

Health data drives innovation



*University of Hasselt
Honorary Doctorate Ceremony
Inauguration of the Data Science Institute*

*Accelerating research
through the greater use
of big health data*

*Dipak Kalra
President of i~HD*

Health system sustainability and resilience

Economic context:

- Legacy of the crisis: high debts and deficits
- Continued increases in public health spending anticipated
- Concerns about how this will be paid for (sustainability of public finances)

Population health:

- Ageing and rising levels of chronic disease and comorbidity
- Public health problems and inequalities

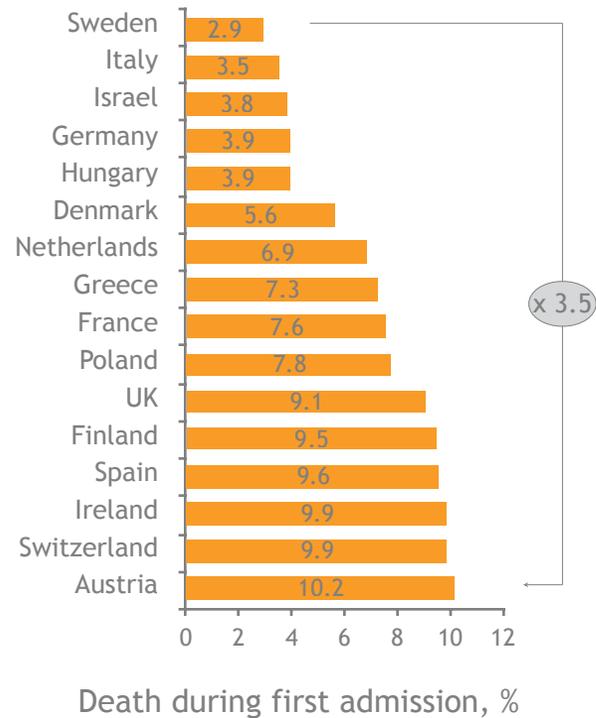
Health systems:

- Challenge of responding to changing population needs
- Need for structural reforms – e.g. integrated care, eHealth
- Evidence of marked variation in clinical practices and significant levels of 'waste'

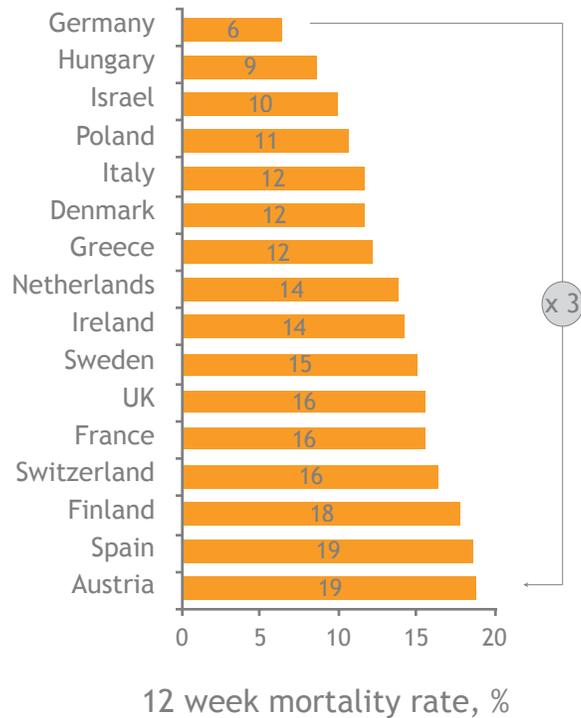


Variation of heart failure outcomes across European countries

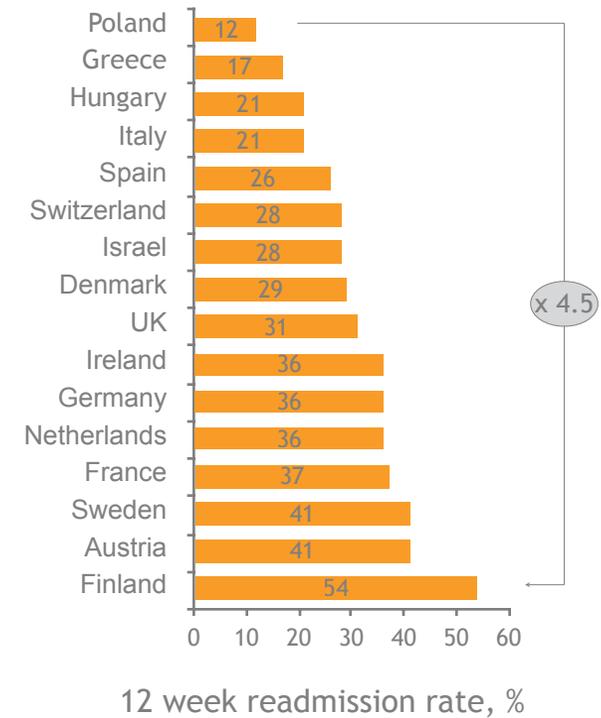
> 3x variation in death during first HF admission



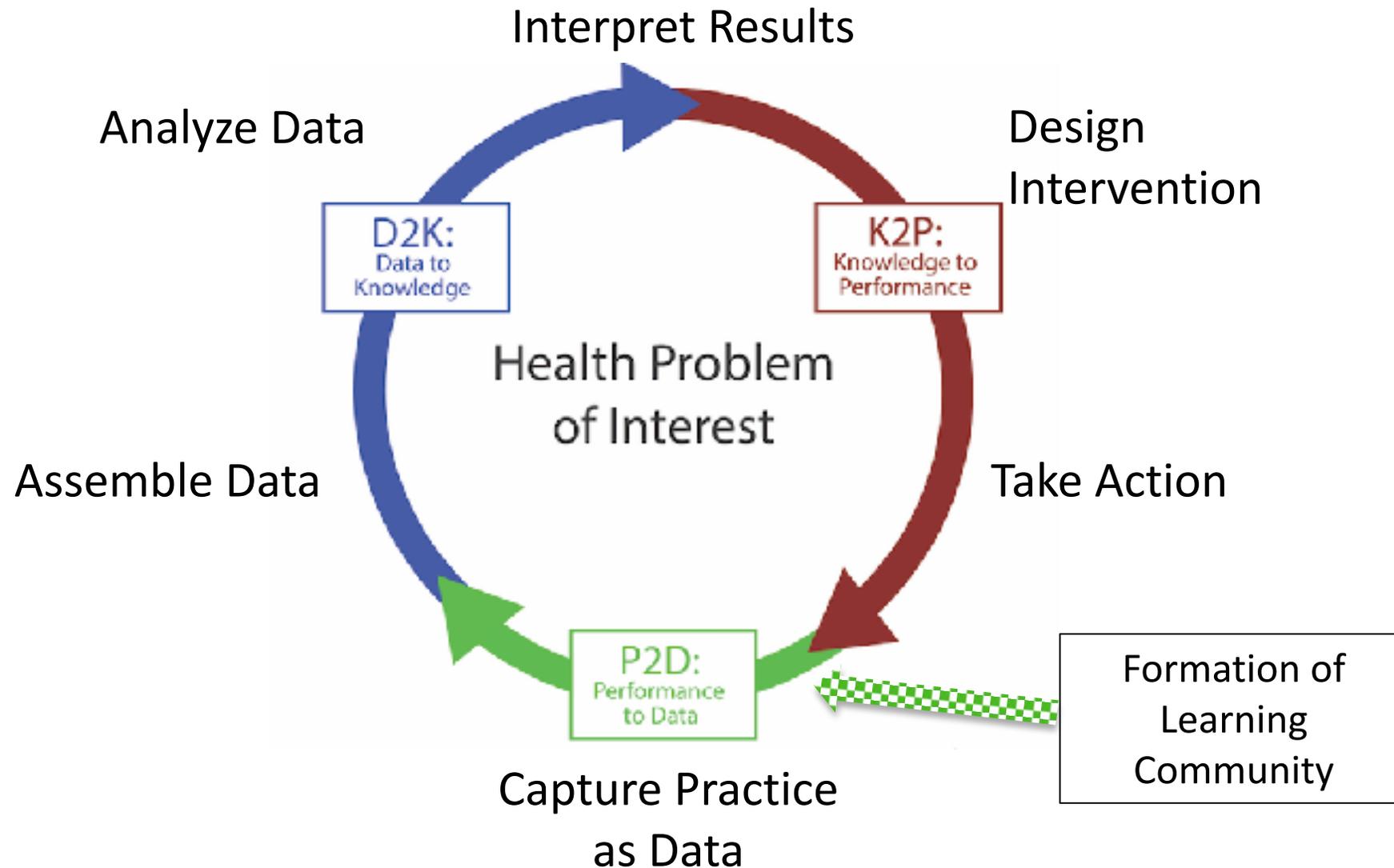
3x variation in 12 week mortality rate for HF



>4x variation in 12 week readmission rate for HF



The Learning Health System: “Virtuous Cycles” of Study and Change



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

How has “big” EHR data been used by health services?

- Demonstrated health improvements through using data in one **Learning Health System**

33% decrease in heart disease deaths

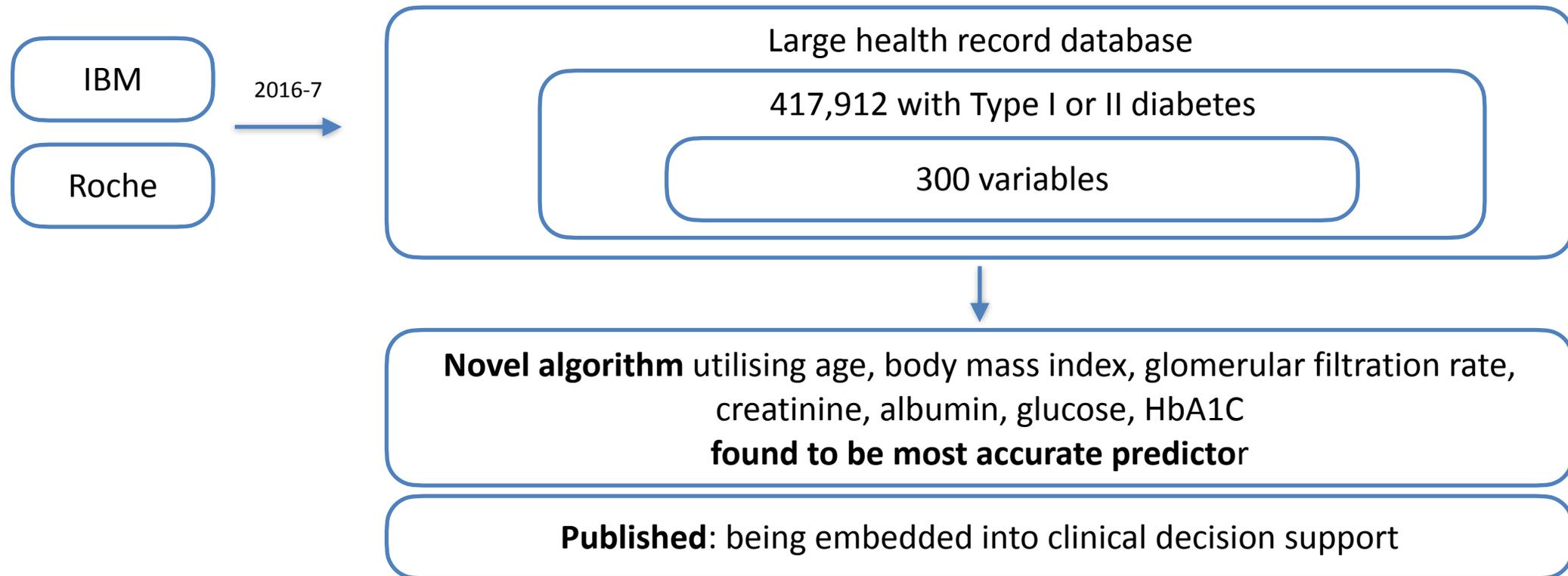
50% decrease in HIV deaths

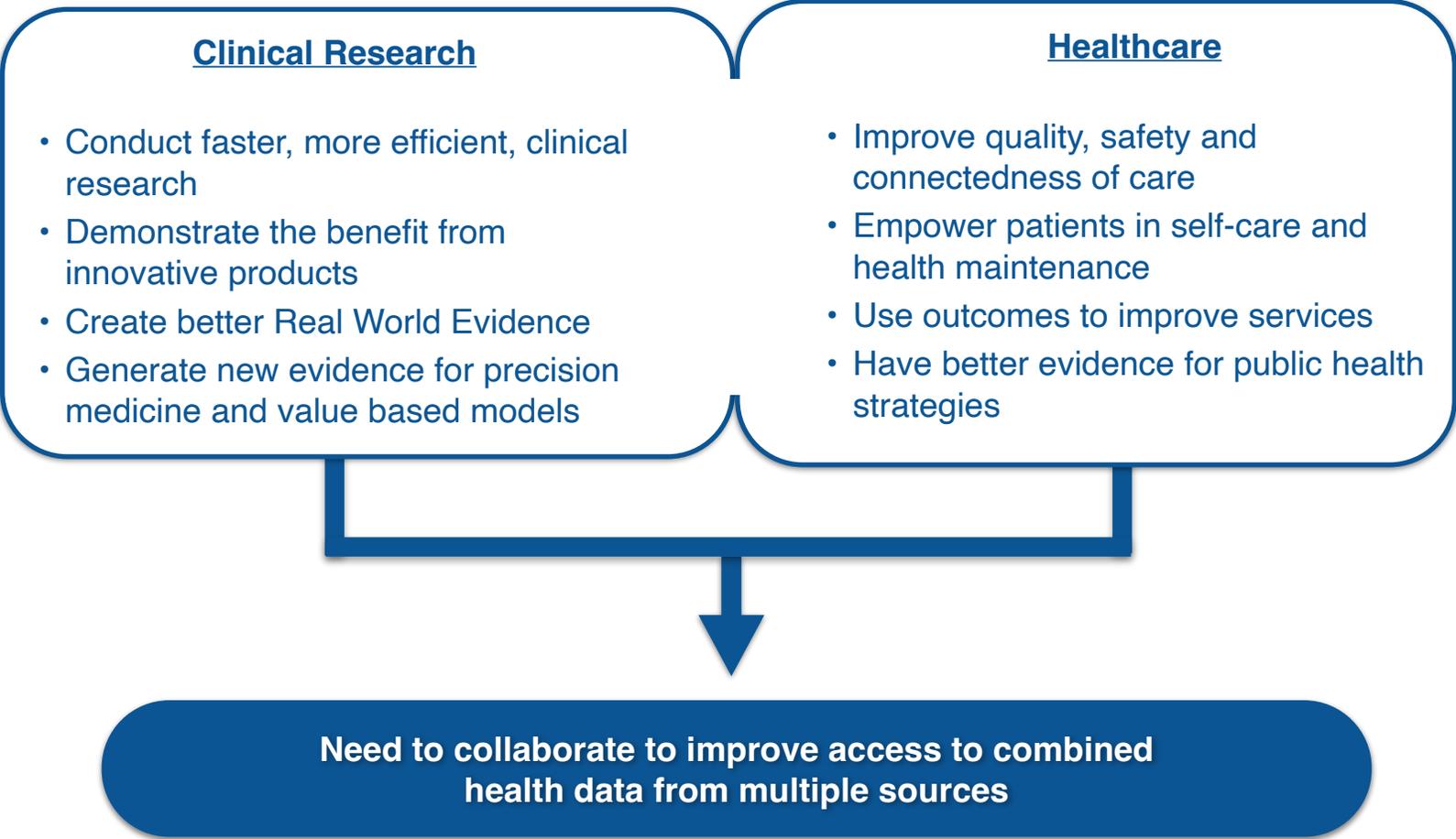
50% decrease in septicemia deaths

67% decrease in pressure ulcers

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)





- Identifying and recruiting suitable patients and trial sites are principal causes of trial delays



The percentage of studies that complete enrolment on time:

18% in Europe,

7% in the US¹



Almost

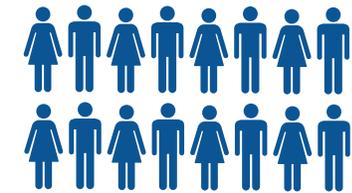
half of all trial

delays caused by patient recruitment problems²



Each day a drug is delayed from market, sponsors lose up to

\$8m³



50%

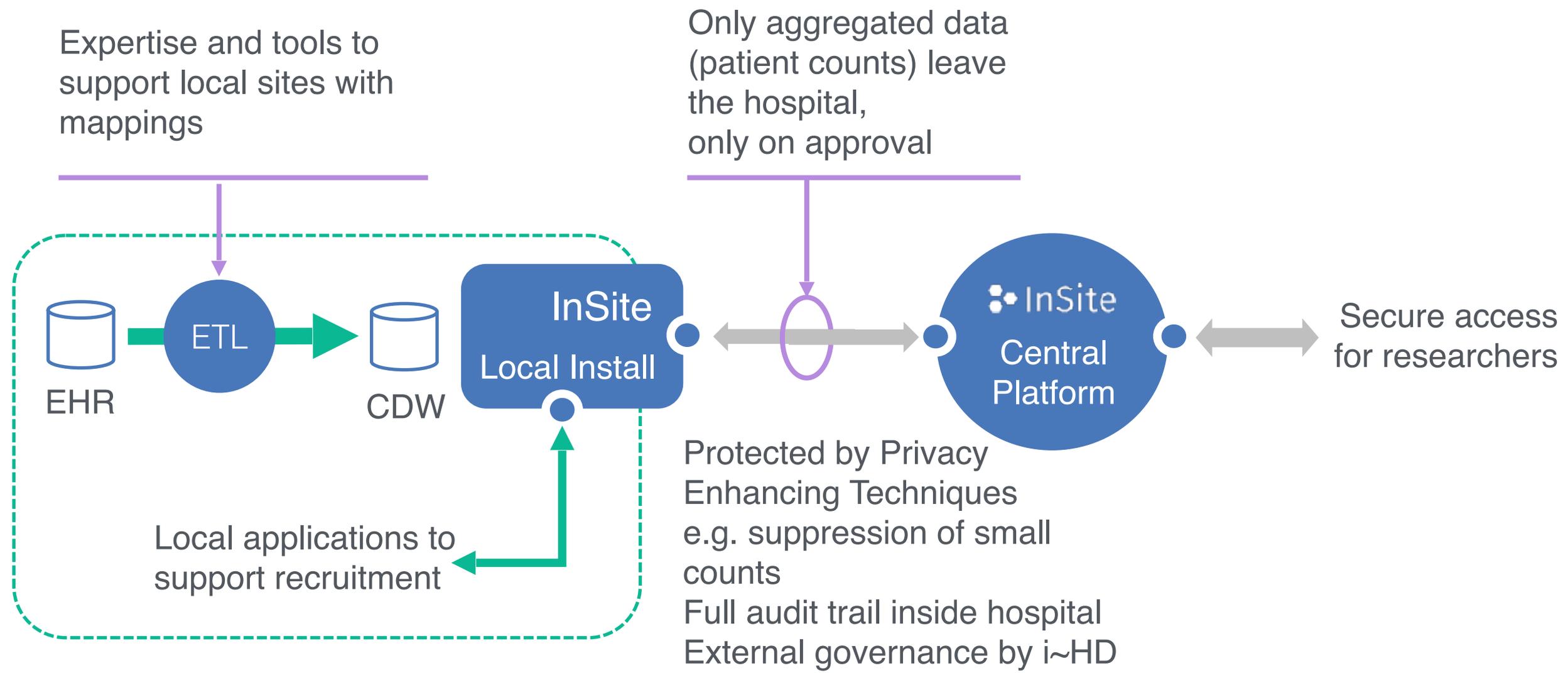
of today's clinical trials fail to achieve the target recruitment rate⁴

1. State of the Clinical Trials Industry: A Sourcebook of Charts and Statistics, Center Watch, 2008.

2. Study Participant Recruitment and Retention in Clinical Trials: Emerging strategies in Europe, the US and Asia, Business Insights, June 2007.

3. Beasley, "Recruiting" 2008

4. Tufts -<http://clinicalperformancepartners.com/wp-content/uploads/2012/07/Fixing-Feasibility-Final-Jan-2012.pdf>



InSite An EHR4CR Service Platform
Study Design Study Recruitment
11-SNAPSHOT P Custodia 2016 Notifications Brecht Claerho...

Search

⚙️ Edit workset properties

All Drafts Final

✓ Version 2 (final)
 by Brecht Claerhout
 Today, 08:34
👤 58 matches

✓ Version 1 (final)
 by demo user
 Yesterday, 23:01
👤 75 matches

Finished results for
Baseline query
 Reference date: Apr 21, 2012

STATUS

Sites succeeded: 2
 Sites failed: 1
 Sites loading: 0

download excel

Executed on Apr 21, 2016

SITE THRESHOLD

Minimum patient matches in site:

SITE SELECTION

All sites
 Selected sites

CRITERIA SELECTION

All criteria
 One criterion

Feasibility study overview > Non-insulin-dependent diab... > Baseline query > Version 2 > Query Results

Patient results have been abstracted for sites ROW. Approximated results are indicated by an * icon.

Patient Reach for Baseline query

58*
PATIENTS

73.6%

PATIENT TOTAL
TARGET N=250

34*
NETHERLANDS

45.19% 64.71%

PATIENT SCORE
PER COUNTRY

34*
MCW

45.19% 64.71%

PATIENT SCORE
PER SITE

Site & Country Scores

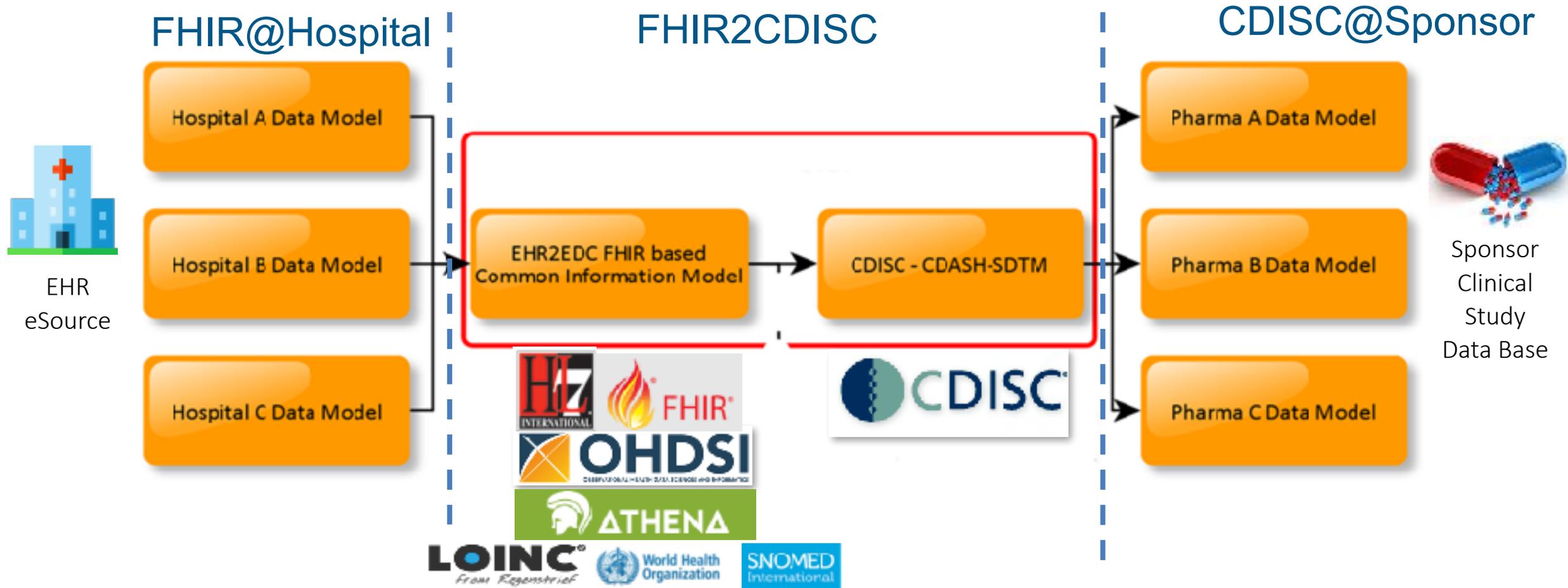
PATIENT MATCHES PER COUNTRY

Netherlands: 16,521
United Kingdom: 24

PATIENT MATCHES PER SITE

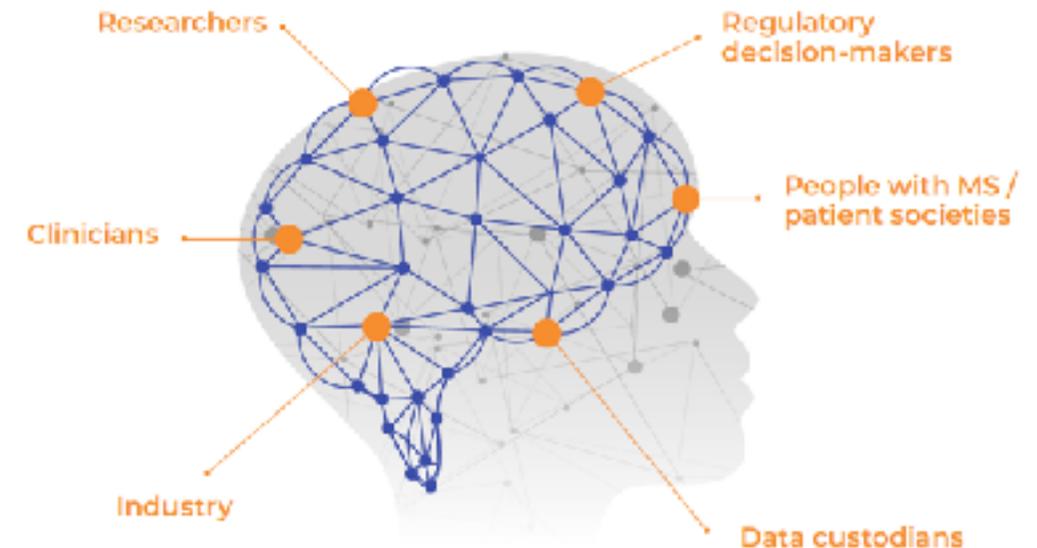
MCW: 16,521
ERHT: 24

📄 COUNTRY 📄 ALL PATIENTS 📄 MATCHING PATIENTS
 📄 SITE 📄 ALL PATIENTS 📄 MATCHING PATIENTS



Multiple Sclerosis Data Alliance (MSDA)

- Scaling-up real-world MS data is necessary to transform the care of people with MS
- MSDA is a global multi-stakeholder collaboration that was launched in 2019
- Founded by Prof Liesbet Peeters, University of Hasselt
- MSDA envisions a patient-centric data ecosystem in which all stakeholders contribute and use big data to co-create innovations to advance timely treatment and care of people with MS



High heterogeneity between MS registries and cohorts (purpose, maturity, size and depth)



Regional or national longitudinal follow-up



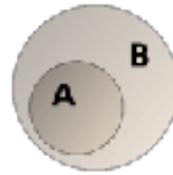
Deep phenotyping/
Biobanking



Research collaborations



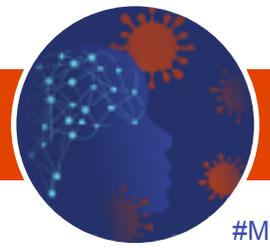
Patient-centred



Special target population



Improve care path concept



Am I at a greater risk of getting COVID-19?

Does MS increase the chances of a severe COVID-19 infection?

Will COVID-19 infection cause my MS to relapse?

Should I stop or change my DMT because of the risk of COVID-19 infection?

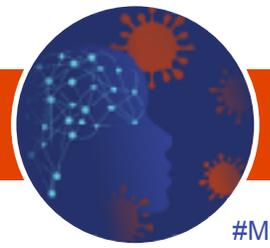
Confounding variables – age, gender, comorbidities
“Control Data” – incidence data, severity in people without MS

- **COVID-19 incidence**
- **COVID-19 severity**

MS history and severity

- EDSS (date of assessment - score)
- MS type
- Disease duration
- Blood data

Disease-modifying therapy
Drug - Treatment start - Stop -
Reasons for discontinuation



Mission

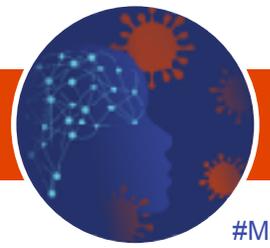
To support people affected with MS, healthcare professionals and researchers during the pandemic

Objective 1: Scale-up COVID-19 data collection efforts

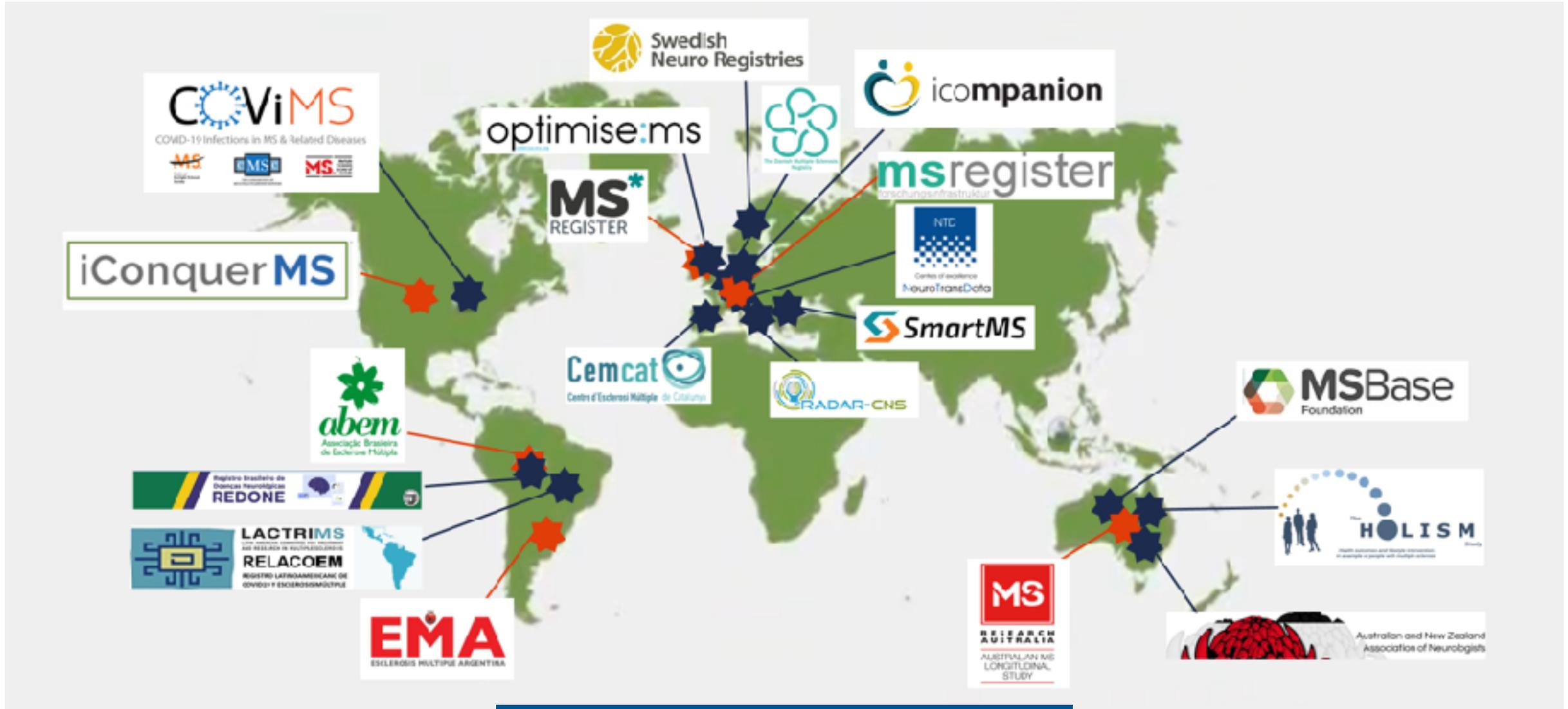
Objective 2: Achieve insights to support care during the pandemic

Objective 3: Act as stimulus to steer ongoing and future scientific research

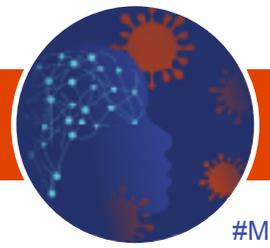
COVID-19 & MS Global Data Sharing Initiative : Current data partners



#MSCOVID19



Slide from Prof Liesbet Peeters, U Hasselt, MSDA lead and founder



+50%
increase in the
number of
participating
registries from 12 to
18



+48%
increase in the
number of
records from
5727 to 8484



- 75%
reducing time
needed for (!)
weekly data
wrangling

MULTIPLE
SCLEROSIS
JOURNAL

MSJ

Future Perspectives

COVID-19 in people with multiple sclerosis: A global data sharing initiative

Liesbet M Peeters¹, Tina Parciak, Clare Walton, Lotte Geys, Yves Moreau, Edward De Brouwer, Daniele Raimondi, Ashkan Pirmani², Tomas Kalincik, Gilles Edan, Steve Simpson-Yap³, Luc De Raedt, Yann Dauxais, Clément Gautrais⁴, Paulo R Rodrigues, Landon McKenna, Nikola Lazovski, Jan Hillert, Lars Forsberg, Tim Spelman⁵, Robert McBurney, Hollie Schmidt, Arnfin Bergmann, Stefan Braune, Alexander Stahmann, Rodden Middleton⁶, Amber Salter⁷, Bruce F Bebo, Juan I Rojas, Anneke van der Walt⁸, Helmut Butzkueven, Ingrid van der Mei, Rumen Ivanov, Kerstin Hellwig, Guilherme Sciascia do Olival, Jeffrey A Cohen⁹, Wim Van Hecke, Ruth Dobson¹⁰, Melinda Magyari, Doralina Guimarães Brum, Ricardo Alonso, Richard Nicholas, Johana Bauer, Anibal Chertcoff, Jérôme de Sèze, Céline Louapre, Giancarlo Comi and Nick Rijke

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MSDA ACADEMY

Raise **awareness** about the importance of research using real-world MS data

Build a multi-stakeholder MS data **community**

Promote **trustworthy and transparent** practices in the use of real-world MS data

MSDA TOOLBOX

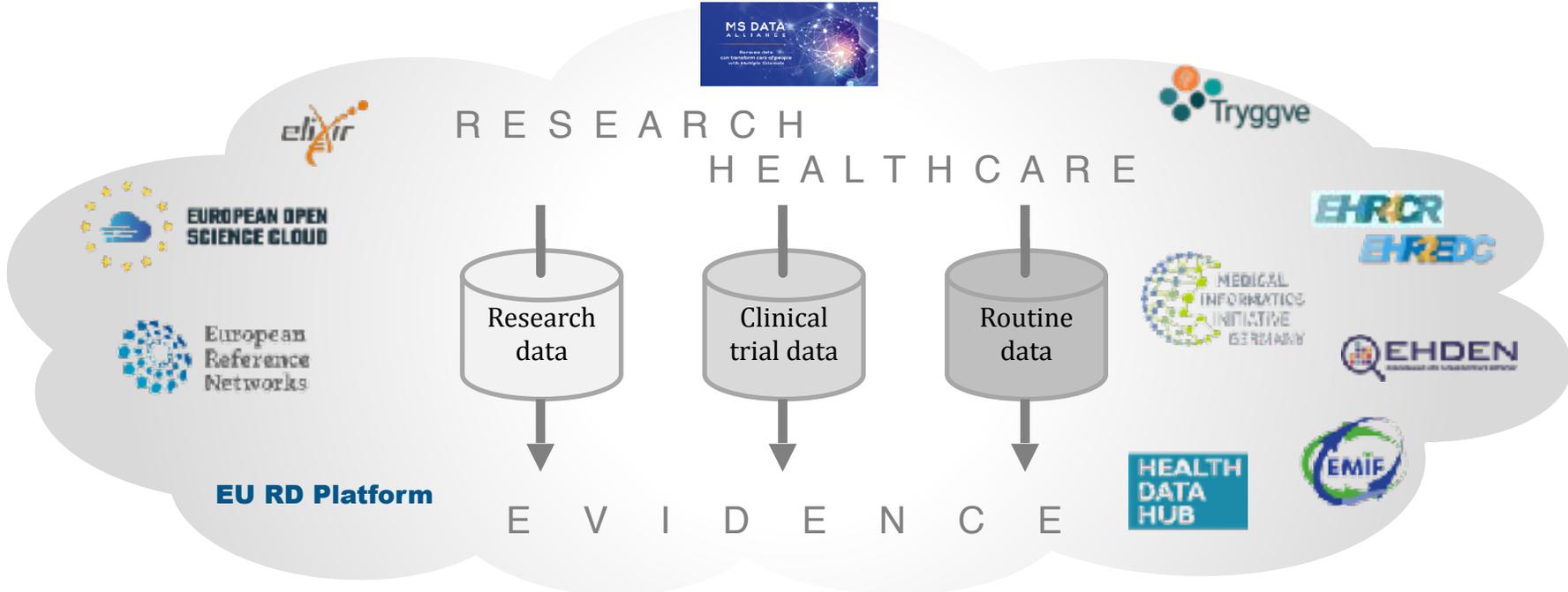
Cataloguing and publishing descriptions of data sources

Develop a standardised MS **data dictionary** and support local harmonisation efforts

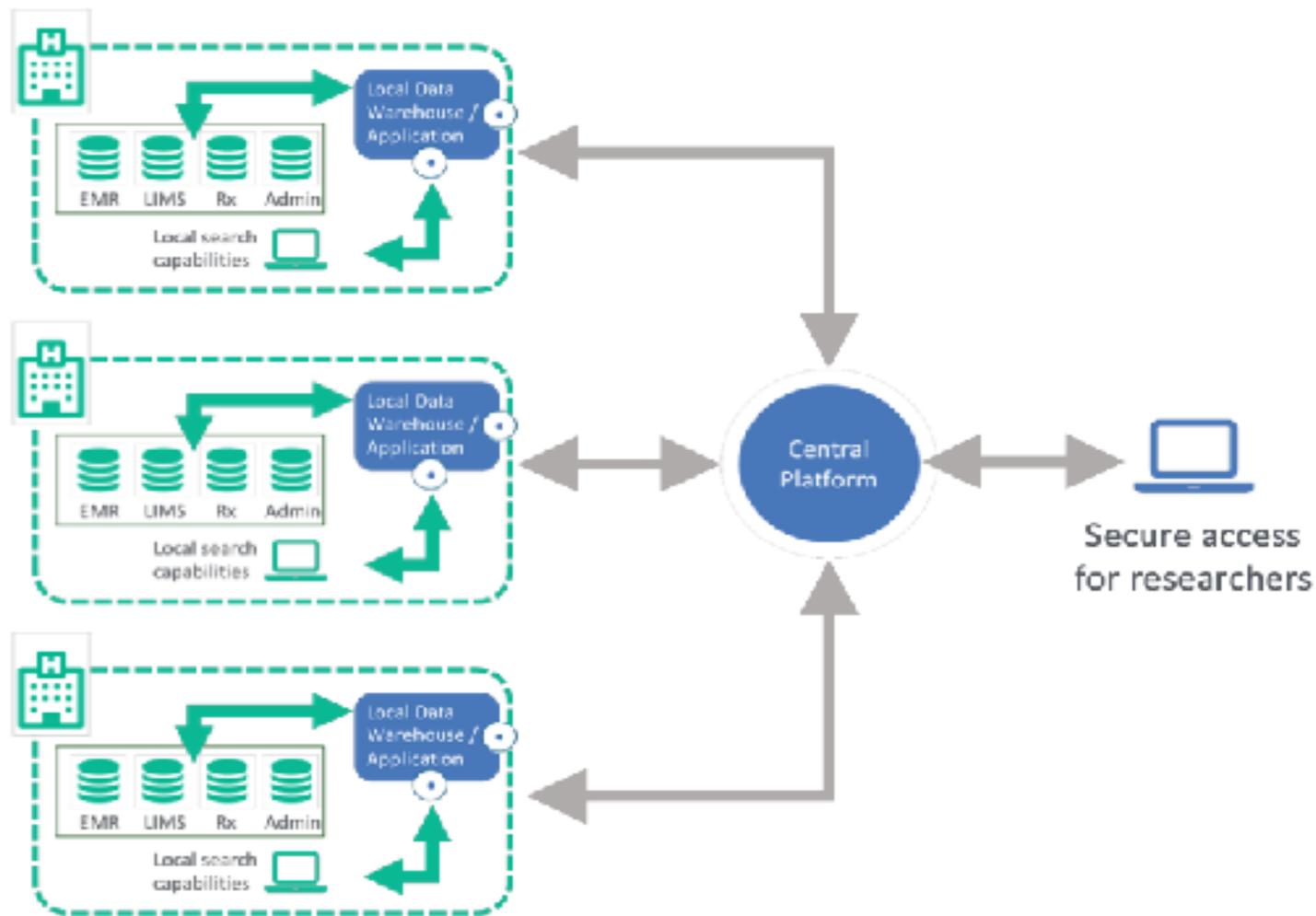
Develop a **federated data network** to allow group level queries on **harmonised datasets**

Big health data sharing initiatives

- Myriad of initiatives to share health data across jurisdictional, institutional and domain borders:
 - Sharing data for cross-border care or for research
- Emerging paradigm for analysing personally-identifiable health data:
 - federated infrastructure model: network of repositories with an overarching governance and interoperability layer

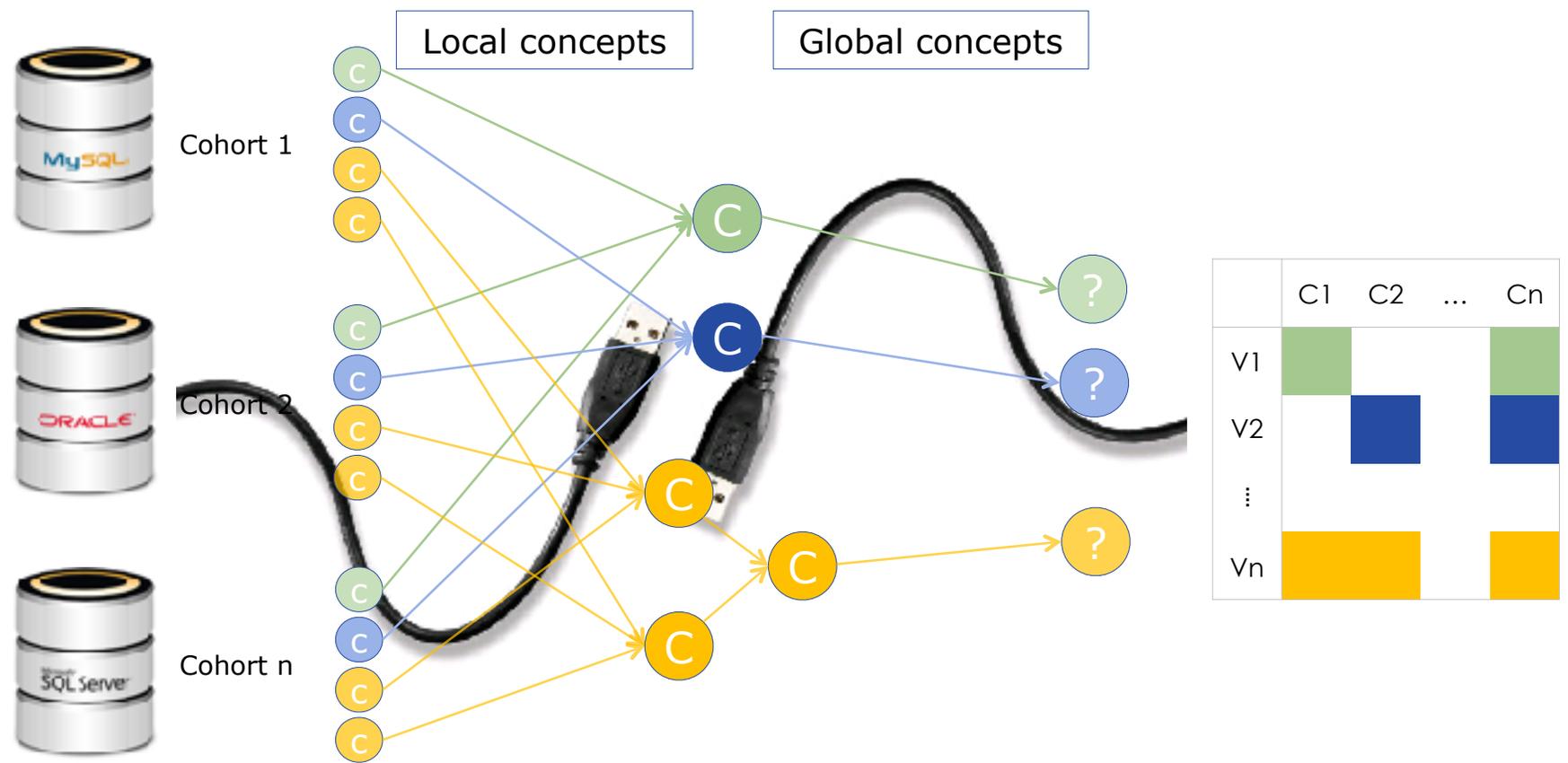


European Health Data & Evidence Network (EHDEN)



Benefits of federated networks

- Data remains under the control of the data owner
- Locally required legal and ethical approvals apply
- No patient level data leaves the owner's site, only aggregated counts, thereby ensuring patient privacy
- GDPR – *'Privacy by Design'*
- Analysis is "brought to the data" rather than creating central data repository
- Use of common data model allows for efficient search / analysis across multiple data sets
- Requires close collaboration with data owners which builds trust



Data custodians

- Identify local concepts
- Specify mappings
- Define security

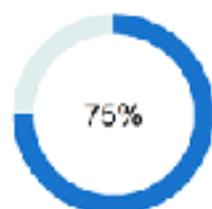
Community

- Specify global and derived concepts
- Define research groups

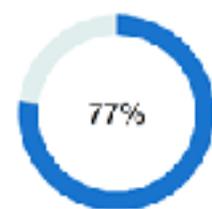
Common
Data
Models

Standardised
Clinical
Models

Completeness



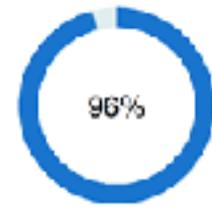
Consistency



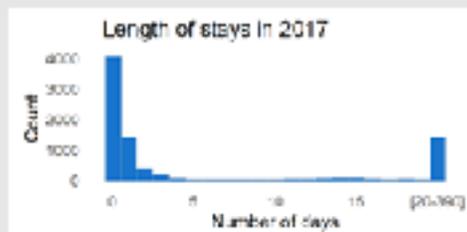
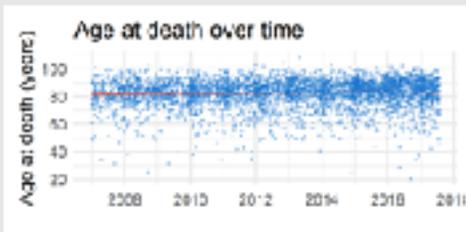
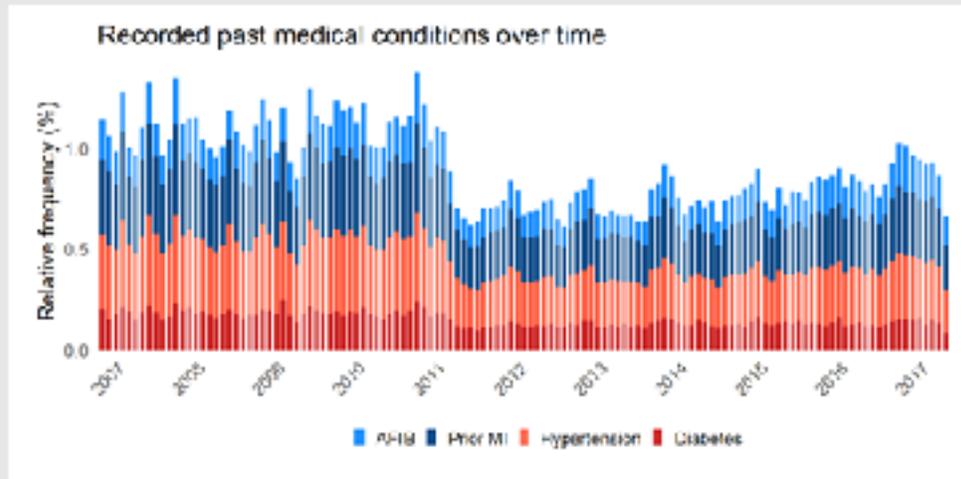
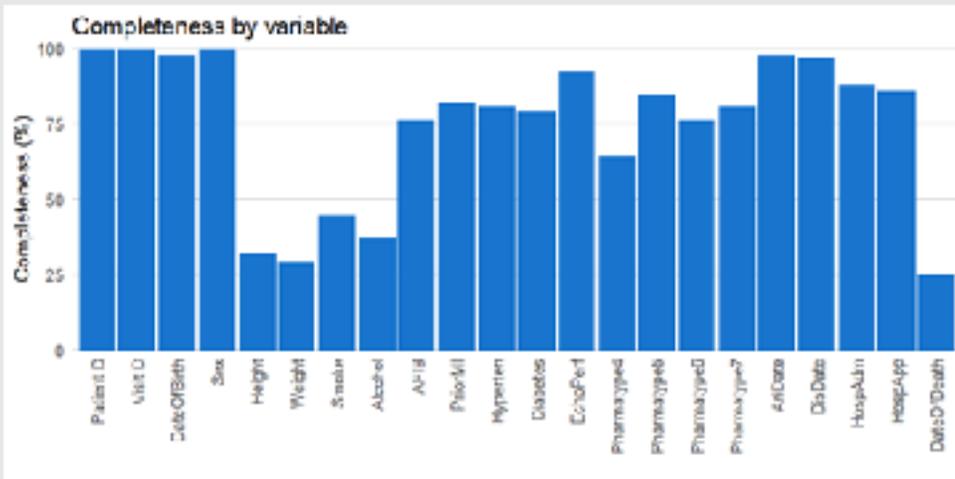
Correctness



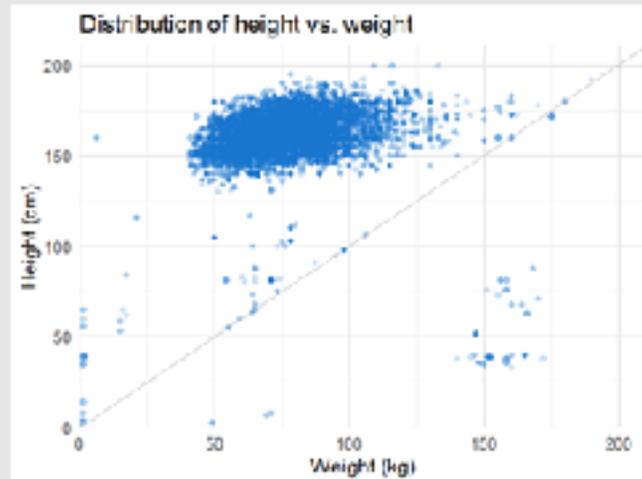
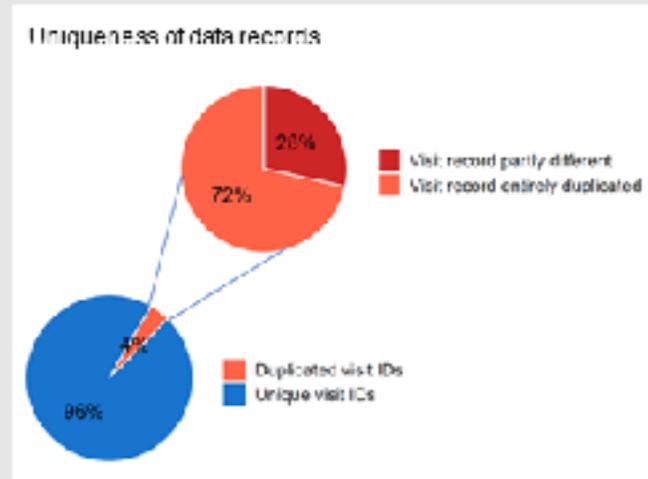
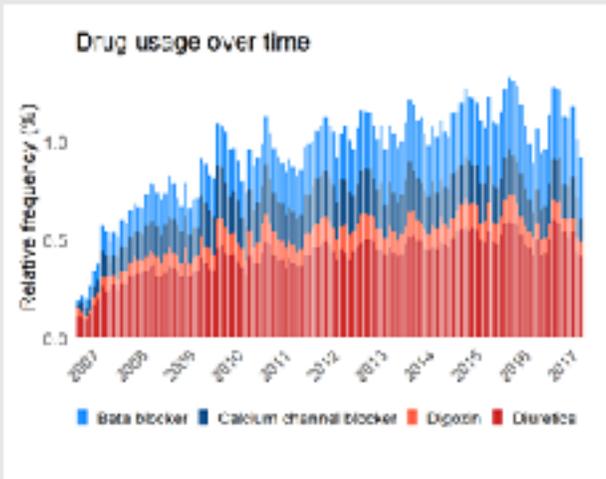
Uniqueness



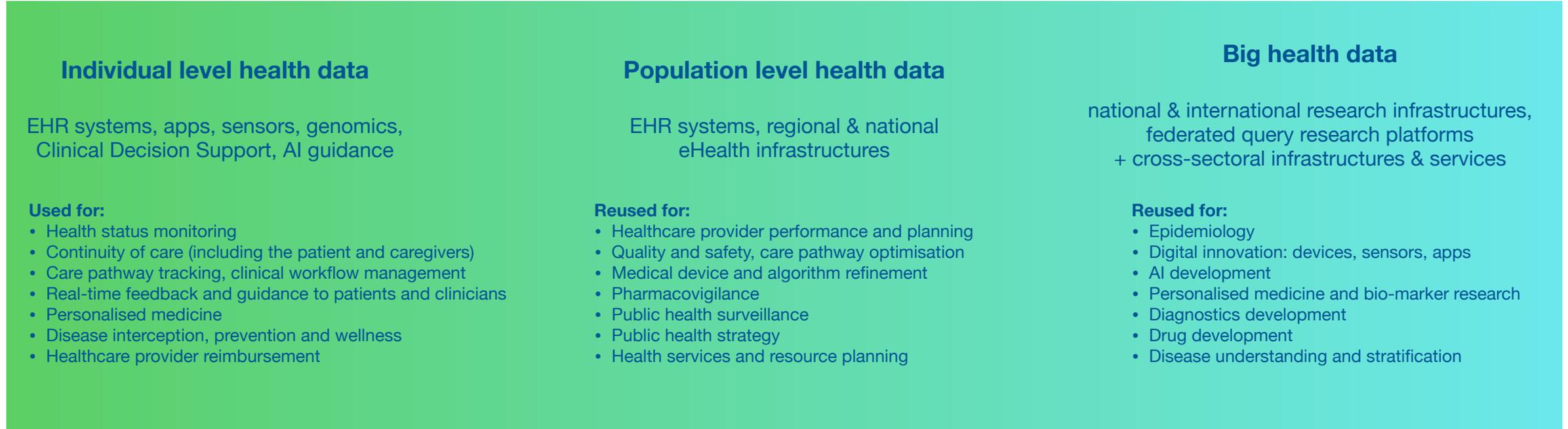
Stability



The European Institute for Innovation through Health Data 



The challenge with gaining public acceptance of health data reuse



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

PUBLIC OPINION IN THE EU

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

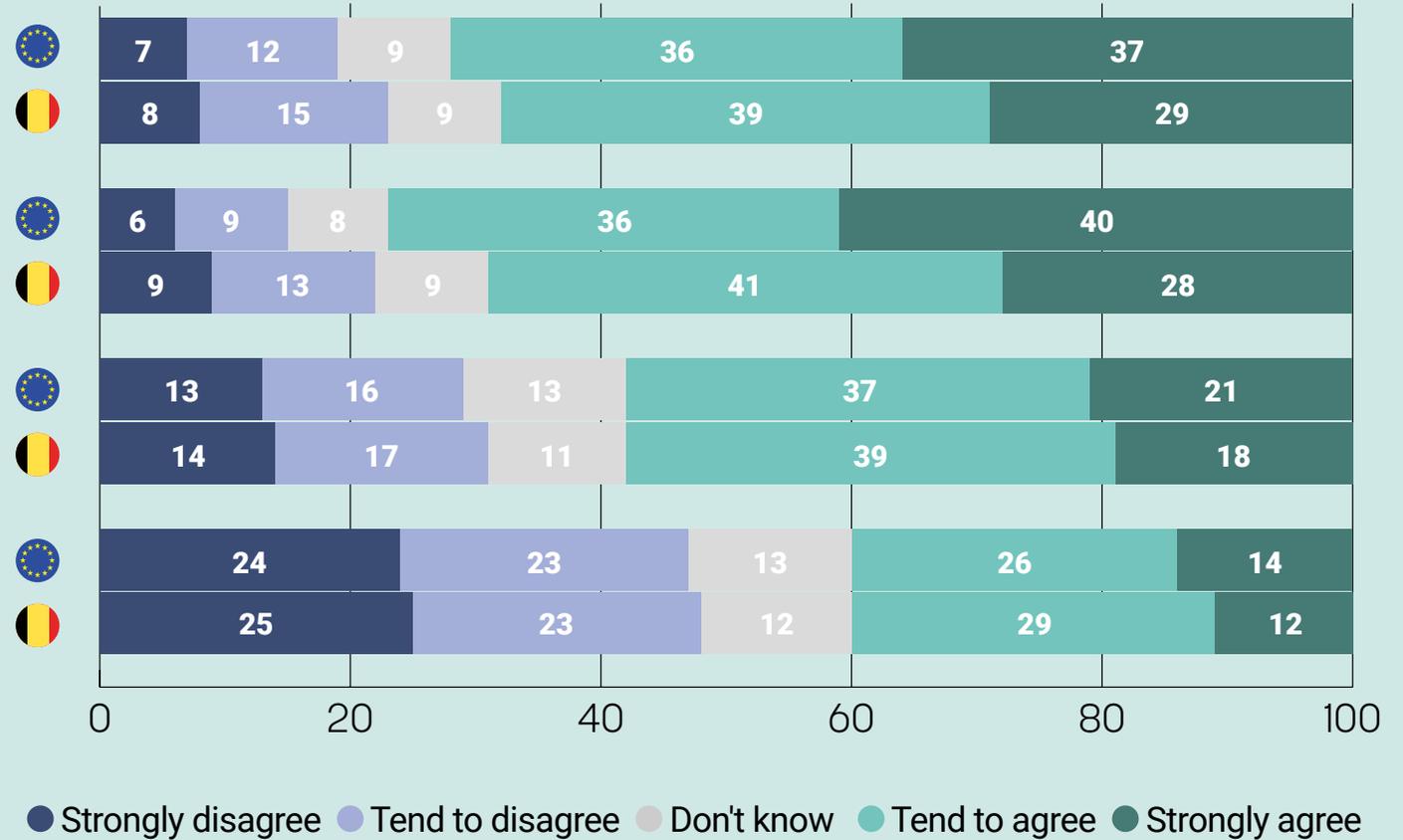
I'm willing to share my genetic information with my family

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

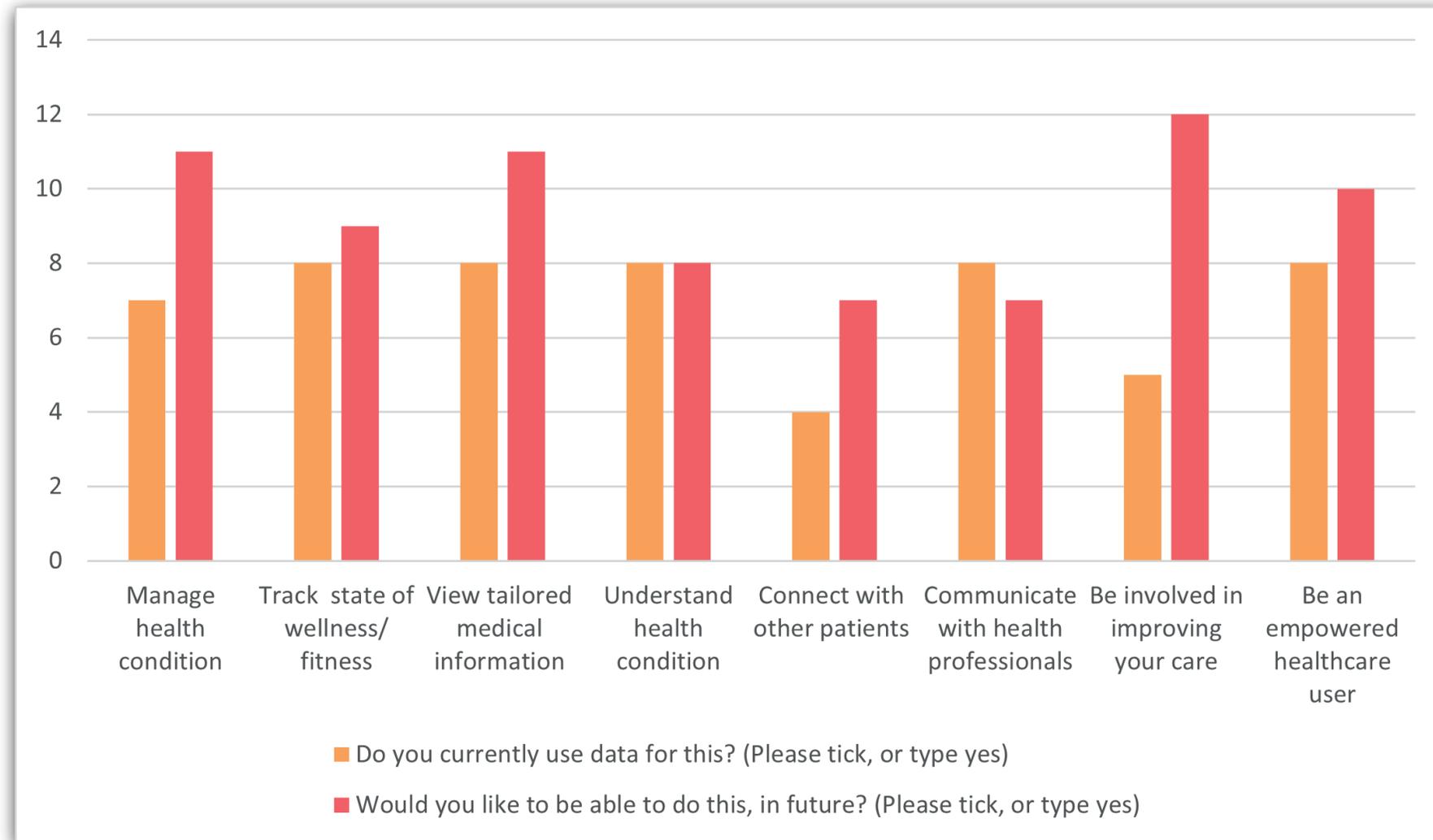
I'm willing to share my genetic information with pharmaceutical companies

n= 28,782

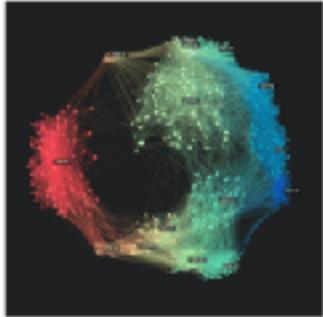
Weighted to be representative of the adult EU population



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



iHD 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

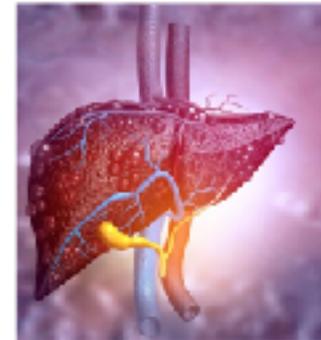
[Learn more](#)



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](#)

How do we reach societal acceptability?

- Data protection regulations prioritise the **rights of the individual** to privacy
- Clinical research can bring important benefits **to society**
- Many surveys indicate **patients are in favour** of their data being re-used for research
 - But the GDPR hype sometimes breeds fear (public, DPOs, CEOs...)
- The public need **greater transparency** about why and how health data are used, safeguarded, and the benefits of that use

We need to find the right balance between the rights of the individual and the benefits for society