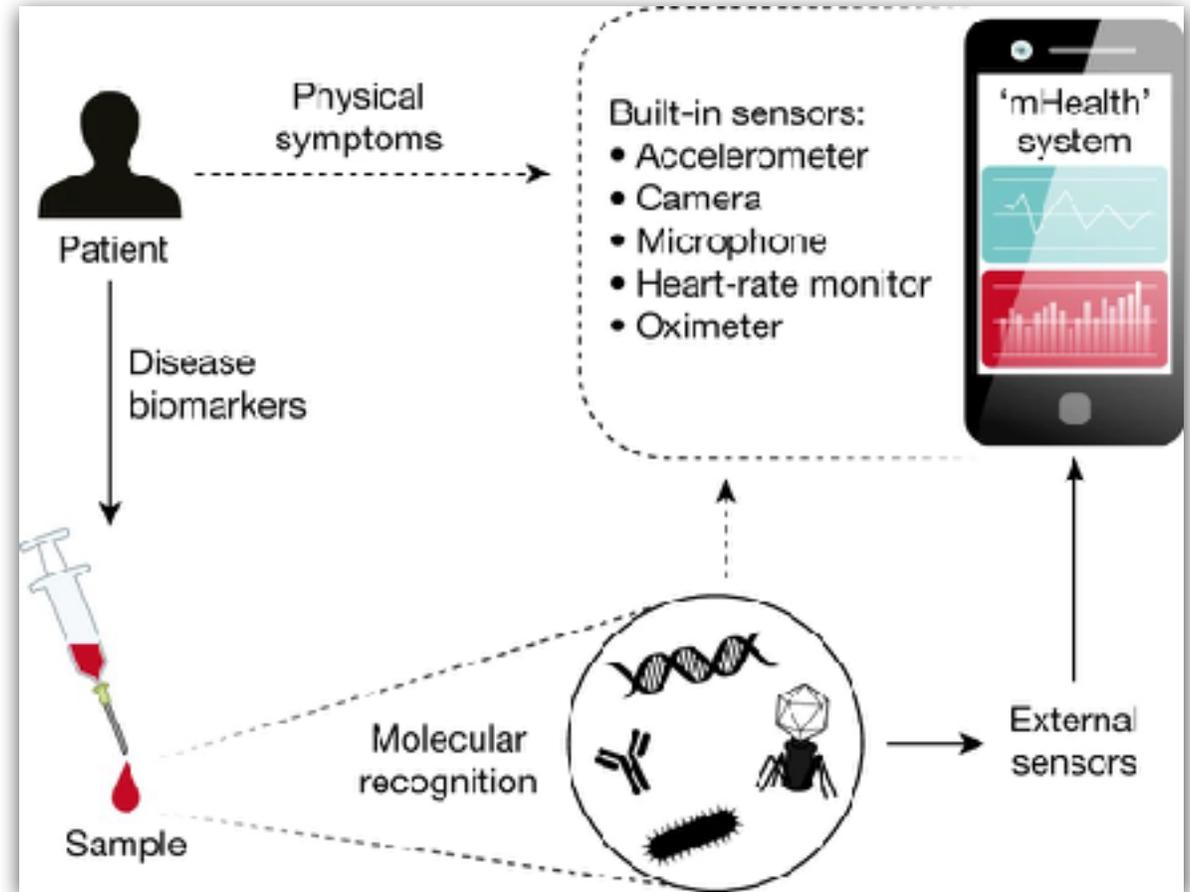
Poll question for the start

- How important will citizen-generated health data be to public health decision making five years from now?
 - Score 1-5
- How well do you think citizens trust public health agencies with their data?
 - Score 1-5

mHealth is effective

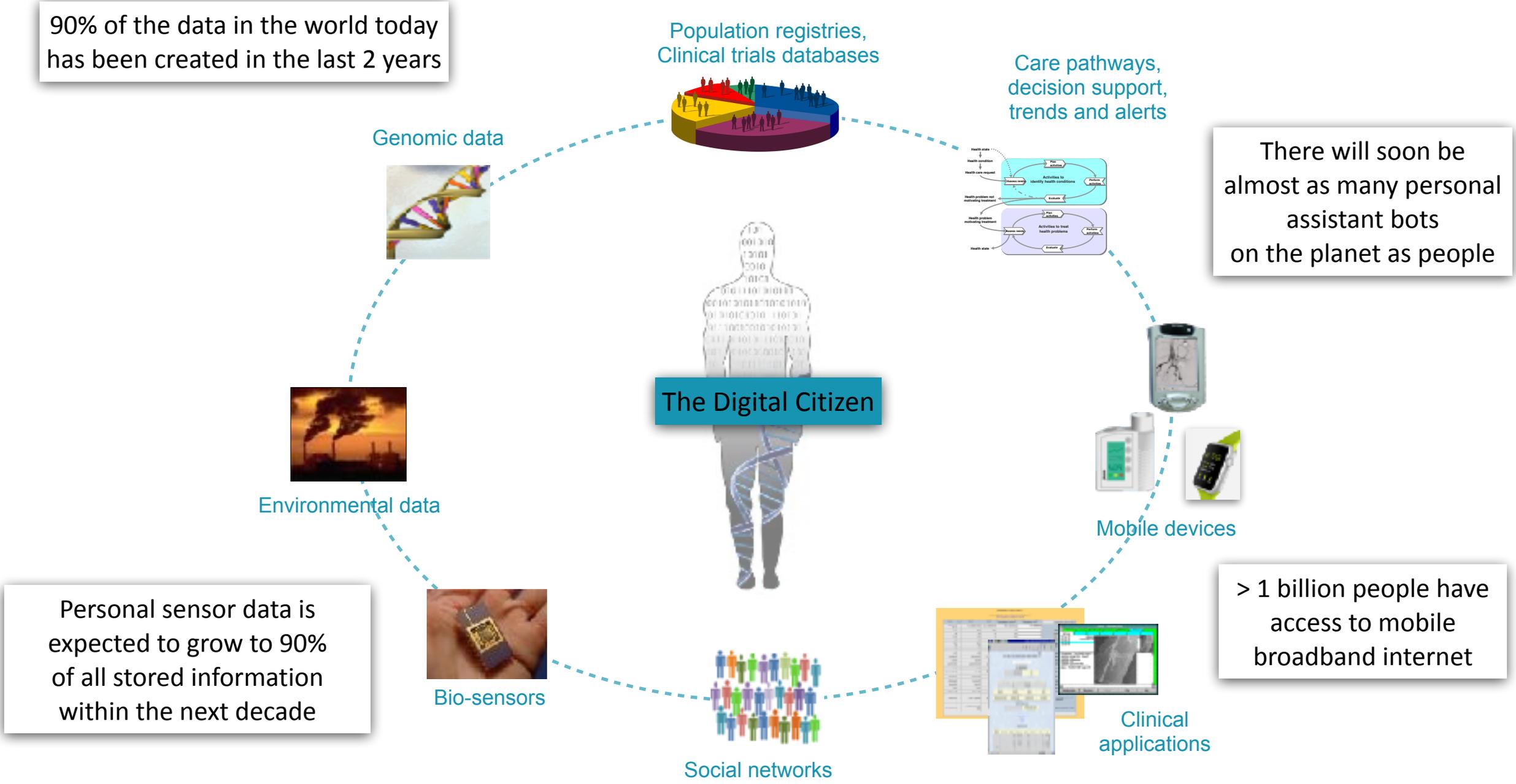
- Remote tele-monitoring of patients with heart failure improves cardiac function, reduces heart failure severity and improves patients' physical and emotional well-being, improves quality of life and reduces future hospitalisations
- In COVID-19, mHealth apps can estimate the probability of infection 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>

90% of the data in the world today has been created in the last 2 years



There will soon be almost as many personal assistant bots on the planet as people

Personal sensor data is expected to grow to 90% of all stored information within the next decade

> 1 billion people have access to mobile broadband internet

Individual level health data

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

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

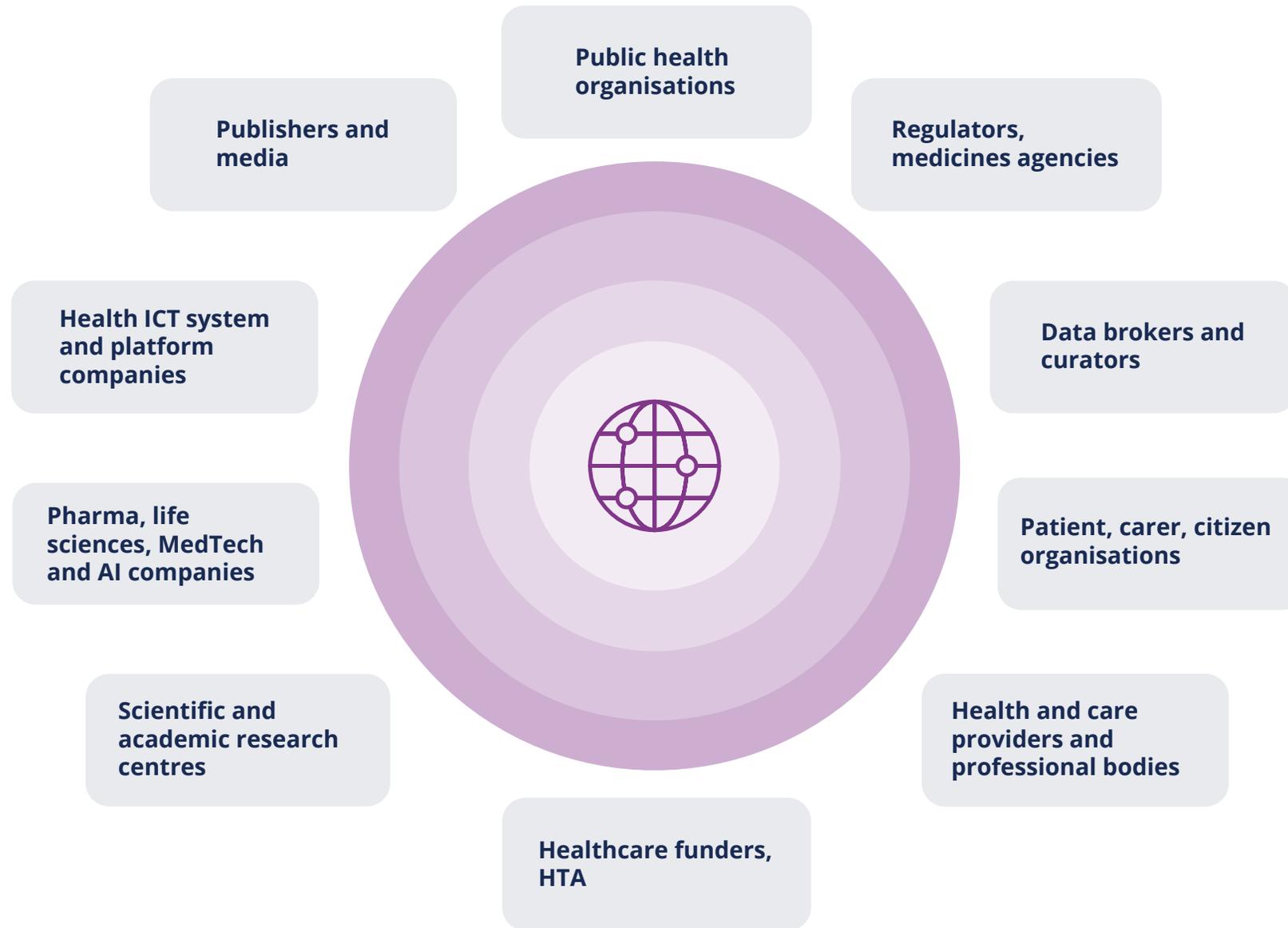
Big health data

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

These are the stakeholders who have to work together



PUBLIC OPINION IN THE EU

I would like to know as much as possible about my DNA

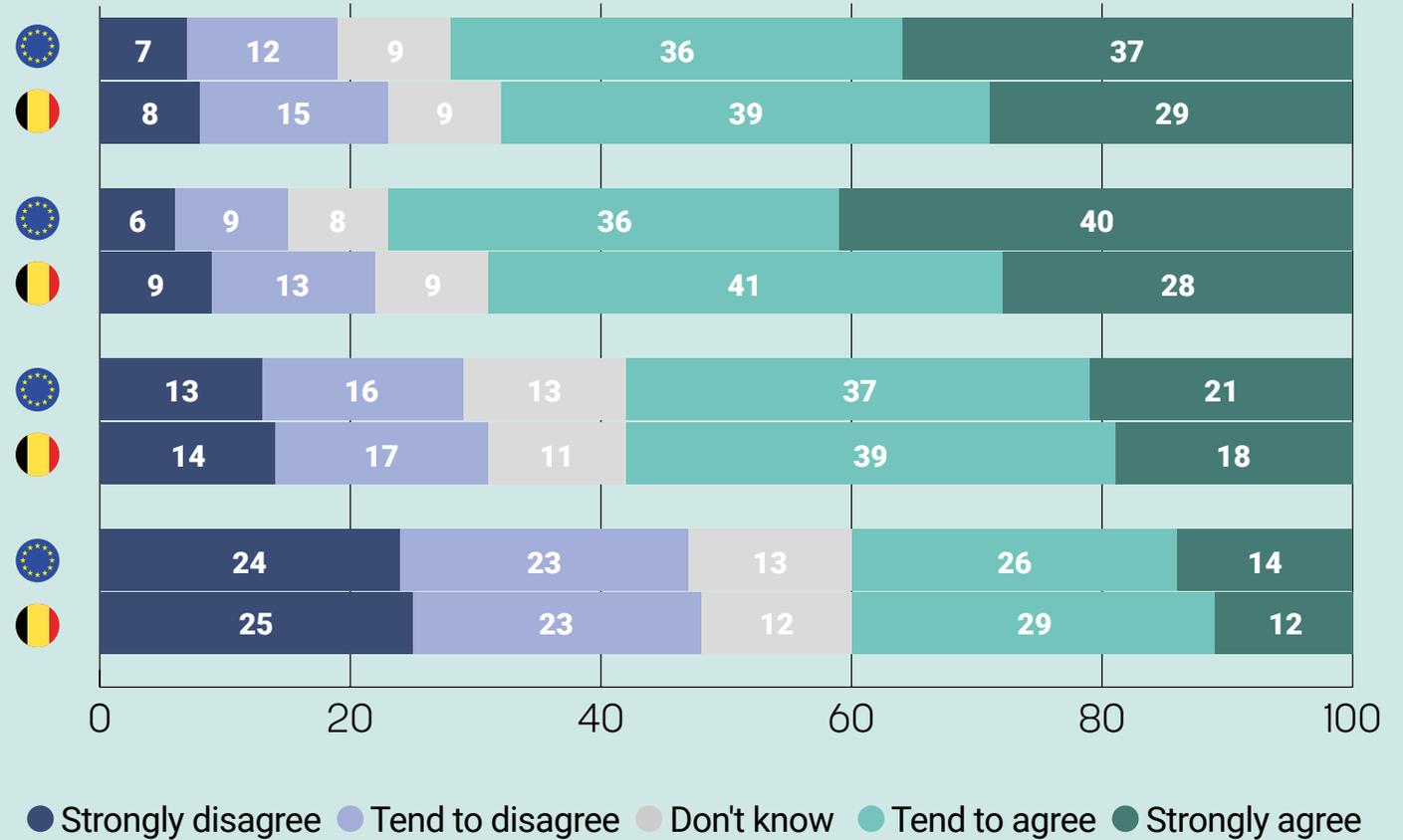
I'm willing to share my genetic information with my family

I'm willing to share my genetic information with academic researchers

I'm willing to share my genetic information with pharmaceutical companies

n = 28,782

Weighted to be representative of the adult EU population



The challenge with gaining public acceptance of health data reuse

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Decreasing public understanding of why and how data are used

Increasingly unfamiliar data users

Increasing distance of data results from the patient

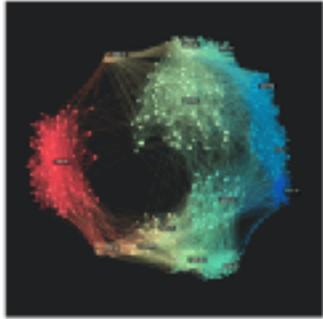
Increasing time from data use to demonstrated value

Perceived lessening choice and greater cybersecurity risk = harder to trust

Some principles promoting trustworthy digital and data use

- **Purpose** must be clearly specified
- **Parties** who will access the data must be declared
- **Permission** must be obtained for any personal data use
- **Protection** of the data must be robust and audited
- **Public** transparency about why and how data is used
- **Promote** the benefits derived from digital public health

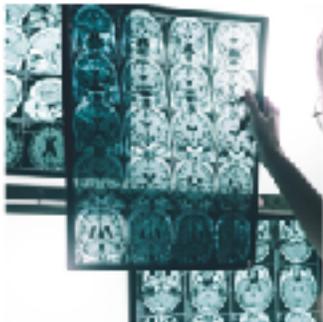
i~HD has provided examples to Data Saves Lives



Big Data' used for the early identification of other diseases associated with cancer

A novel computer programme to help doctors and scientists to better understand which other diseases are likely to occur in patients with cancer.

[Learn more](#)



Helping the Fight Against Alzheimer's

Discovering a test to detect those at risk of developing Alzheimer's Disease

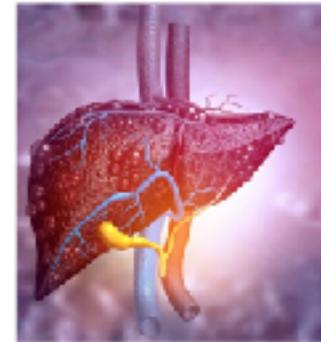
[Learn more](#)



Early Detection of a Cancer Killer

Helping identification of people at high risk of colorectal cancer from an existing blood test

[Learn more](#)

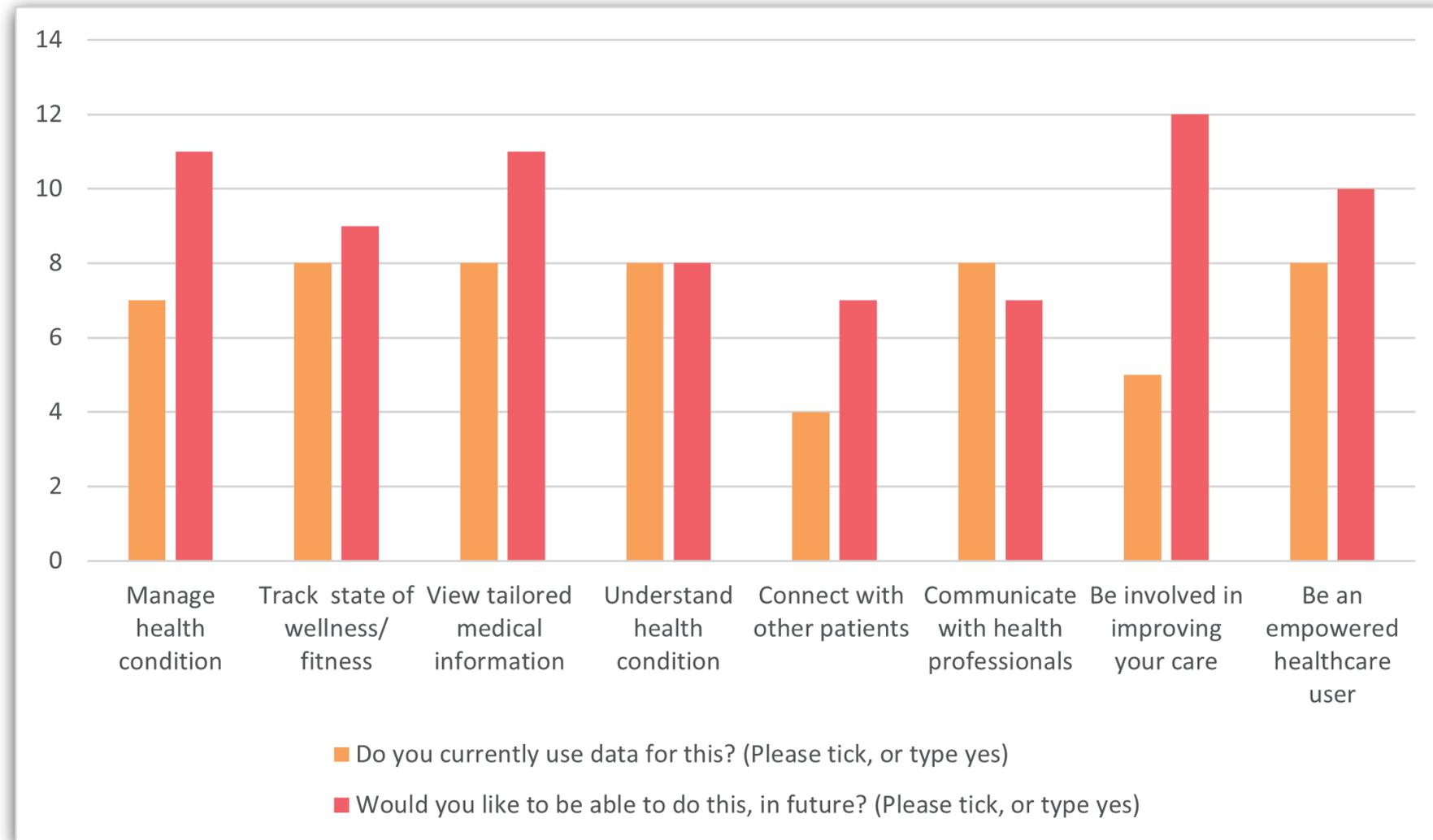


Using health data to explore a link between Body Mass Index and non-alcoholic fatty liver disease

Analysis of over 2 million anonymous patient records to establish how increasing body weight approaching obesity increases the risk of developing liver disease

[Learn more](#)

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



Poll question at the end

- How important are these factors to win public trust in sharing their data through public health agency digital applications?
- Vote for the two you feel are the most important
 - Specifying a narrow range of data use purposes
 - Promising to only use anonymised data
 - Declaring which other agencies will be able to access the data
 - Publishing openly how the data has been used
 - Providing guidance back to individuals through their apps