



The European Institute For
Innovation Through Health Data

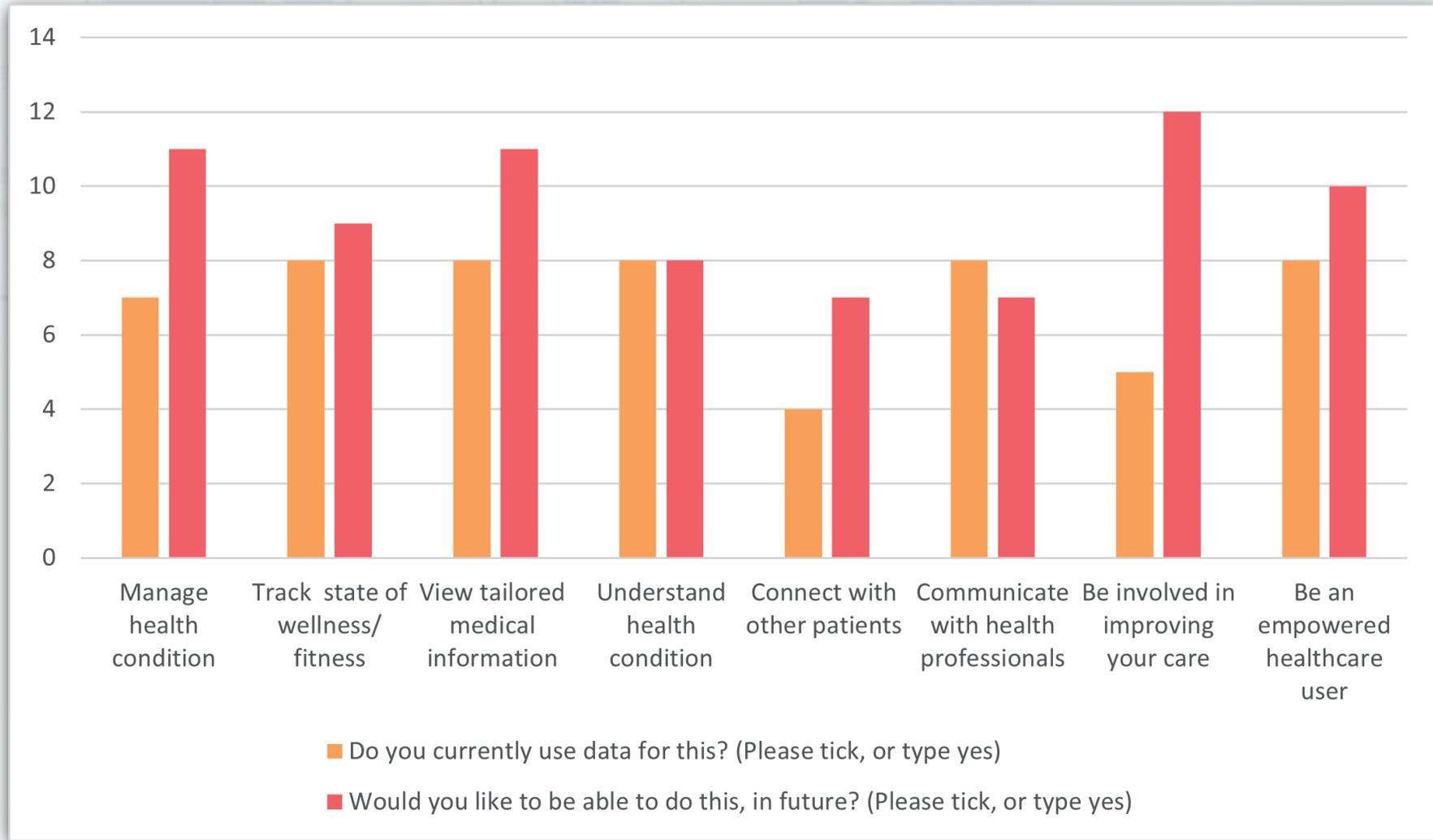
THE POTENTIAL OF HEALTH DATA FOR PATIENTS

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President of i~HD





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



What it covers



Why it is important



mHealth market



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



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

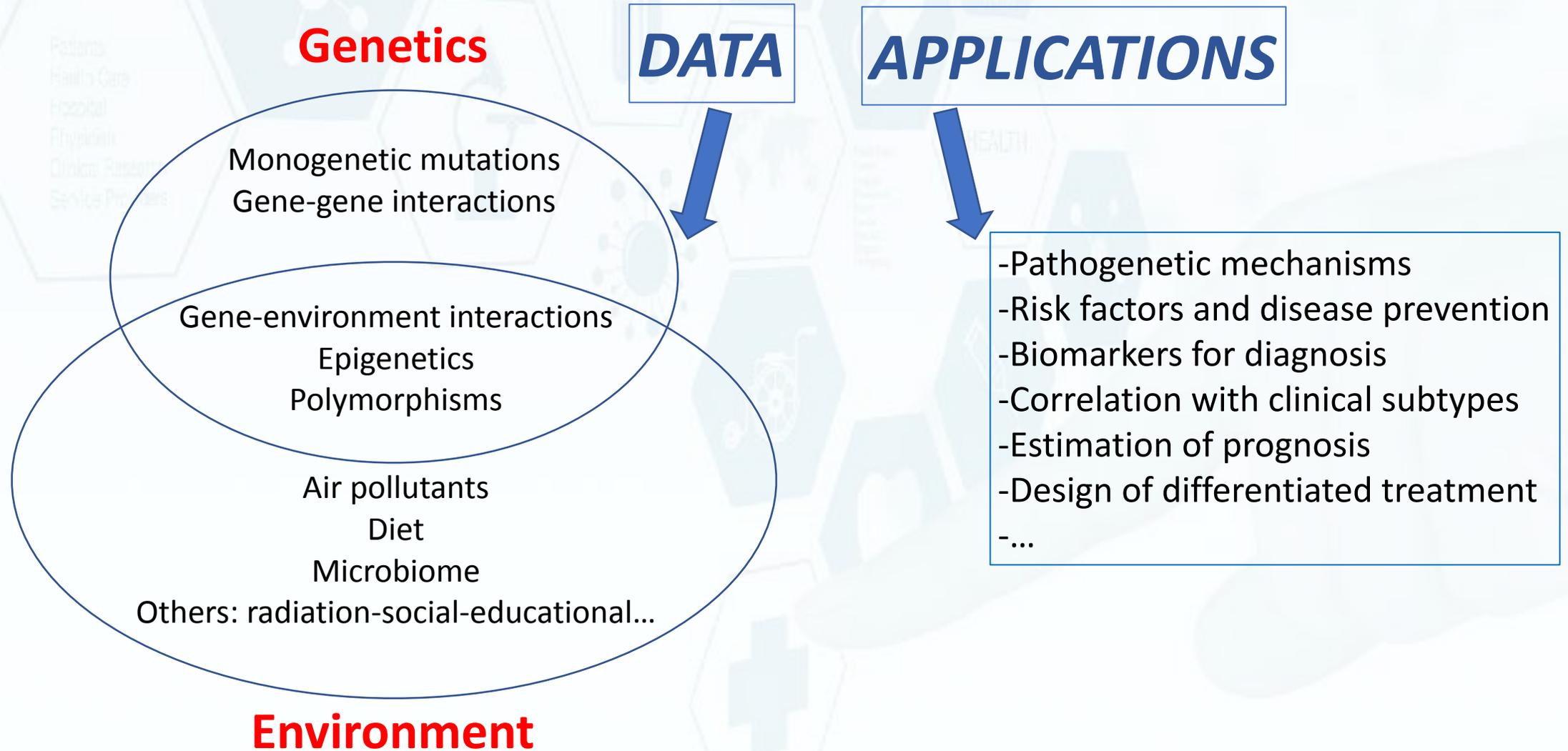
Allow their clinical data to be used for research

Why do physicians often value the digital engagement of their patients?

- Help to detect the development of chronic conditions at an early stage through self-assessment tools and remote diagnosis
- Help to detect the worsening of a condition, so they can respond quickly
- Offer interesting and interactive ways of promoting a healthy lifestyle
- Enable remote consultation and care, reducing hospital visits
- Support patient active participation and empowerment

- **A more engaged population that is healthier, for longer, will reduce the pressure on healthcare systems - help to prioritise services**
- **Analysis of the big data that patients generate will help to improve healthcare quality, safety and accelerate new treatments**

Real World Data in Parkinson's Disease research



Consider a patient newly diagnosed with a raised blood pressure

- Which blood pressure treatment is the best one to start with?
- There are several kinds of blood pressure lowering treatment a doctor could choose from



Thiazide or thiazide-like diuretics



Angiotensin-converting enzyme inhibitors,
angiotensin receptor blockers



Dihydropyridine or non-dihydropyridine
calcium channel blockers

- Which kind is most likely to protect a patient from complications, like having heart attack, a stroke or developing heart failure?

The challenge with finding out

- All of these drugs have some benefit
- The difference between them is small
- It may take many years for a patient develop a complication from raised blood pressure
- So, a large number of patients need to be studied over a long period to discover if one of these drug categories is better than the others

ARTICLES | [VOLUME 394, ISSUE 10211](#), P1816-1826, NOVEMBER 16, 2019

Comprehensive comparative effectiveness and safety of first-line antihypertensive drug classes: a systematic, multinational, large-scale analysis

[Prof Marc A Suchard, MD](#)   • [Martijn J Schuemie, PhD](#) • [Prof Harlan M Krumholz, MD](#) • [Seng Chan You, MD](#) • [RuiJun Chen, MD](#) • [Nicole Pratt, PhD](#) • et al. [Show all authors](#)

Published: October 24, 2019 • DOI: [https://doi.org/10.1016/S0140-6736\(19\)32317-7](https://doi.org/10.1016/S0140-6736(19)32317-7)



The best choice?



Thiazide or thiazide-like diuretics



Angiotensin-converting enzyme inhibitors,
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calcium channel blockers



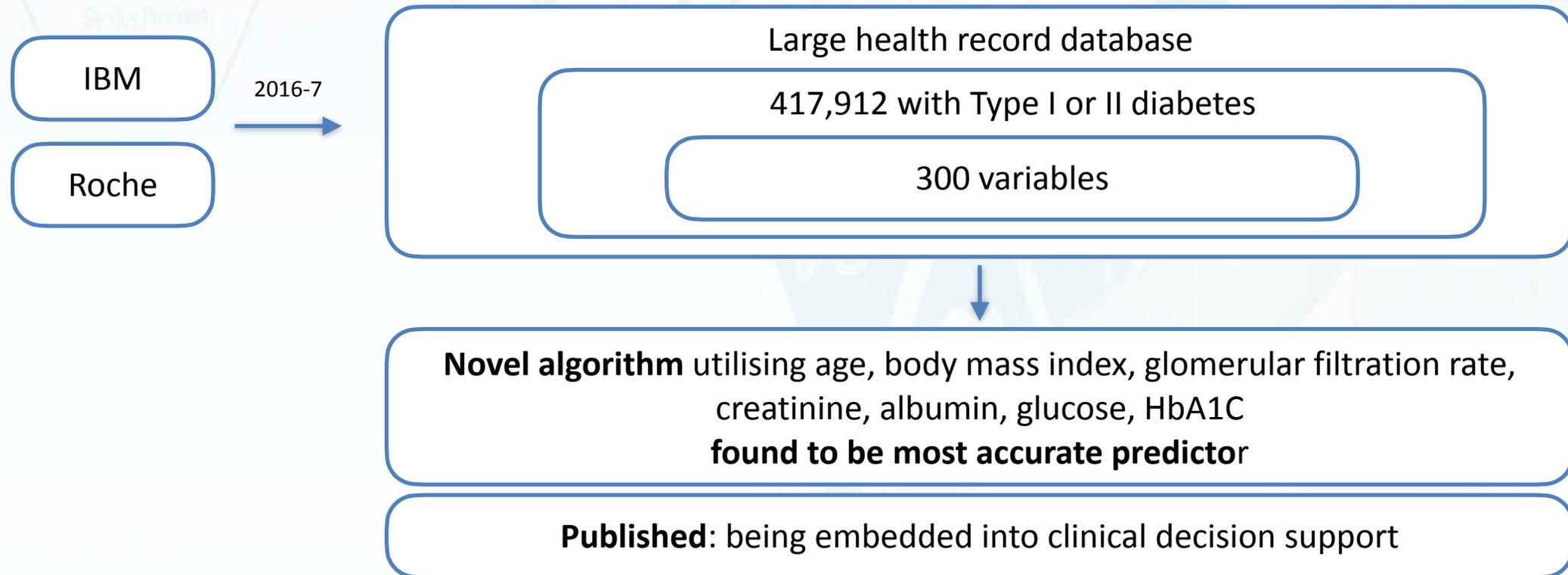
What made this research possible?

- 4.9 million records of patients treated for high blood pressure
- 9 large patient data bases in the US, Japan, South Korea and Germany
- Able to look back at the records over several years
- Able to extract data on 55 health and disease facts about each patient

- It would have taken 22,000 conventional clinical trials to generate this much data!
- The research took months rather than many years!
- Low cost of conducting that research

Big data predicts diabetes-related chronic kidney disease

- Chronic kidney disease (CKD) is one of the most severe complications related to diabetes (10% within 3 years of developing diabetes)



Some other research findings from real world data

>700 million patient records

new cancer risk prediction

200 new clinical measurements

better cardiac prevention

8,000 leukaemia outcomes

stronger case for treating elderly

174,000 prescriptions

quality of respiratory treatments

How has research been used by health services?

- Demonstrated improvements by one healthcare system through analysing its own data

33% decrease in heart disease deaths

50% decrease in HIV deaths

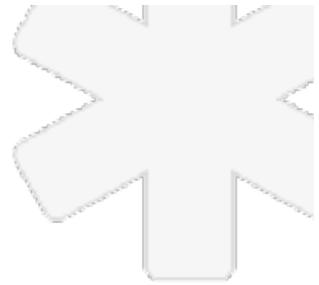
50% decrease in septicaemia deaths

67% decrease in pressure ulcers

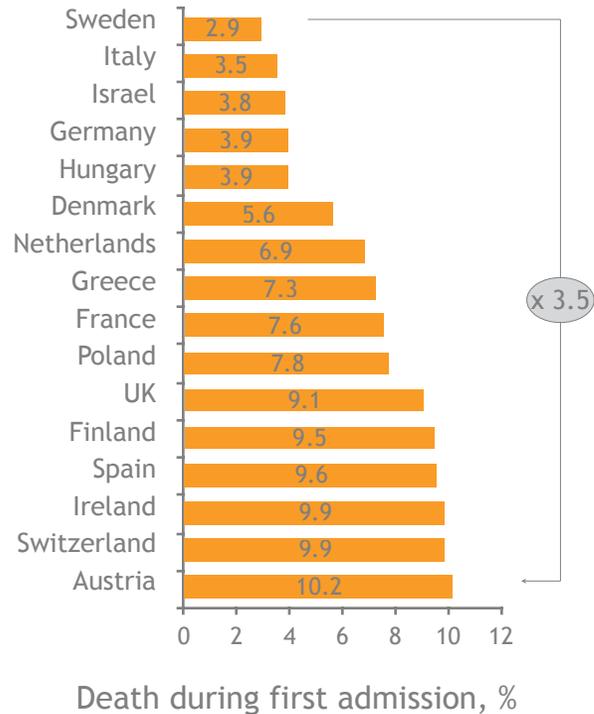
How have research results been used by companies?

- A new drug to tackle a cancer that is difficult to treat, developed by a pharmaceutical company
- An infusion pump that delivers a controlled dose of medication to somebody continuously while they are at work or home, developed by a medical device manufacturer
- A smart monitoring system that gives the patient an alert on their mobile phone when a blood measurement needs urgent attention, developed by a health software company

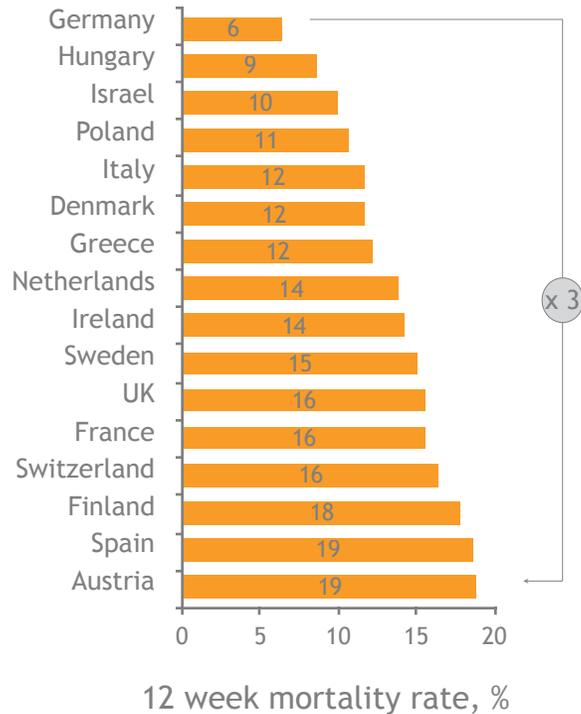
We still have unanswered questions



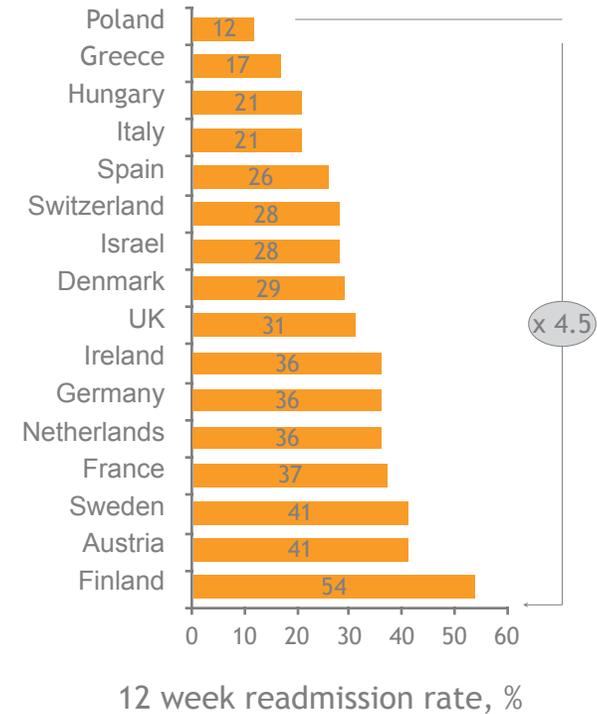
> 3x variation in death during first HF admission



3x variation in 12 week mortality rate for HF



>4x variation in 12 week readmission rate for HF



Why is there a variation of heart failure outcomes across Europe?

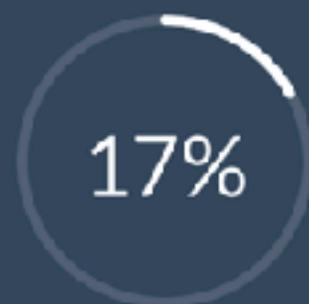
Between 2015 and 2035, multi-morbidity prevalence is estimated to increase, the proportion with 4+ diseases almost doubling

Kingston A et al. Projections of multi-morbidity in the older population in England to 2035: estimates from the Population Ageing and Care Simulation (PACSim) model

Age and Ageing, Volume 47, Issue 3, May 2018, Pages 374–380, <https://doi.org/10.1093/ageing/afx201>



2015



2035

We need to conduct more research from health data

How do diseases and treatments interact?

Which treatment gives the best results?

Is this new medicine safe?

Who should we screen for which diseases?

How are new viruses transmitted, treated?

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

We all need trust

- Patients and the public
 - Healthcare organisations, national registries
 - Research users - public and private
 - Society as a whole
-
- **We need to find the right balance between protecting the individual and benefits for the individual - and society**

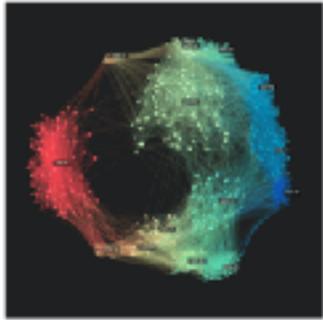
Examples of organisations usually considered to be trustworthy research users

- Health and social care provider
- Academic research organisation (e.g. university)
- Public health organisation
- Healthcare funder (health ministry, commissioning group, health insurer)
- Patient association or charity
- Regulatory body (e.g. medicines agencies)
- Pharma company, biotech company, AI company
- Manufacturers of medical devices, appliances, systems etc.
- ICT (software, platform) developer or service provider, digital therapeutics

Codes of conduct help ensure trust

- Organisations that conduct research need to
 - have a legitimate and legal basis for using the data
 - conduct the research ethically, usually with the approval of an independent ethics review board or committee
 - have an approved purpose for using health data
 - adopt strict codes of practice and security measures that comply with the European Regulation on data protection (the GDPR)

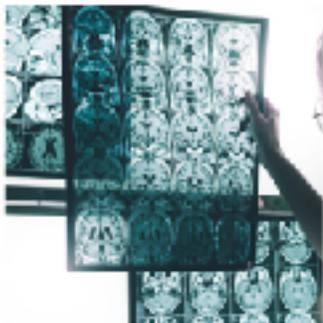
We need to explain the benefits of using health data



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

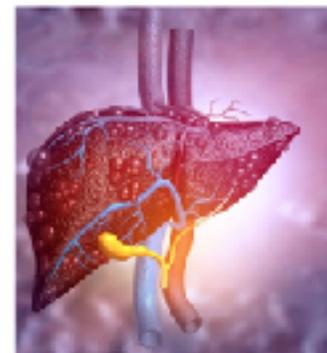
[Learn more](#)



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](#)



