



EUROPEAN COLLABORATION FOR HEALTHCARE OPTIMIZATION

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HEALTHCARE OPTIMIZATION

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# Improving data collection and information channels to support performance improvement

Insights from the ECHO Project

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# KNOWLEDGE TRANSITION



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Incremental data growth  
Quasi-static information  
Fragmented data



Exponential data growth  
Constant data production  
Integrated data





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From DATA to KNOWLEDGE



THE BIG CHALLENGE

MAKING SENSE OUT OF DATA  
TO IMPROVE HEALTH SYSTEMS



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# RESEARCH INITIATIVES IN EUROPE AIMING THE TRANSITION



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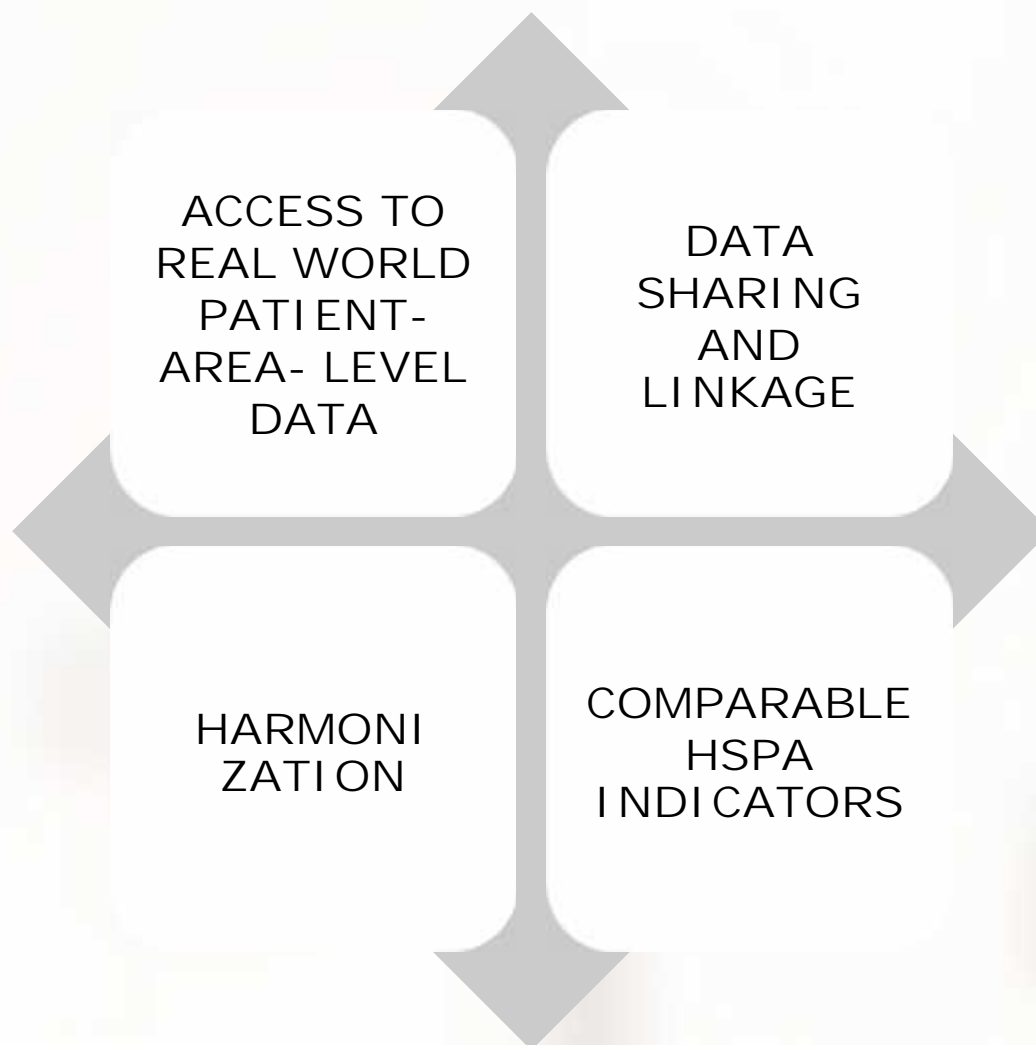
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Demonstration project aimed at eliciting unwarranted variations in health systems value

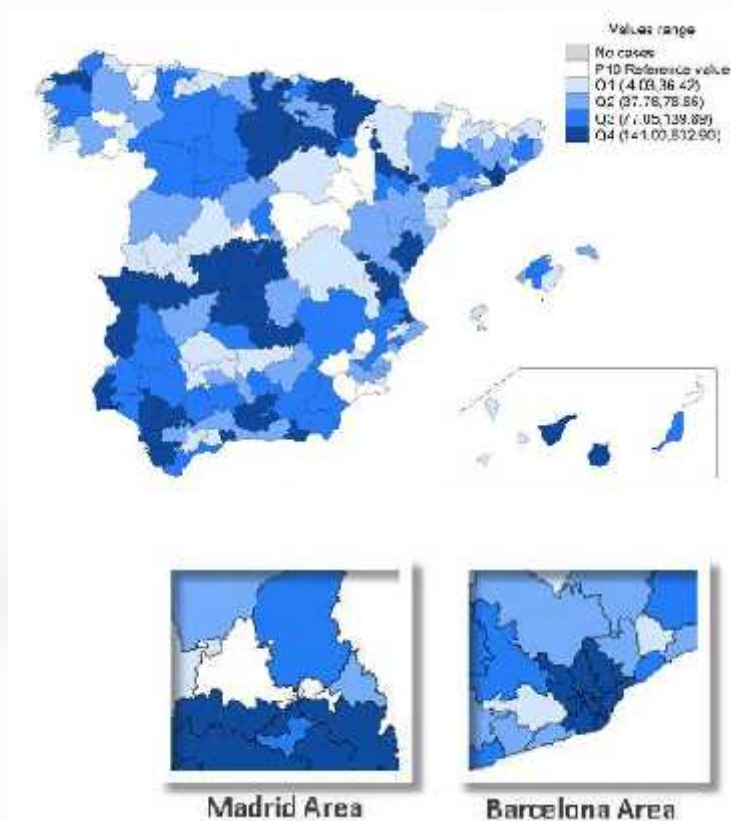
<http://www.echo-health.eu/>

## DATA CHALLENGES ADDRESSED IN ECHO

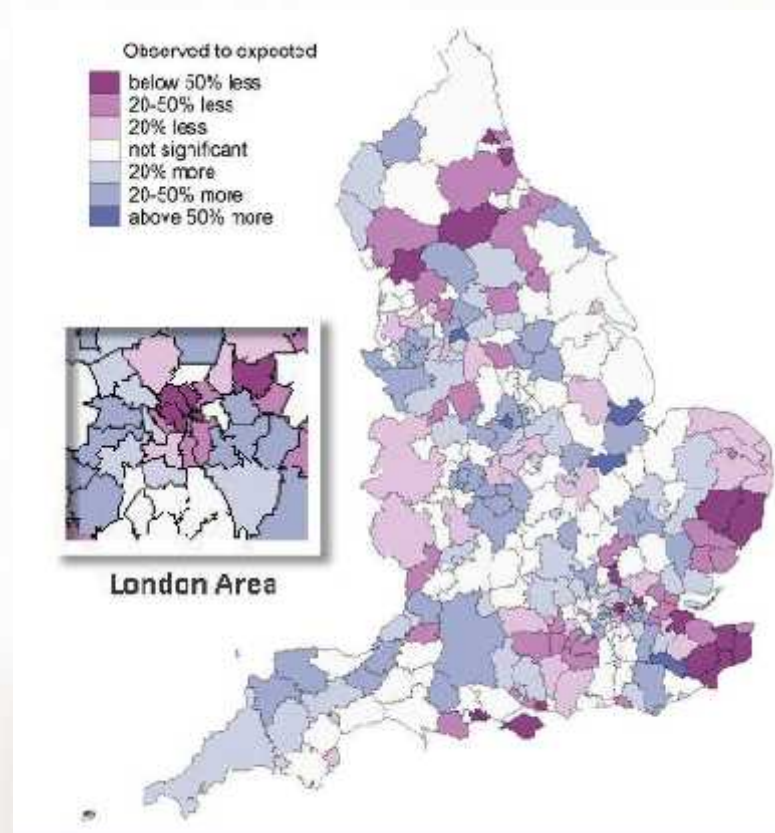




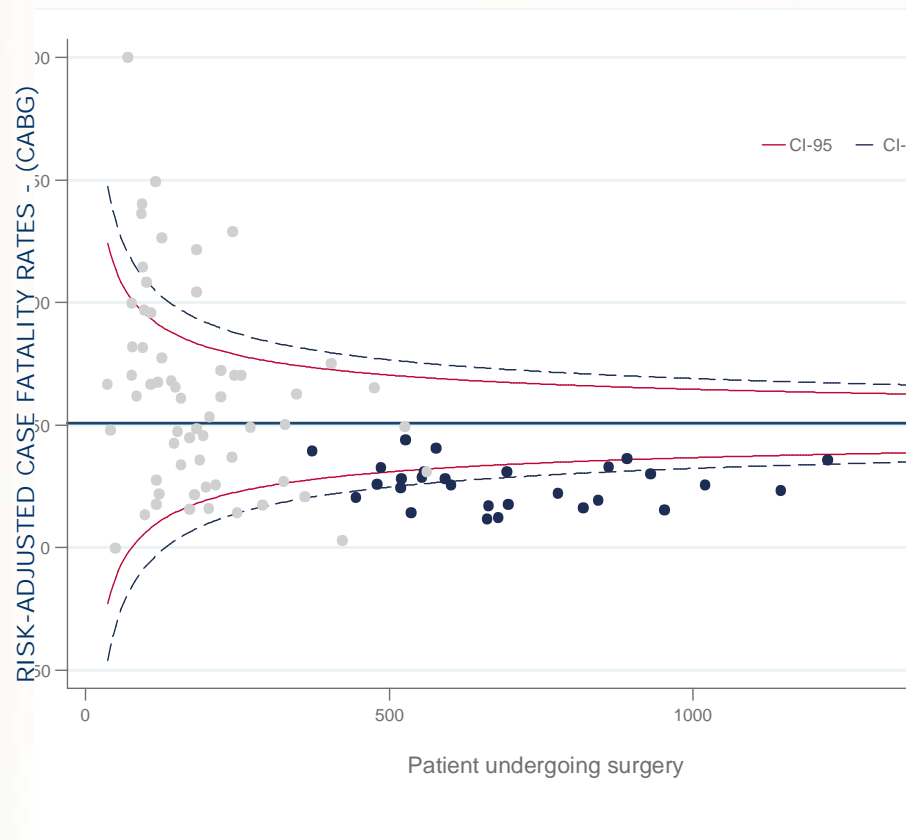
Essentially ineffective care  
[Tonsillectomy in children]



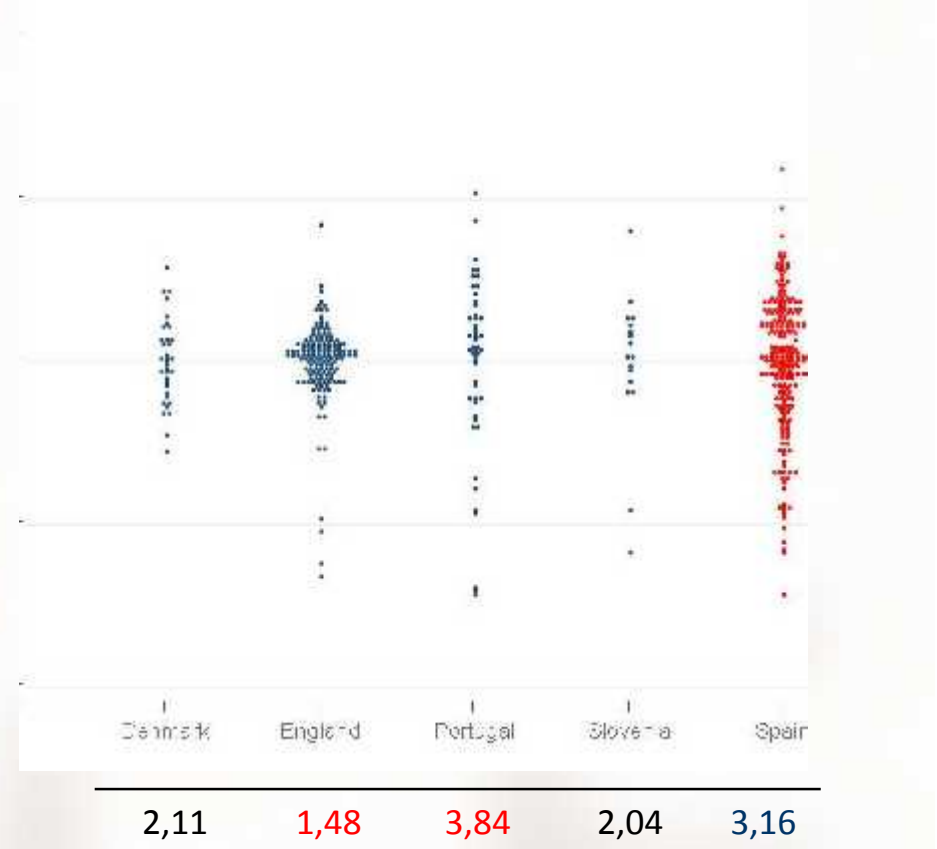
Effective surgery in non-eligible patients  
[C-section in low risk deliveries]



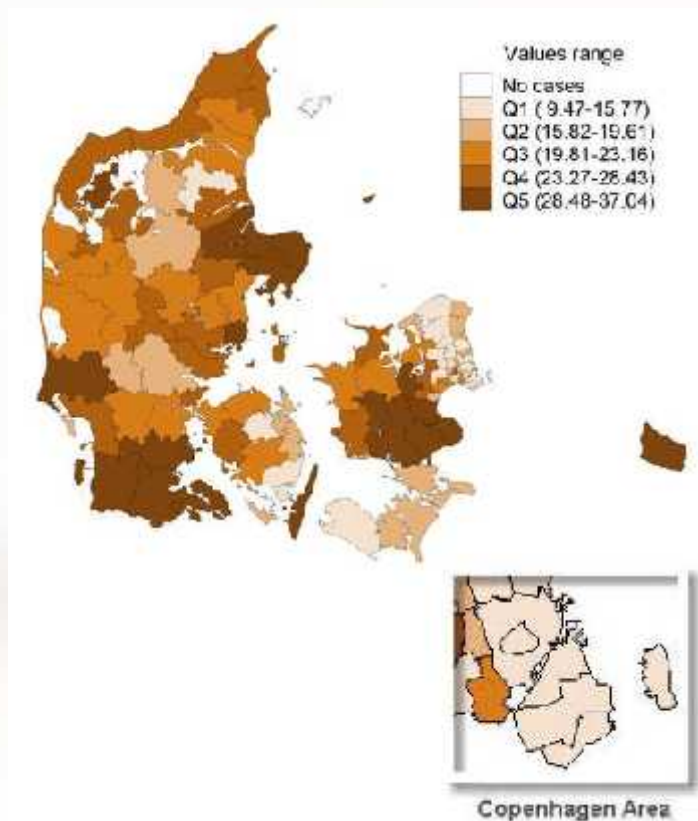
## Low quality care [Mortality after CABG]



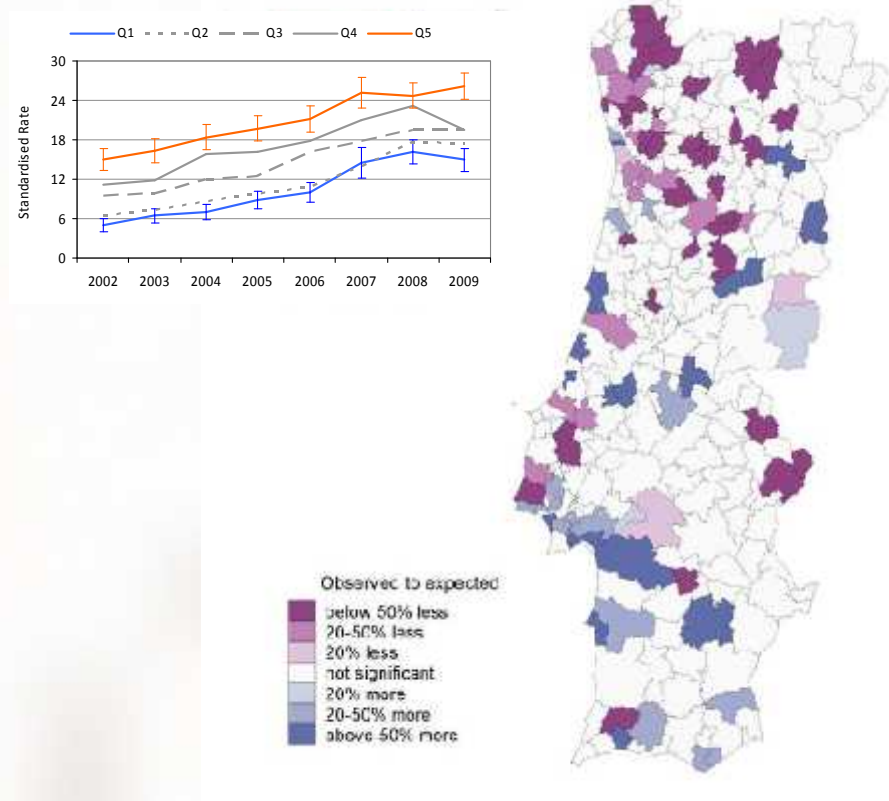
## Unsafe care [PTE & DVT after surgery]



## Interventions with a more cost-effective alternative [Hysterectomy in benign conditions]



## Underuse of effective care [PCI in low-income areas]







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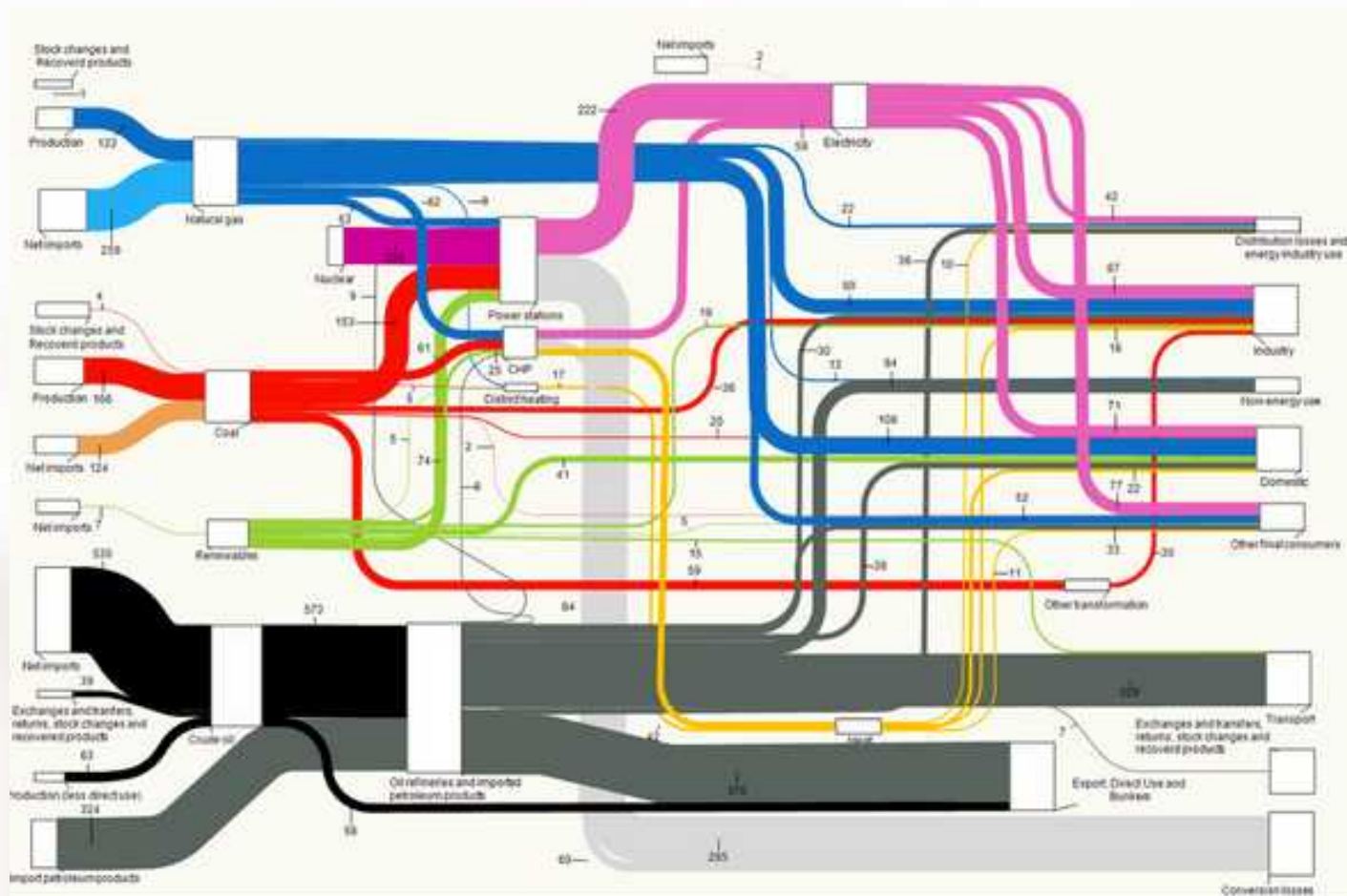
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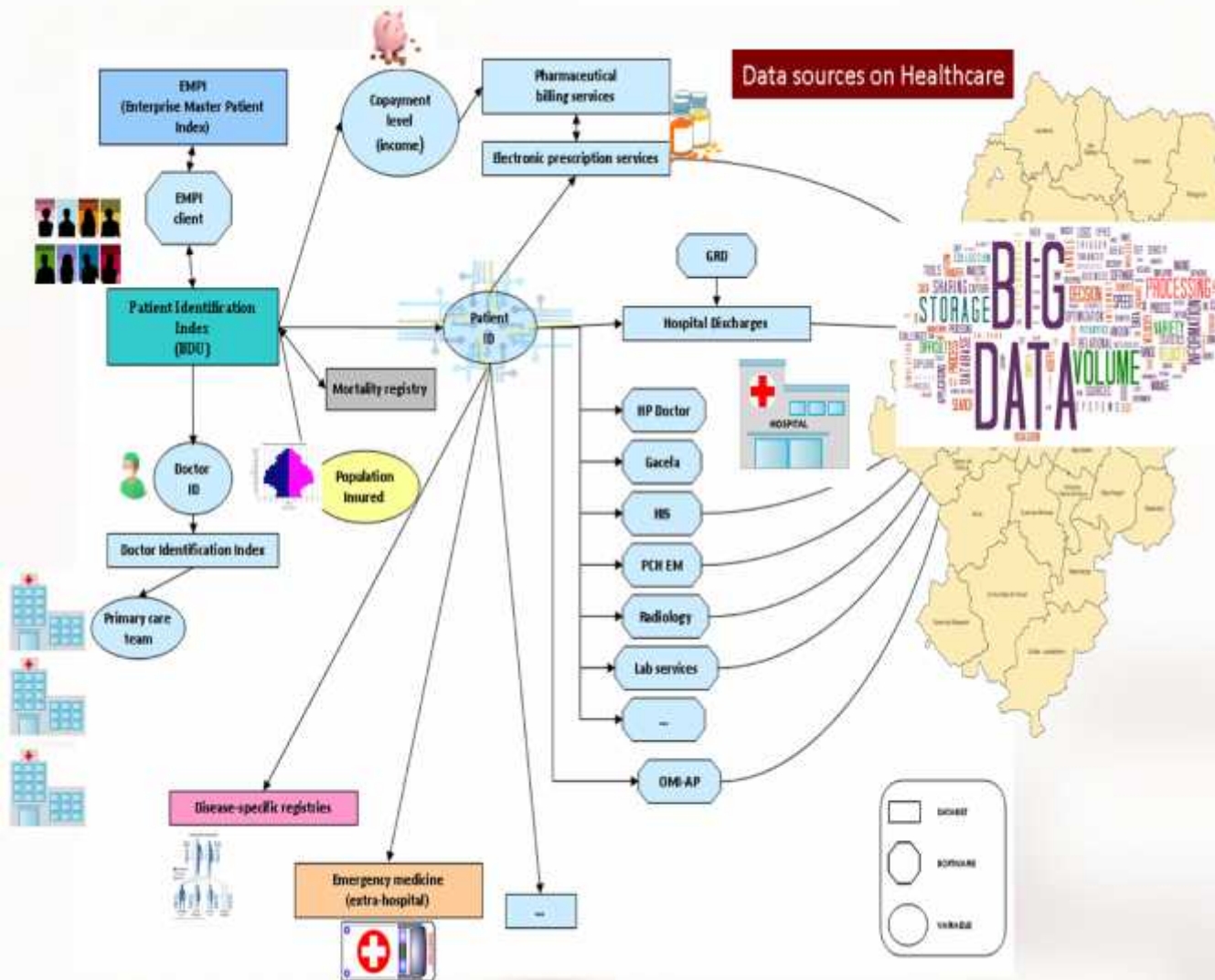
THIS IS A BIG JUMP,  
ALTHOUGH NOT ENOUGH



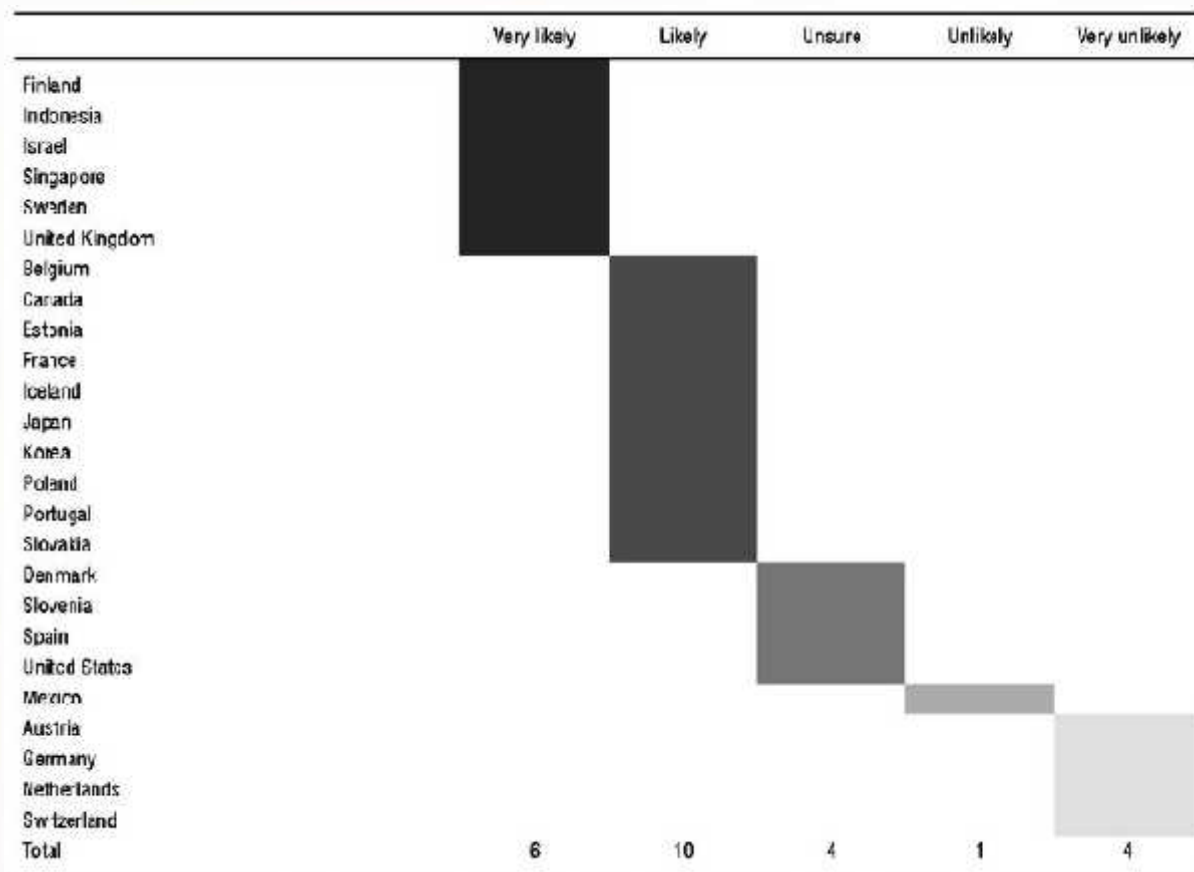
# HEALTH SYSTEMS IMPROVEMENT REQUIRES TIMELY, MEANINGFUL AND PRONE-TO-ACTION INFORMATION



# EHR



## How likely is it that EHR will be used for National Health Care Quality Monitoring in the next five years?







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THE EU LANDSCAPE









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## WORKSHOP ON BIG DATA – DG RESEARCH AND INNOVATION

BBMRI ERIC, BLUEPHINT (A Blueprint of Haematopoietic Epigenomes, FP7-n°282510), BRIDGEHealth (BRidging Information and Data Generation for Evidence-based Health policy and research, H2020-n°664691), CANCER-ID (Cancer treatment and monitoring through identification of circulating tumour cells and tumour related nucleic acids in blood FP7-n°115749), CASyM (Coordinating Action Systems Medicine–Implementation of Systems Medicine across Europe, FP7-n°305033), COMBIMS (A novel drug discovery method based on systems biology: combination therapy and biomarkers for Multiple Sclerosis, FP7-n°305397), DECIPHER PCP (Distributed European Community Individual Patient Healthcare Electronic Record, FP7-n°288028), ECHO (European Collaboration for Healthcare Optimization, FP7-n°242189), ELIXIR (European Life-science Infrastructure for Biological Information, FP7-n°211601), EMIF (European Medical Information Framework, IMI-n°115372), EpiGeneSys (Epigenetics towards systems biology, FP7- n°257082), ERA-IB (ERA-Net for Industrial Biotechnology 2, FP7-n°291814), ERASynBio (Development and Coordination of Synthetic Biology in the European Research Area, FP7-n°291728), ERASysAPP (Systems Biology Applications, FP7-n°321567), ESGI (European Sequencing and Genotyping Infrastructure, FP7-n°262055), eTRIKS (Delivering European Translational Information & Knowledge Management Services, IMI-n°115446), EU-MASCARA, EUROBIOFORUM, European Lung Foundation, IDeAI (Integrated Design and Analysis of small population trials, FP7-n°602552), KConnect (H2020-n°644753), MedBioinformatics (Creating medically-driven integrative bioinformatics applications focused on oncology, CNS disorders and their comorbidities, H2020-n°634143), MeDALL (Mechanisms of the Development of ALLergy, FP7-n°261357), MIMOmics (Methods for Integrated analysis of Multiple Omics datasets, FP7-n°305280), MULTIMOD (Multi-layer network modules to identify markers for personalized medication in complex diseases, FP7- n°223367), IMI ND4BB TRANSLOCATION (New Drugs 4 Bad Bugs, IMI-n°115525), PARENT (PATient REGistries iNiTiative, CHAFAEA Project Grant n°2011 23 02), p-medicine (From data sharing and integration via VPH models to personalized medicine, FP7-n°270089), PREDEMICS (Preparedness, Prediction and Prevention of Emerging Zoonotic Viruses with Pandemic Potential using Multidisciplinary Approaches, FP7-n°278433), PREPARE (Platform for European Preparedness Against (Re-)emerging Epidemics, FP7-n°602525), READNA (Revolutionary Approaches and Devices for Nucleic Acid analysis, FP7-n°201418), CHAARM (Combined Highly Active Anti-retroviral Microbicides, FP7-n°242135), ProteomeXchange (International Data Exchange and Data Representation Standards for Proteomics, FP7-n°260558), PSIMEx (Proteomics Standards International Molecular Exchange–Systematic Capture of Published Molecular Interaction Data, FP7-n°223411), RADIANT (Rapid Development and Distribution of Statistical Tools for High-Throughput Sequencing Data FP7-n°305626), SEMCARE (Semantic Data Platform for Healthcare, FP7-n°611388), SPRINTT (Sarcopenia and Physical fRailty IN older people: multi-component Treatment strategies, IMI-n°115621), STATEGRA (User-driven Development of Statistical Methods for Experimental Planning, Data Gathering, and Integrative Analysis of Next Generation Sequencing, proteomics and Metabolomics data FP7-n°306000), SysCLAD (Systems prediction of Chronic Lung Allograft Dysfunction, FP7-n°354457), SYSMEDIBD (Systems

Auffray et al. *Genome Medicine* (2015) 8:7  
DOI 10.1186/s13073-015-0122-4

Genome Medicine

OPINION

Open Access

### Making sense of big data in health research: Towards an EU action plan



Charles Auffray<sup>1,2\*</sup>, Rudi Balling<sup>3\*</sup>, Inês Barros<sup>4</sup>, László Bencze<sup>5</sup>, Mikael Besson<sup>6</sup>, Jay Bergeron<sup>7</sup>,  
Enrique Bernal-Deigado<sup>8</sup>, Niklas Blomberg<sup>9</sup>, Christoph Bock<sup>10,11,12</sup>, Ana Conesa<sup>13,14</sup>, Susanna Del Signore<sup>15</sup>,  
Christophe Delogne<sup>16</sup>, Peter Devilee<sup>17</sup>, Alberto Di Meglio<sup>18</sup>, Marinus Eijkemans<sup>19</sup>, Paul Flicek<sup>20</sup>, Norbert Graf<sup>21</sup>

- Piloting the application of Big Data to inform on health
- Leverage the potential of open science for the exploitation of Big Data in health
- Harmonize regulatory frameworks for health-related research and data sharing
- Development of research infrastructures
- Rapid transition to new computational and/or mathematical methods
- Involvement of relevant stakeholders in projects



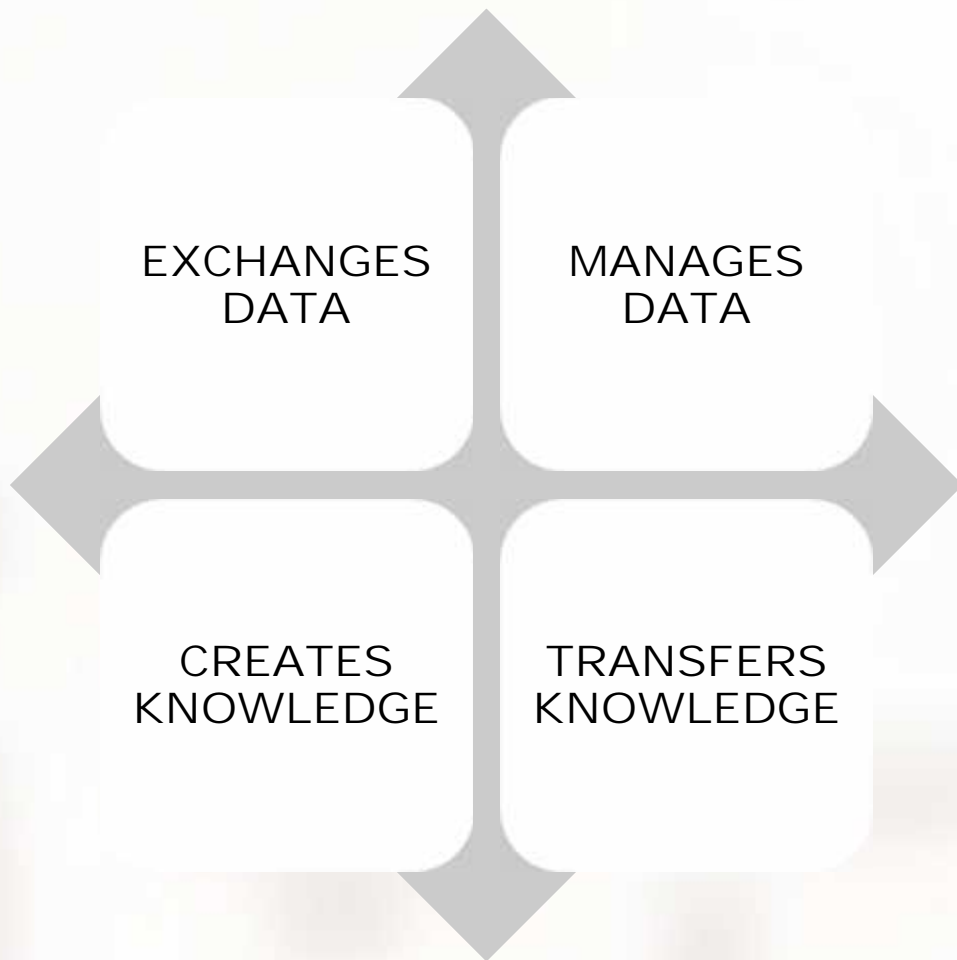


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**ERIC  
on  
DATA  
REUSE**

INFRASTRUCTURE DEVELOPMENT  
CAPACITY BUILDING





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