The Joint Action on Health Information InfAct

Final meeting – 21/01/21

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40 institutions in 28 countries:

Austria, Bosnia Herzegovina, Belgium, Croatia, Cyprus, Czech Republic, Estonia, Finland, France, Germany, Greece, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Moldova, Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovenia, Spain, Sweden, United Kingdom

➔ 20 public health or research institutes, 13 ministries, 3 universities and 4 others
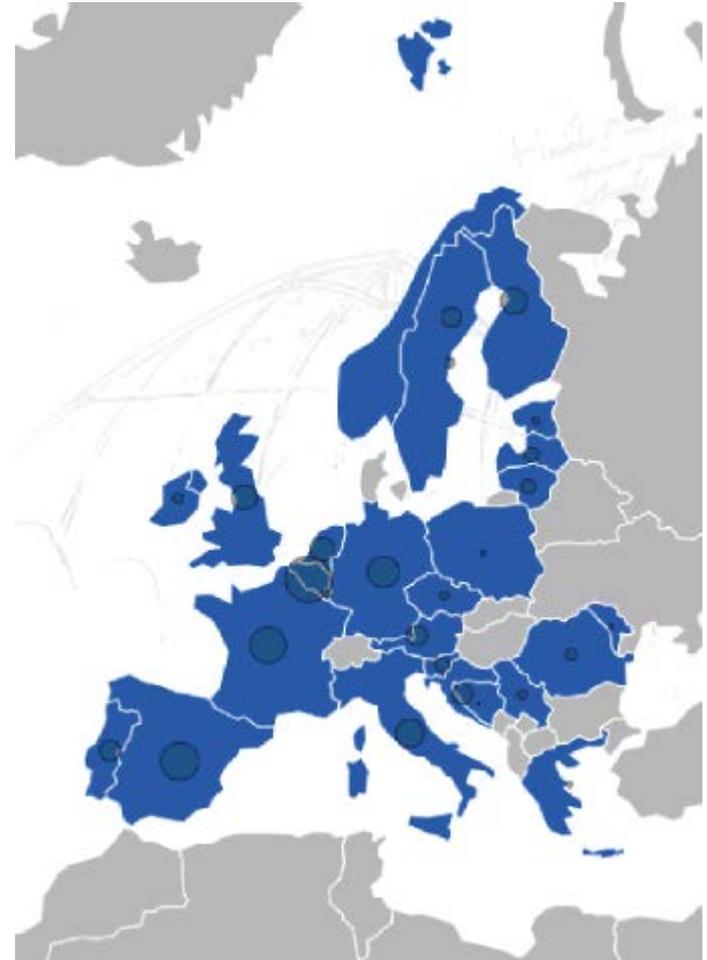
InfAct's goals are to strengthen national and EU health information systems by:

1. Establishing a sustainable research infrastructure which will support population health and health system performance assessment.
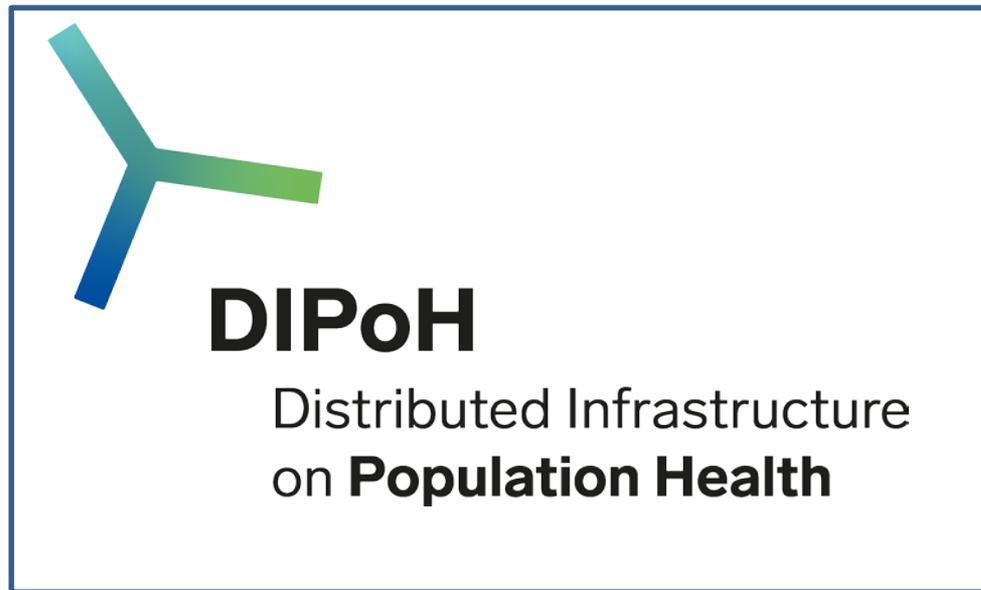
2. Strengthening European health information and knowledge bases and health information research capacities to reduce health information inequalities,

3. Supporting health information interoperability and innovative health information tools and data sources.

To conceptualize a sustainable Research Infrastructure and carry out a proof of concept:

Integration into national policies and sustainability

Status of health information systems in the EU

Strengthen health information capacity

Proof of concept for sustainable structure

Assessing and piloting interoperability for public health policy

Tools and methods for health information support

Innovation in health information for public health policy development

INFACT
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Integration into
national policies and
sustainability

- Organisation of **Assembly of Members** with representatives from Ministries of Health and Research.
- Sustainability plan.

Status of health information
systems
in the EU

- Assessment of health information systems through peer-review.
- Cataloguing of networks and projects.
- Prioritization of health information

Strengthen health
information
capacity

Proof of concept
for sustainable
structure

Developing a capacity strengthening baseline programme at EU level to support critical areas of health information use and management

- Flagship training programme
- Roadmap for capacity building

Developing a proof of concept of a sustainable organisational structure - working towards ERIC by:

- Application for ESFRI roadmap
- Connection of MS health information networks
- Connection pan-European research networks
- Development business case and roadmap
- Creation of web-based platform

WP8, WP9, and WP10

Tools and methods for health information support

- Health monitoring data collection methods and indicators
- Guidelines on accessibility, availability, and reporting in health information

- Sharing inspiring examples from MS on emerging indicators and data sources to target priority public health actions and health care strategies
- Enlarging the set of morbidity indicators available across the EU

Innovation in health information for public health policy development

Assessing and piloting interoperability for public health policy

- Mapping and analysing (inter)national inspirational case studies on public health interoperability
- Developing empirical work through case studies and pilots

EUROPE
EXPERTISE NATIONAL
RESEARCH
KNOWLEDGE SHARING
HEALTH
INFORMATION
DATA NODES
FAIR
PORTAL REUSE
CONNECTING
UNIQUENESS

The road to DIPoH

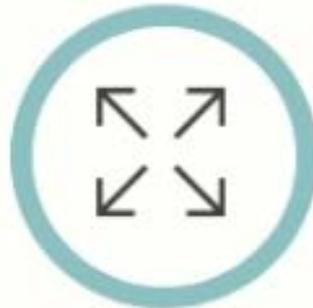sciensano

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FRAGMENTATION

Disperse knowledge

Incomplete data

Difficult access

INEQUALITIES

Differences in quality

Diversity in research capacity

PROJECT BASED

No long term planning

Waste of resources

Duplication

➔ Need for EU health information infrastructure

Why a Research Infrastructure?

- Allows responses to current needs and demands with high usability for Member States and EU institutions → focus efforts on priority aspects

- Innovation in science and technology is vital to solving economic and societal challenges

- Build bridges between research communities and with decision-makers

- Facilitate innovation and knowledge-sharing

- Can ensure continuity of existing health information activities

  → Is the most feasible solution in the current setting

Population Health

Health Status
How healthy are citizens, what are their health needs and healthcare utilisation options?

| Disease states | Functioning and Quality of Life | Healthy Life Expectancy | Mortality by cause, sex and age |

Determinants of Health
What are the factors that determine the health of a population?

| Health Behaviour | Personal Risks and Resources | Socio-Economic factors (participation, financial safety) | Physical Environment |

Health Care System
How does the health system perform? What is the level of care across the range of patient needs? What does this performance cost? How is prevention implemented (health protection, disease prevention [screening, vaccination], health promotion)?

| Expenditure | Input (personnel, infrastructure, technology) | Accessibility | Utilisation | Quality, Effectiveness, Safety |

- Covers the population as a whole (healthy and non healthy)
- Facilitate secondary use of routine data sources
- Include individual and aggregated level data
- Does not include experimental research
- Boost national population health research

- Filling a Gap in the RI landscape

Health
of
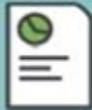Populations
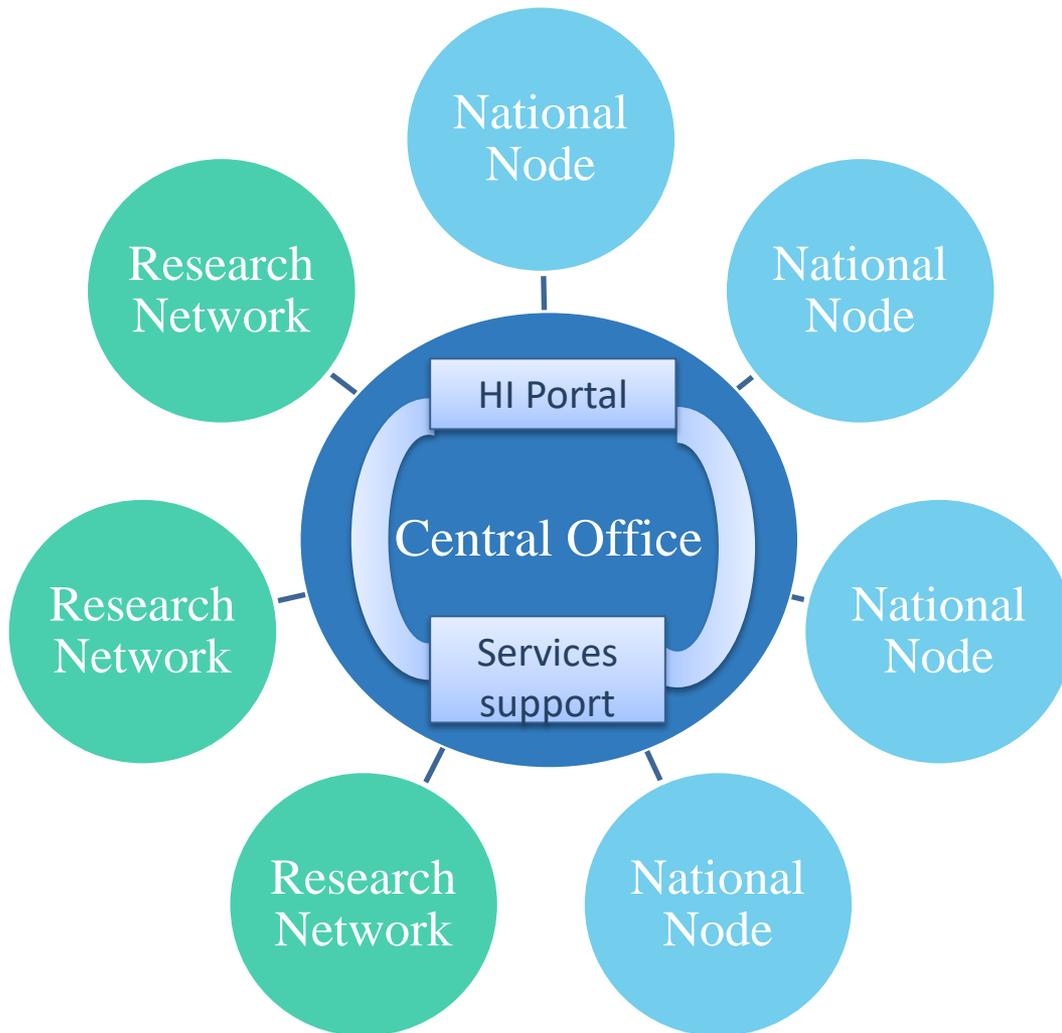
The Structure

- **National Nodes** (NN) units within MSs representing national network,

- **Research Networks** (RN) and their research communities,

- A **Central office and** governance structure,

- A **Health Information (HI) portal** as gateway to data, services and tools on population health

The Services of DIPoH

1 One-stop shop for EU health information research

Find the data, expert, network, guidelines or tool you are looking for

2 Innovative research in health information

Be the first to know and use the latest developments and methodologies

3 Capacity building in health information

Get expert support and training on collection, analysis, reporting and transformation

4 Knowledge translation research for evidence based decision-making

Know your (health) policies are based on proper evidence

What we accomplished

→ Developed concept of National Nodes and started set up

→ Engaged Research Networks of Excellence (criteria, LoS)

→ Engaged Public Health Institutes (MoU)

→ Engaged Ministries of Health and Research (EoS)

→ Set up one-stop shop for European Health Information (HIP)

→ Submitted RI concept to ESFRI road map (DIPoH)

→ Business plan and 5-year road map (finalizing)

1 One-stop shop for EU health information research

Find the data, expert, network, guidelines or tool you are looking for

- Metadata catalogue of existing health information projects and networks
- Metadata catalogue of existing health information data sources
- ELSI and FAIR guidelines

➔ Health Information portal . eu

Innovative research in health information
Be the first to know and use the latest developments and methodologies
2

- Leading-edge study designs and analytical methods (Machine learning techniques)

- Semantic and technological interoperability across datasets within and between countries

  ➔ Demonstrated feasibility of distributed infrastructure

3 Capacity building in health information

Get expert support and training on collection, analysis, reporting and transformation

- Training course provided:

  - European School on Health Information

  - Burden of Disease

  ➔ Material available on Health Information portal

- Health information system assessment

Knowledge translation research for evidence based decision-making

Know your (health) policies are based on proper evidence

4

- Building of National Nodes

- Define priority actions in health information

  - Priority setting study

  - Health information system assessment

  - Inspiring cases of innovation of data sources with AI to estimate health indicators

  - Piloting and inspiring cases interoperability

Outcomes of InfAct

Advanced Scientific Knowledge

Enhanced Sustainability and Robust Data Collection

EU Research Infrastructure

Increased Capacity Building and Research Targeting

Improved Inter-operability and Innovation in HI

Informed Decision Making for Research and Policy

Website: www.inf-act.eu
Twitter: @JA_InfAct