



Breakout session on data sources Room I for decision makers/investors

21 January 2021

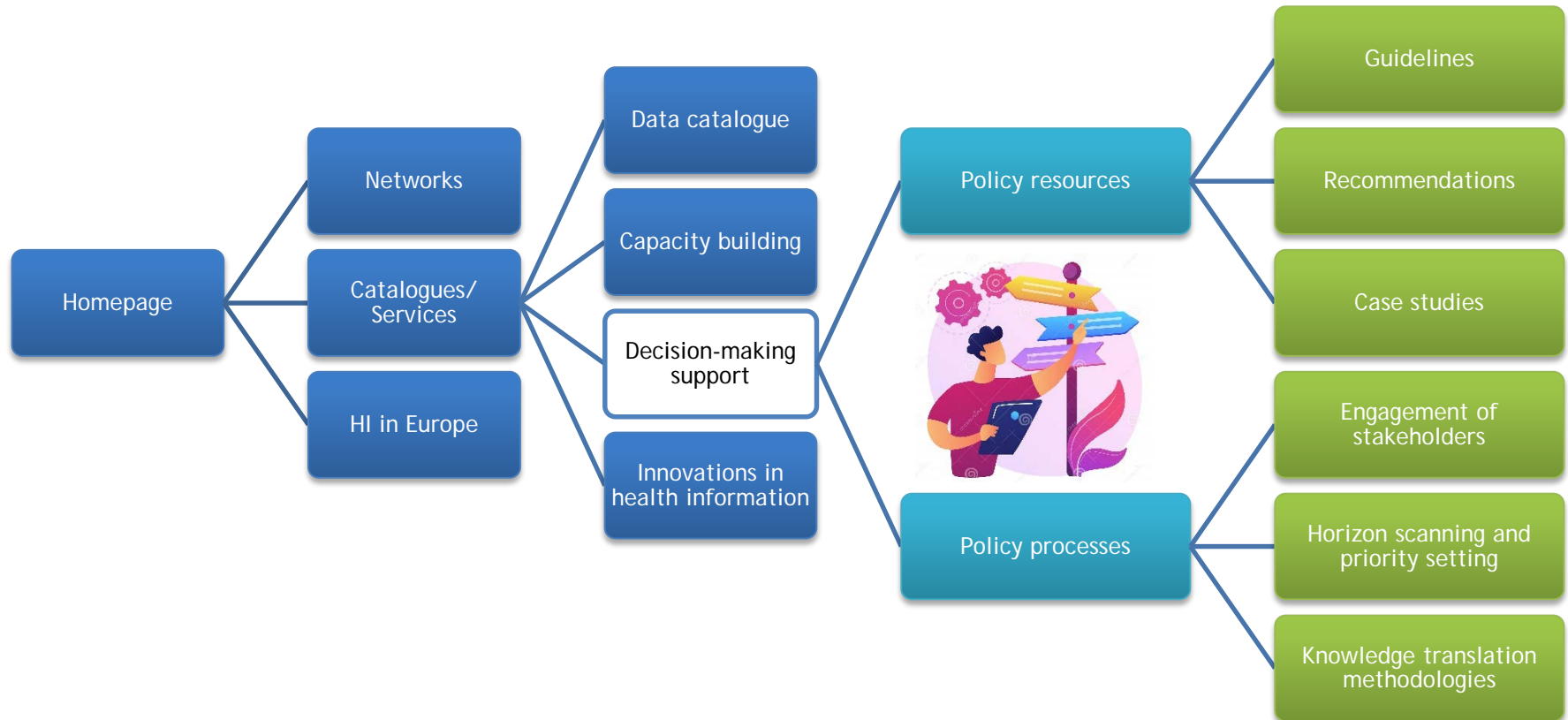


This project is funded by
the Health Programme of
the European Union



One-stop-shop for
health information in Europe

Decision-making support



Impact on policy and decision making



1. Making the best knowledge available for evidence-informed and timely policy-making
2. Optimising instruments to facilitate the provision and uptake of latest and best evidence on population health for decision making
3. Closing the gaps of population HI in Europe



Network of networks

National Nodes

InfAct kick-started the set up of National Nodes in EU partner countries



The added value for policy makers:

1. Bring together regional/national stakeholders in health information in a more systematic manner
2. Facilitate share discussions on core issues on health information domains (nationally and internationally)
3. Provide a 'spider web' role

Research Networks

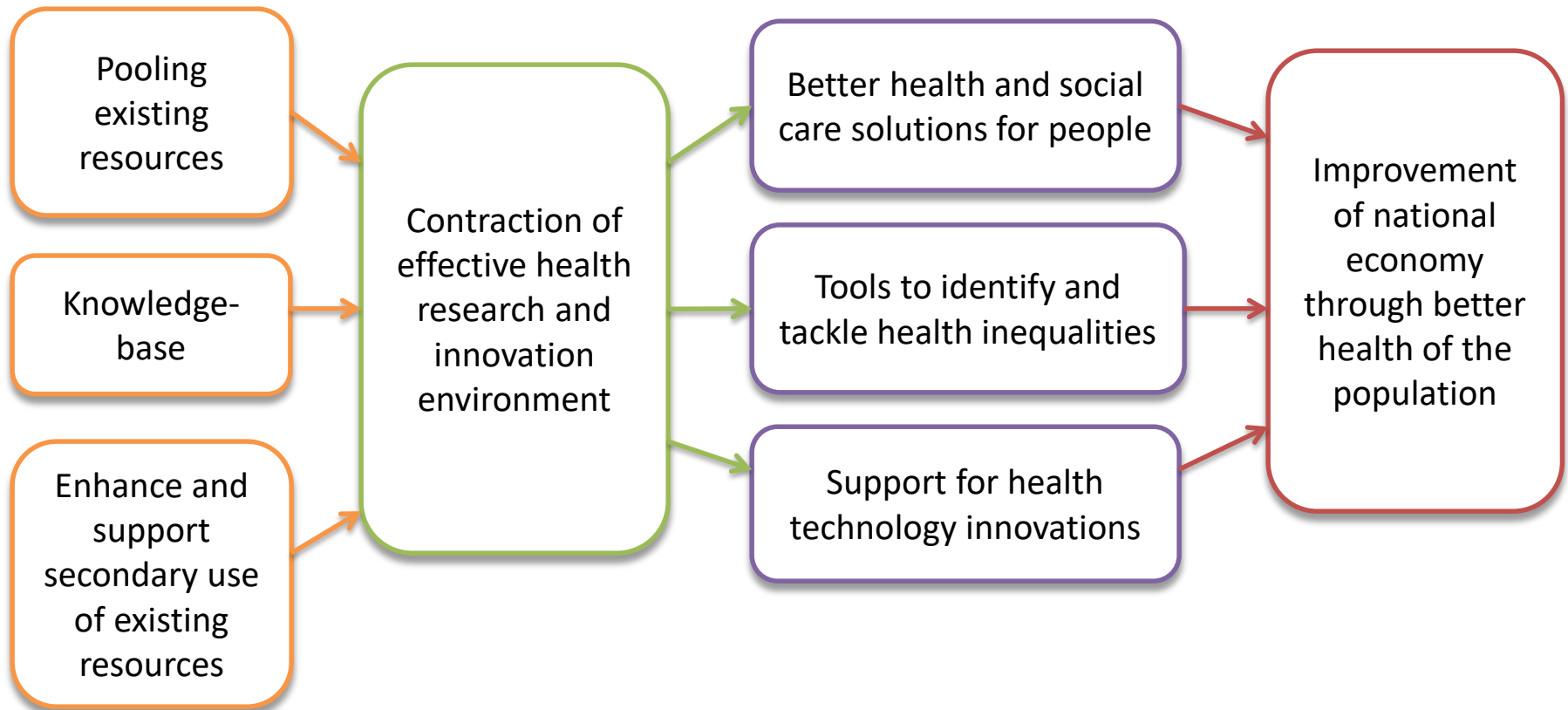


- Represent a group of collaborating experts that collect, exchange, harmonise and analyse data and information on a shared health topic.
- Generate new data and research output, improve research methods and tools, develop standards and guidelines, and contribute to international research capacity building to support health policies and healthcare management.

National Nodes and Research Networks provide for decision making



At national and EU level DIPoH will



Data accessibility and availability



FAIR principle

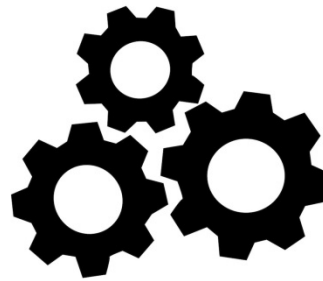
F_{indable}



A_{ccessible}



I_{nteroperable}



R_{eusable}



Availability and accessibility of data and results



- Research networks generate data, guidelines, article, reports, and training materials
- Accessibility to the materials often ends when project ends, i.e. web sites and repositories are closed
- During the project period, access to macrodata (aggregated level information or metadata) often available
- Usually microdata (individual level information) on request only

- DIPoH and health information portal support availability, accessibility, comparability and secondary use of health data and information generated by stakeholders of the National Nodes and Research Networks
- Enhances the use of these materials to support evidence-informed policy making in and across EU countries



Interoperability as the foundation of successful exchange



What is interoperability?

- “the ability to operate with others”;
- “the ability of two or more systems or components to exchange information and to use the information that has been exchanged”.



Legal
Interoperability



Organisational
Interoperability



Semantic
Interoperability



Technical
Interoperability



No meaningful exchange without interoperability

Interoperability in population health data reuse



InfAct mapped cross-national inspirational experiences on data reuse for both public health research and monitoring initiatives

InfAct gained insight in enablers and barriers to cross-border linkage and sharing of health data

Aligned legislation so that exchanged data is accorded proper legal weight

Coordinated processes in which different organisations achieve a previously agreed and mutually beneficial goal

Precise meaning of exchanged information which is preserved and understood by all parties

Planning of technical issues involved in linking computer systems and services

Examples

enablers

Mandatory data collection

central national health data / information body

Health data standards

Open source code

barriers

Different GDPR interpretations

Control over data

Specific national classifications

Lack of technical understanding



legal



organisational



semantic



technical

Contribution to the sustainable infrastructure

- An important step towards understanding and applying the concept of interoperability, in its four levels, for population health data
- Necessary for well-functioning, sustainable infrastructure





A sustainable list of core indicators for public health



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the European Union

Decision
1400/97/EC

Regulation
1338/2008

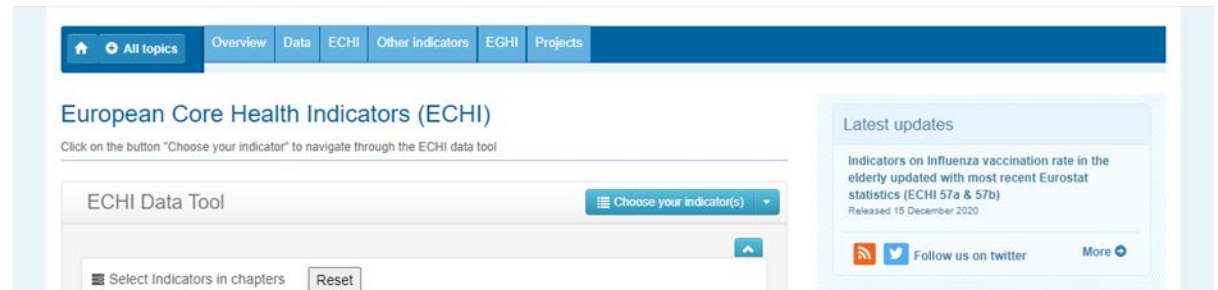
Regulation
2015/359

What are the ECHI?

- Result of EC guided collective MS effort starting in 1998



- Core of a European public health monitoring system
- List currently containing 88 indicators, ~60 implemented across EU
- Demographic and socioeconomic aspects, health status, health determinants and health interventions
- EC (SANTE & ESTAT) maintains a data tool in which the indicators can be consulted

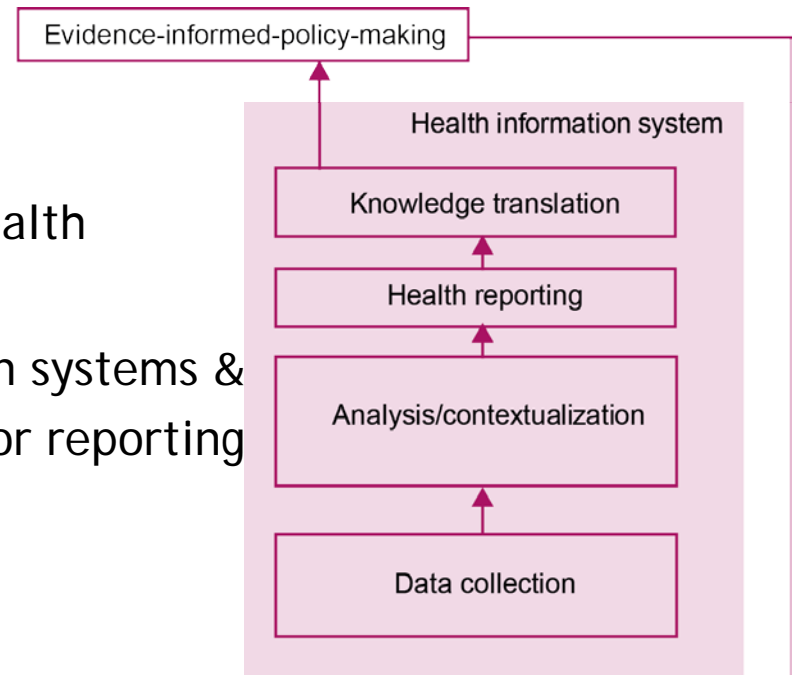


- General consensus on having a system like ECHI in place
- But: official documentation from 2012, no formal modernization, no governing entity



What is the value of the ECHI list?

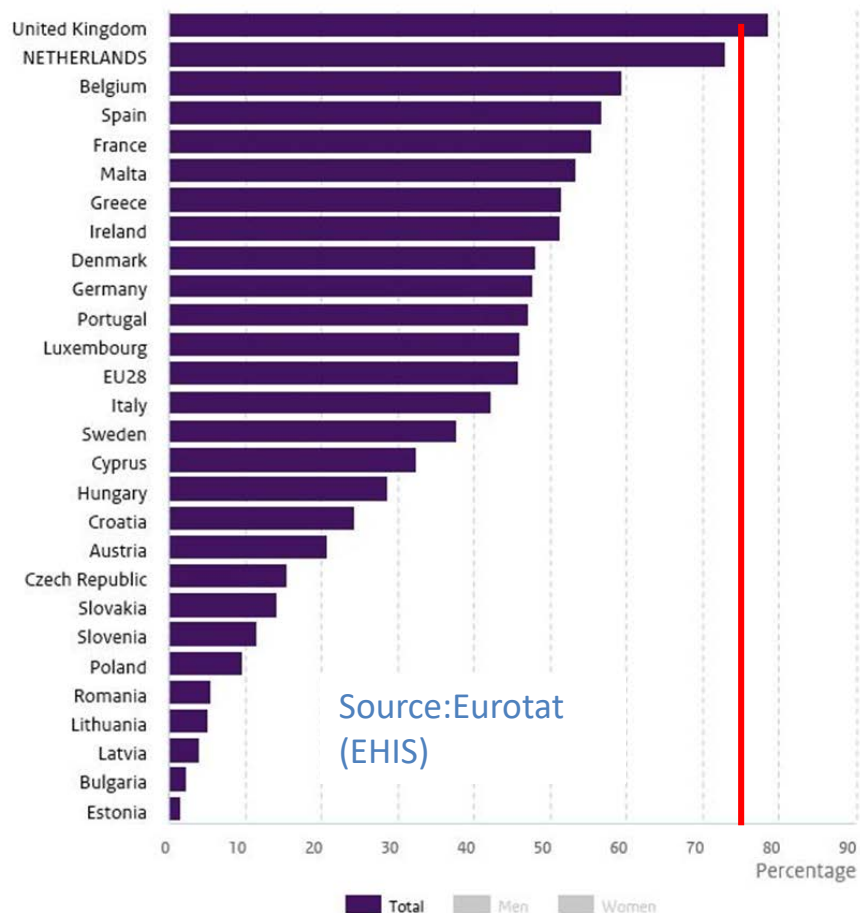
- Provides 'snapshot' of European Union public health and health care
- Supports development and evaluation of public health policy by providing a solid evidence base
- Provides good basis for
 - national health reporting
 - international comparisons of public health
- Has assisted in
 - structuring national health information systems &
 - standardising European health indicator reporting





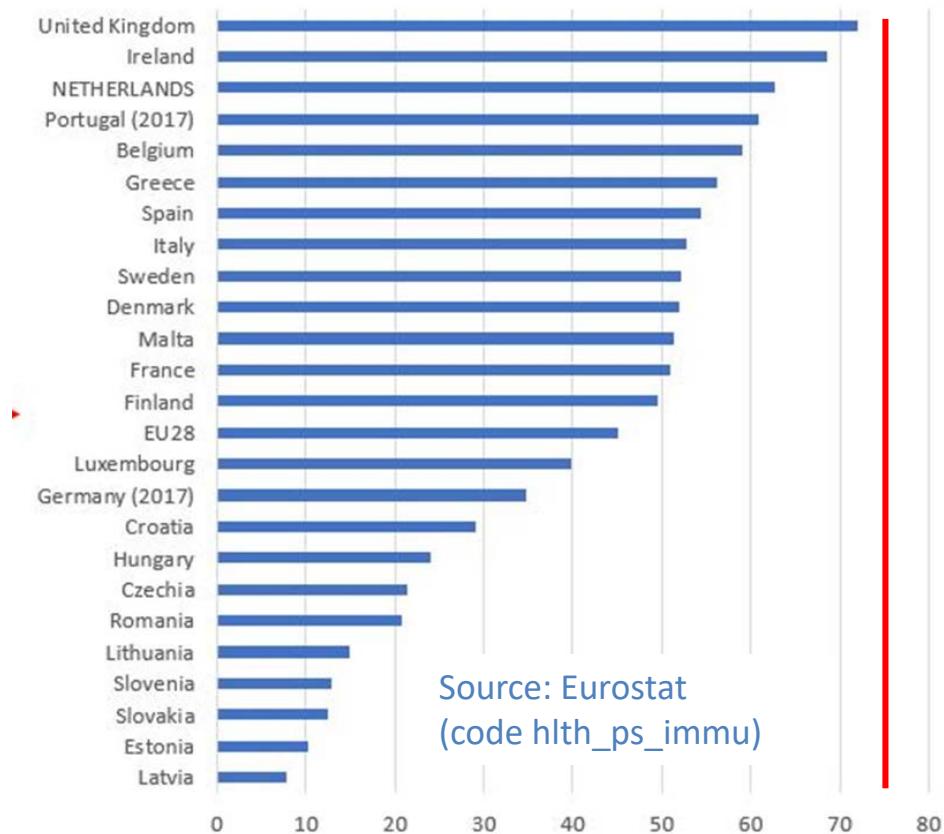
ECHI can provide valuable insights for example: influenza vaccination rate (65+)

Influenza vaccination rate in elderly 2014



Source: Eurostat

Percentage vaccinated (population 65+)



The Health Information Portal

healthinformationportal.eu



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- Single point of access to ECHI-related information
- Increase visibility and use
- Potentially: provide forum for discussion
 - domain experts, generalists;
 - policy makers, researchers
- Potentially: provide a “home” for the ECHI

The role of DIPoH

- An indicator set needs upkeep: are the meta-data still up-to-date, does the list still cover EU and MS policy needs?
- This requires governance and procedures and something to land in
- ECHI is an example of a succesful project-based initiative that will benefit from a sustainable health information infrastructure where MS and EC can collaborate on its maintenance

