Roadmap for the operationalization of an EU health information system

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Structural options

- BRIDGE Health assessed the various possibilities to accommodate the operationalization of an EU health information system whilst taking into account the feasibility.

- Conclusion:

   **ERIC on Health Information for Research and Evidence-based Policy (HIREP-ERIC)**
Why choosing for an ERIC?

- Setting up an ERIC
  - Is the most feasible solution in the current setting.
  - Allows responses to current needs and demands with high usability for Member States and EU institutions → focus efforts on priority aspects.
  - Has possible funding mechanisms: participation in calls of MS, EC and MS contribution.
  - Ensures linkage with the scientific community, national infrastructures and international organisations.
  - Is a flexible tool: reduction or expansion of activities based on the health information needs.
  - Facilitate research through networks and platforms.
  - Can provide relevant information for decision makers and has the capacity to bring together different actors in health information.
  - Can ensure continuity of existing health information activities.
An ERIC and the way forward

- A European Research Infrastructure Consortium on Health Information for Research and Evidence-based Policy (HIREP-ERIC)
- Basis and infrastructure for a better integrated and sustainable EU health information system
- Backbone and sustainable infrastructure
  - To support population health and health systems research
  - To support policy through population health monitoring and health system performance analysis
An ERIC and the way forward

- Function as a network of networks
- Linking networks of national and international experts and research facilities
- Allowing research collaboration across Europe with strong ties to existing research collaborations and projects, national and international institutions and organizations
The HIREP-ERIC enhances people’s health and health system performance in the EU by stimulating, facilitating and supporting comparative health research to enhance our knowledge about EU citizens health and health systems and to facilitates multi-level decision-making and actions.
- Through improved data collections, more and better comparative research and innovation, the HIREP-ERIC will provide a sustainable policy relevant knowledge base to improve the well-being and health of EU citizens and populations.
This project is funded by the Health Programme of the European Union.

Health status:
- Quality of life and disability
- Health conditions
- Mortality: life expectancy and cause of death
- Morbidity: symptoms and diagnosis
- ...

Determinants of health:
- Health behavior & lifestyle
- Socio-Economic conditions
- Environment
- Technology
- Life course
- ...

Health systems:
- Access
- Effectiveness
- Quality & safety
- Responsiveness
- Expenditure/cost
- Utilization
- ...

Scope:
- Societal values and policy
- Individual / Populations
- Equity (population subgroups and regions)
Goals

1. bringing transparent coordination and centralised governance;
2. collecting more and better comparable data (by (pre-/post-) harmonisation and standardisation of definitions, tools and methods);
3. aiming at high relevance and usefulness of the information (by a transparent priority setting method);
4. delivering high quality research (timeliness, high internal and external validity);
5. reducing information inequalities and addressing knowledge needs;
6. solving gaps and efficiencies in health information;
7. providing better access to comparable health data, methods and tools;
8. supporting stronger health research networks and communities (through capacity building and exchange of expertise and knowledge);
9. enhancing evidence synthesis and knowledge translation;
10. addressing relevant ethical and legal issues (privacy, data security).
A variety of services that will support research are to be provided by the HIREP-ERIC. The core activities of the HIREP-ERIC will revolve around

1) generating knowledge: health data and indicators, 
2) hosting knowledge management 
3) supporting knowledge exchange and transfer for policy and decision-making, 
4) planning health information strategies, and 
5) liaising with regional, national, European and international organisations.
1) Generating knowledge: health data and indicators

Provide technical and expert support for comparable, standardised and accessible data and indicators for health status and health determinants, health services and health systems.

- Updating and developing new indicators, and improving and evaluating existing indicator sets
- Identify gaps, exploiting efficiencies in data collection and facilitating finding solutions in data gaps, including collecting data if necessary
- Facilitate the regular generation of comparable data sets and aims to mediate in hosting these data sets in a sustainable and highly accessible way
- Facilitate research to enhance the efficiency of health and health monitoring systems
2) Hosting knowledge management

Facilitate and support the development and hosting of repository platforms.

- Central coordination for MS to provide data and exploit economies of scale by facilitating the extension of existing data repositories where possible.
- Provide repository platforms for data and metadata that is not stored elsewhere, and facilitate data merging and linkage.
- Tools and methods for data collection, quality assessment, analysis, reporting and knowledge translation.
- Guide users to available and comparable data.
- Facilitate research to share health and health system data.
- Provide through research content and technical solutions for virtual but integrated EU-wide health information system.
3) Supporting knowledge exchange and transfer for policy and decision-making

- Support the exchange and transfer of research into policy through dissemination activities, the strengthening of networks and capacity building.
  - Publication of newsletters, scientific papers and organisation of meetings and workshops as well as expert exchanges.
  - Capacity building activities will be organised in the Member States in areas needed, e.g. with training programmes enhancing researchers’ mobility.
  - Create EU-wide networks of cohorts of experts and scholars in health and health systems analysis.
4) Planning health information strategies

- Horizon scanning activities to detect early signs of potentially important developments through a systematic examination of potential threats and opportunities
- Facilitate through research the development of methods to set health information priorities
- Support Member States, the European Commission and international organisations in designing workplans, setting priorities and drawing up agendas in health information.
- Coordinate research project development
  - assist projects in obtaining funding.
5) Liaise with regional, national, European and international organisations

- Take into account existing infrastructures and build on existing expertise and knowledge
- Attention to initiatives promoted at the European level and their integration at the global scale
- A platform for international cooperation and collaboration on health information
- Liaise or coordinate relevant players in the ERIC competence area upon MS request
This project is funded by the Health Programme of the European Union.
- **Assembly of Members (AoM):**
  - The AoM is the governing body of the HIREP-ERIC and is composed of representatives of the members of the ERIC.
  - One representative of the Scientific Advisory Board and the Ethics and Privacy Board is invited as an observer in the Assembly of Members.
  - The Director General is the rapporteur of the Central Executive Management Office to the Assembly of Members.
- The **Scientific Advisory Board** and the **Ethics and Privacy Board** offer advice on request of the AoM or the Central Executive Management Office on all scientifically and technologically relevant matters
  - including questions regarding the research agenda, scientific strategies, ethical issues and the annual work programme.

- The Scientific Advisory Board is also tasked to periodically evaluate the activities and products of HIREP-ERIC including the strategic and operational objectives.
Governance structure

- The **Central Executive Management Office** is composed of the Director General and a Core Team.
  - the executive body of the HIREP-ERIC
- Responsible for the management, operational and budgetary day-to-day decisions.
- Provides an administrative governance structure, which carries out scientific, technical and administrative coordination tasks in addition to the delivery of core services.
Governance structure

- The Core Team is responsible for daily operations
  - preparations of meetings,
  - the implementation of the HIREP-ERIC programme,
  - servicing the various Boards and Committees,
  - external relations and communications,
  - providing services to support the hubs and the user community,
  - and grant-application functions.

- The Core Team comprise legal and technical expertise, which is necessary for a large distributed research infrastructure and the effective interfacing and coordination.
Governance structure

- The **Network Committee** consists of a representative of the nodes that are operational in the HIREP-ERIC.
- Responsible for scientific activities related to HIREP-ERIC.
- Maintain coherence and consistency across the nodes, to discuss issues related to the activities of the nodes, and to interact with the Central Executive Management Office.
- The Committee may support the Central Executive Management Office in developing the programme, scientific strategy and grant-funding opportunities.
This project is funded by the Health Programme of the European Union.

Central Executive Management Office

- National node
- Domain specific node
- National node
- Domain specific node
- National node
- Domain specific node
- Advancing scientific knowledge
- Building capacity and targeting research
- Create interactive networks of research networks
- Member States involvement and Member State driven
- Open and structured methods for health information priority setting
- Informing decision-making, practice, and policy
- Providing access to better and comparable data, tools and methods through data sharing methodologies

Dissemination and transferring knowledge

Added value
## Added value

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<tr>
<th>Decision-makers</th>
<th>Researchers</th>
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<tr>
<td>• High quality data and information for evidence-based decisions</td>
<td>• EU-comparative data</td>
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<td>• Better preparedness</td>
<td>• Better data quality, availability and comparability</td>
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<td>• International comparison: evaluate and discuss how to tackle similar challenges</td>
<td>• Sustainable data availability</td>
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<td>• Programme evaluation</td>
<td>• Enhanced research capacity</td>
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<td>• Priority setting</td>
<td>• Larger study populations and cohorts</td>
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<td>• Organise and coordinate public health expertise and systems</td>
<td>• Enhanced data access flow</td>
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<td>• Better access to existing knowledge and expertise</td>
<td>• Structured scientific exchange</td>
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<td>• Quicker results</td>
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<td>• Better access to existing knowledge and expertise</td>
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<tr>
<td>Healthcare providers</td>
<td>Citizens</td>
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<td>• Data to set standards and protocols for evidence-based care and to evaluate their policies</td>
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<tr>
<td>• Benchmarking i.e. learning from best practices</td>
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<td>• Better access to existing knowledge and expertise</td>
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<td>• Improved health and wellbeing by enhanced monitoring of health risks, health status, health determinants, and the safety and quality of healthcare services</td>
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<tr>
<td>• Reduced health inequalities</td>
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<td>• Better access to existing knowledge and expertise</td>
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<th>Administrators/data providers</th>
<th>Financers</th>
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<tr>
<td>• Reduce burden by increasing harmonisation of international data collection to reduce duplication</td>
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<td>• Assist in obligation to provide data to international sources</td>
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<td>• Better value for money in international health information activities and health research</td>
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<td>• Optimise funds allocation</td>
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