



Prof. Dipak Kalra

**President of The European Institute for
Innovation through Health Data**


Welcome by the workshop chair

The importance of good EHRs for Learning Health
Systems





Patients
Health Care
Hospital
Physician
Clinical Research
Service Providers



The European Institute For
Innovation Through Health Data

THE IMPORTANCE OF GOOD EHR'S FOR LEARNING HEALTH SYSTEMS

Prof Dipak Kalra
President of i~HD

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EFPIA Executive Director for Strategy and
Healthcare Systems

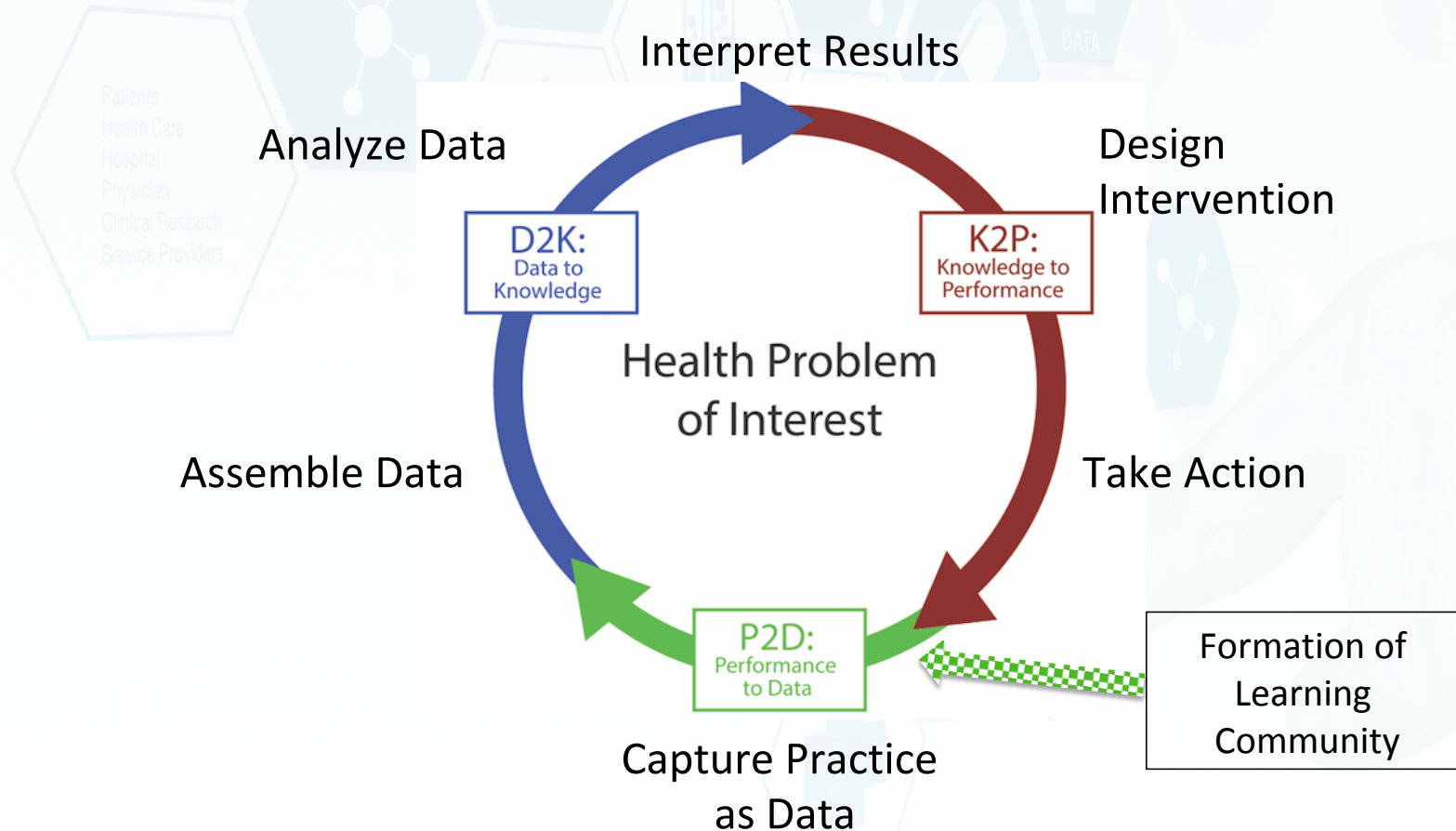
Health Care
Doctor
Hospital
Pharmacist
Nurse
Dentist
First Aid
Surgeon
Emergency

HEALTH

DATA

EAHM Congress, Ghent
13th September 2019

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

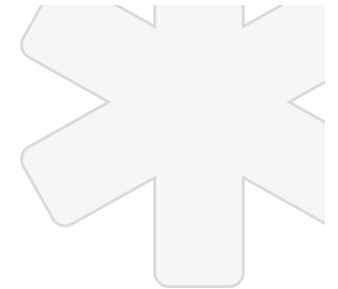


The Learning Health System: Going global

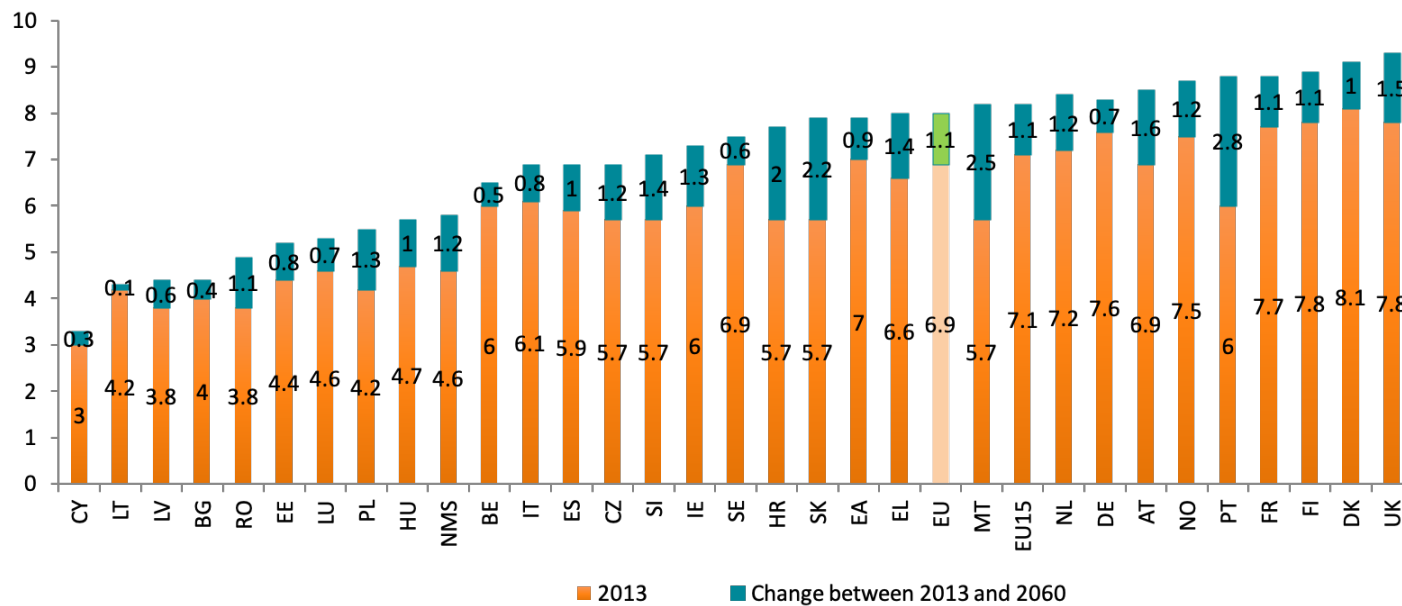
- Initiatives at Varying Scales
 - Single Organisations
 - Networks
 - Regional
 - National
 - International



Population ageing creates sustainability challenge for EU health systems



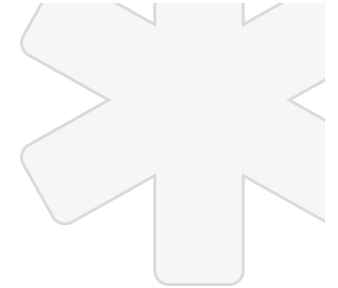
Projected increase in public expenditure in healthcare due to demographic change (2013-2060) (% of GDP)



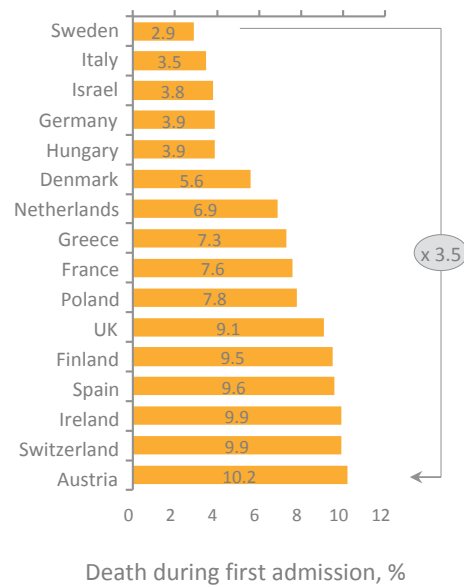
NOTE: FOR THE EU, NMS (NEW MEMBER STATES) AND THE EA (EURO AREA) THE AVERAGE ARE WEIGHTED ACCORDING TO GDP. EUROPEAN COMMISSION (2015). THE AGEING REPORT.

Slide courtesy of Thomas Allvin, EFPIA

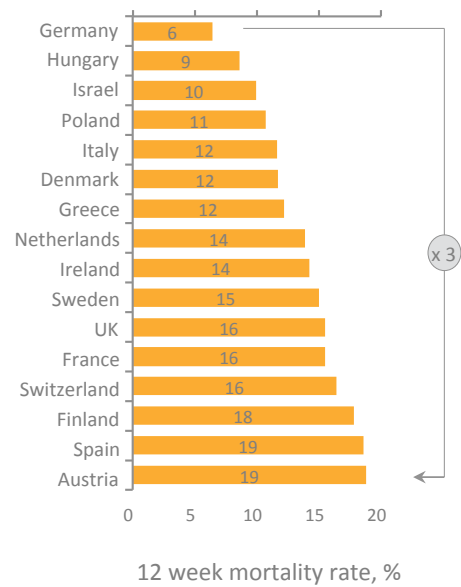
Variation of heart failure outcomes across European countries



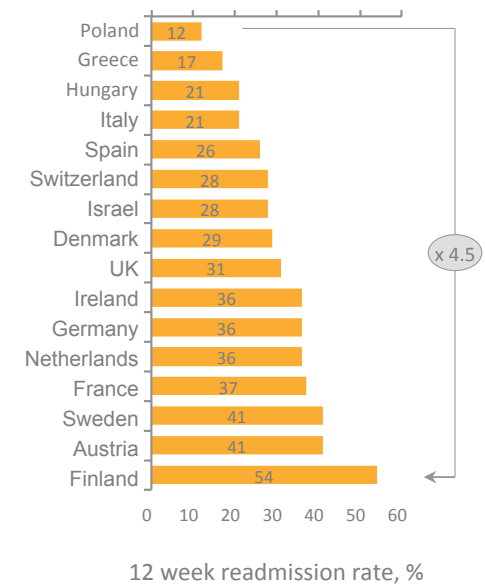
> 3x variation in death during first HF admission



3x variation in 12 week mortality rate for HF



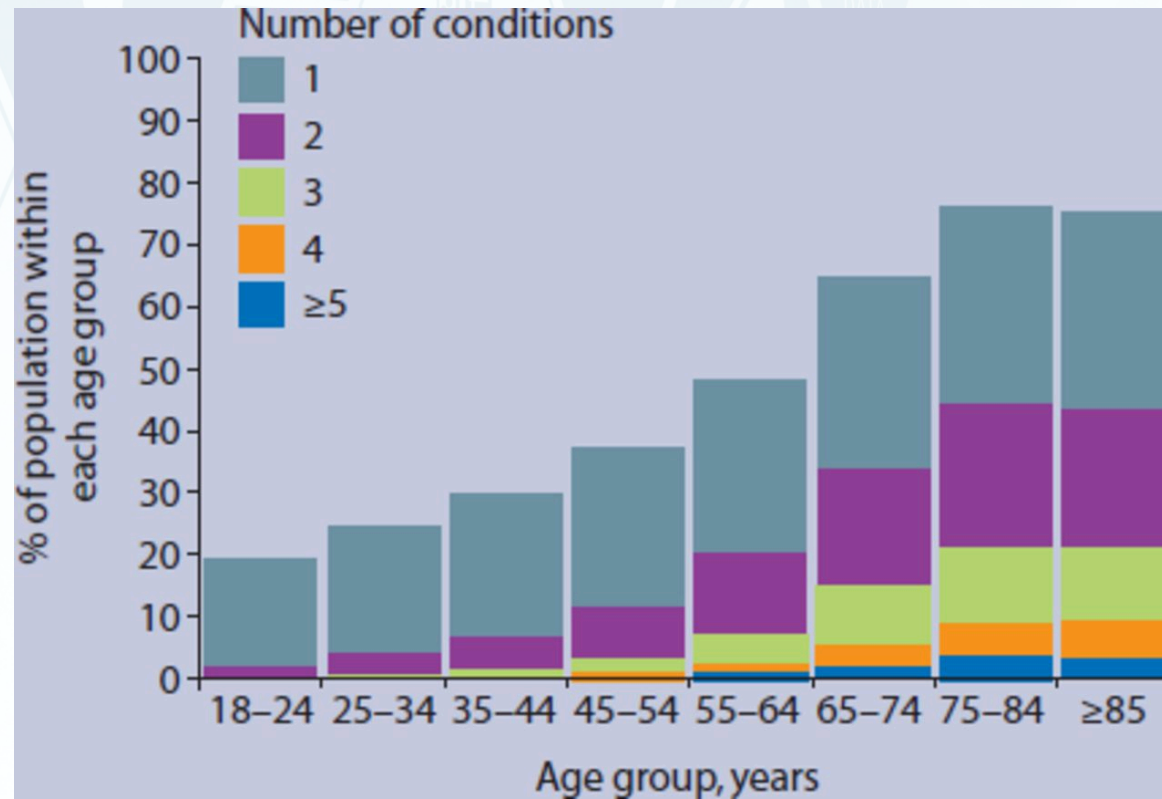
>4x variation in 12 week readmission rate for HF



Slide courtesy of Thomas Alvin, EFPIA

Multi-morbidity: the scale of the challenge

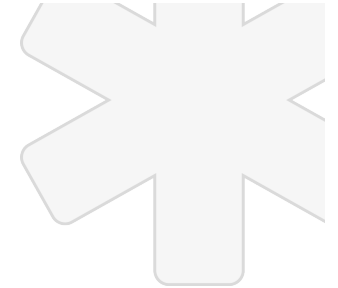
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Chris Salisbury, Leigh Johnson, Sarah Purdy, Jose M Valderas and Alan A Montgomery
Br J Gen Pract 2011; 61 (582): e12-e21

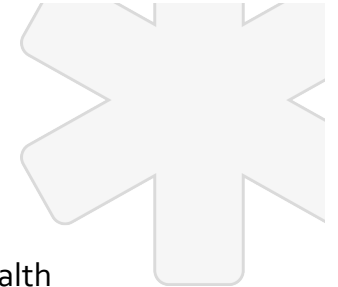
Estimated 20 – 40 % waste in health systems

- According to a WHO report from 2010, on average 27% of healthcare expenditure is wasted
- There are several sources of waste, but **half** of the total waste is estimated to be due to **practice variation** and use of low-value interventions
- A recent OECD report concludes that around one fifth of healthcare expenditure could be channeled towards better use



Slide courtesy of Thomas Alvin, EFPIA

Value-Based Health Care (VBHC) is helping shift focus from volume of services to value created for patients



Source: "What is Value in Health Care" (Michael Porter, New England Journal of Medicine, 2010)

- The fundamental **goal and purpose** of health care is **to improve value for patients**

$$\text{Value} = \frac{\text{Health outcomes that matter to patients}}{\text{Costs of delivering these outcomes}}$$

- Value is the only goal that can **unite the interests** of all system participants
- Value is created in caring for a patient's **medical condition** over the **full cycle of care**



The most powerful single lever for reducing cost and improving value is improving outcomes

Source: ICHOM 2019

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By learning from its data...

- ...Kaiser Permanente is able to track outcomes and develop data driven algorithms embedded within its EHR systems, to achieve:
 - HIV death rate half of national average
 - Decrease in coronary heart disease death rate by a third
 - Decrease in pressure ulcers by two thirds
 - Death due to sepsis reduced by > 50%

The LHS ambitions of many European hospitals

- Shift the focus of performance and reward from activities to outcomes
- Optimise care pathways to maximise health care whilst making best use of resources
- Respond to payer and public demands for more integrated and person centred care
- Implement continuous learning and improvement cycles
- Enhance their clinical capability to undertake research, for reputation and business reasons
- Collaborate across hospital networks, and across Europe, to share good practice and support each other with improvement

Good EHR and reusable data is a critical success factor



The European Institute for Innovation through Health Data (i~HD)


was created as an outcome of European R&D projects, to address needs confirmed by multiple healthcare and research stakeholders

Developing solutions for improving health data and its trustworthy use

Enriching knowledge and enhancing care through health data

i~HD is registered in Belgium as a not-for-profit organisation

It is financed by membership fees,
by providing services e.g. data quality, certification and governance
and through funded projects



i~HD targets a convergence of opportunity from health data

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Clinical Research

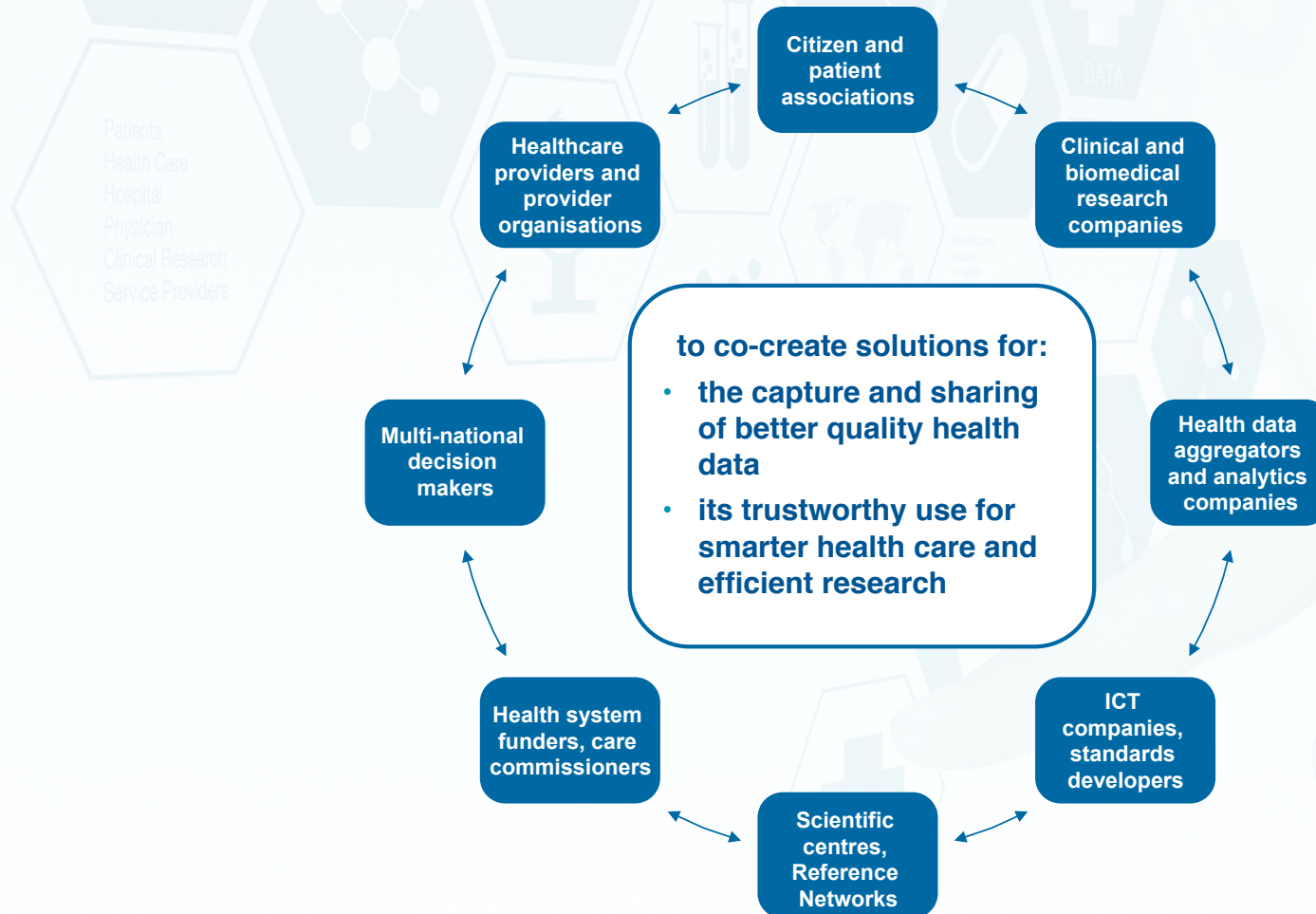
- Conduct faster, more efficient, clinical research
- Demonstrate the benefit from innovative products
- Create better Real World Evidence
- Generate new evidence for precision medicine and value based models

Healthcare

- Improve quality, safety and connectedness of care
- Empower patients in self-care and health maintenance
- Use outcomes to improve services
- Have better evidence for public health strategies

Need to collaborate to improve access to combined health data from multiple sources

i~HD is a neutral body, bringing stakeholders together



Issues that hospitals have raised with us

- Limited reuse of their EHR data at present
- Poor EHR data quality, difficulties in improving it
- Concerns about data protection, especially with the GDPR
- Often working to locally-defined outcomes, so impossible to compare or collaborate with other hospitals
- Limited capacity to measure patient reported outcomes

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**A community of hospitals
sharing their learning and innovations
with EHR data
for clinical research & learning health systems.**

Good practice demonstrating value

Communities co-operating and working synergistically

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The i~HD Information Governance Task Force is
engaging across stakeholders
to promote codes of good practice
for privacy protection, security & ethics
when
using data for healthcare and clinical research

Creating a trustworthy environment

i~HD information governance initiatives

GDPR

IMI code of practice on secondary use of medical data in scientific research projects, and other codes

Principles and Standard Operating Rules

Educate and train research and ICT staff

Certify research platforms and EHR systems

Promote consistent practices across Europe



Patient
Health
Hospit
Physic
Clinic
Servic

i~HD

GDPR Tutorial

FOR HEALTH DATA
DRIVEN INNOVATION

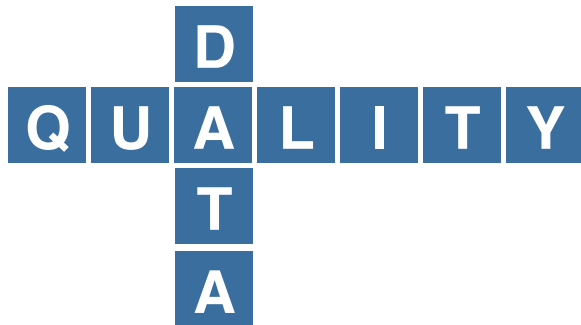
GDPR & health data challenges

- 1 Which **legal basis** is best suited to different scenarios of reusing health data for research?
- 2 Who are the **data controllers, joint controllers** and **processors** in a federated big data & analytics ecosystem?
- 3 What safeguards would be adequate for **accountability & security**?
- 4 How can **rights** - especially to erasure & portability - be upheld in the health data innovation space?
- 5 How can we be meaningfully **transparent** with patients & the public about **health data reuse** for research?

i~HD Quality Seal for Research Platforms



- This Seal provides assurance to healthcare organisations, research centres and research sponsors, that ICT products and services used for research using EHRs do so in secure ways that protect data privacy, including GDPR compliance
- Service providers of clinical research platforms can apply for this Seal
- We hope in the future that hospitals and other organisations will insist on only connecting to platforms with this Seal

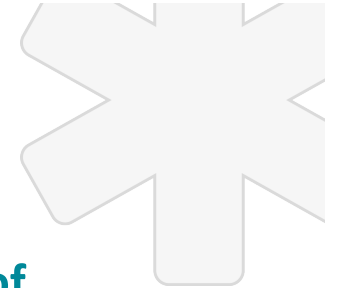


**Assessment methods to improve data quality,
promoting the importance of data quality,
scaling this up across Europe**

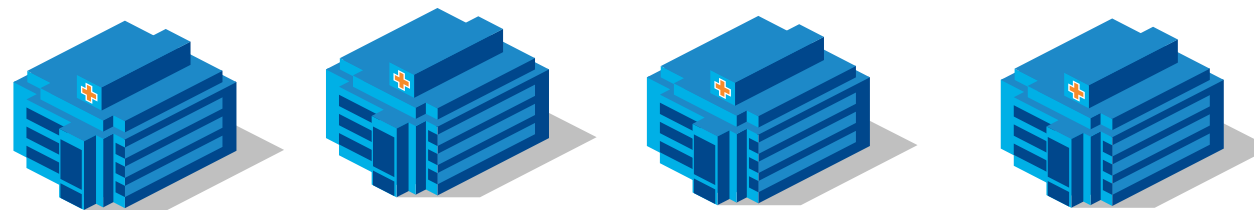
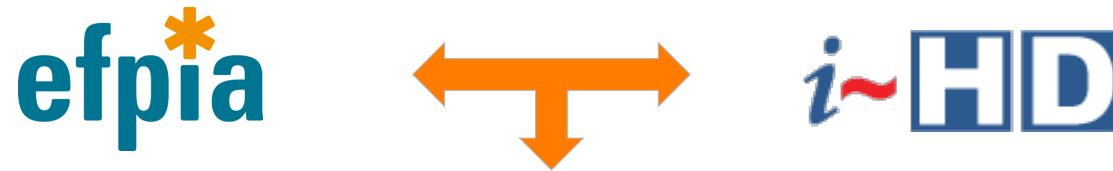
**to enable the best quality data
for learning health systems
& clinical research**

Having great data to use & making great use of data

Do European healthcare providers have the right data for value-based healthcare?

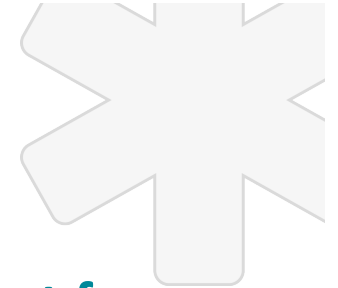


EFPIA is working with i-HD to assess the data readiness in a number of European hospitals, using the ICHOM standard set for Heart Failure



Slide courtesy of Thomas Alvin, EFPIA

Key components of project



- **Agree the ICHOM heart failure indicators that are most relevant for an outcomes-based approach.**
- **Re-formulate the indicators as EHR variables**
- **Compile a list of approximately ten hospitals and confirm willingness to participate via a collaboration agreement, with assurance about data protection and GDPR compliance**
- **Conduct data item assessment and data quality assessment**
- **Draw overall conclusions including common areas for improvement**

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Datasaveslives.eu