



BRIDGE Health

EGHI Meeting

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This project is funded by
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the European Union

Overview BRIDGE Health



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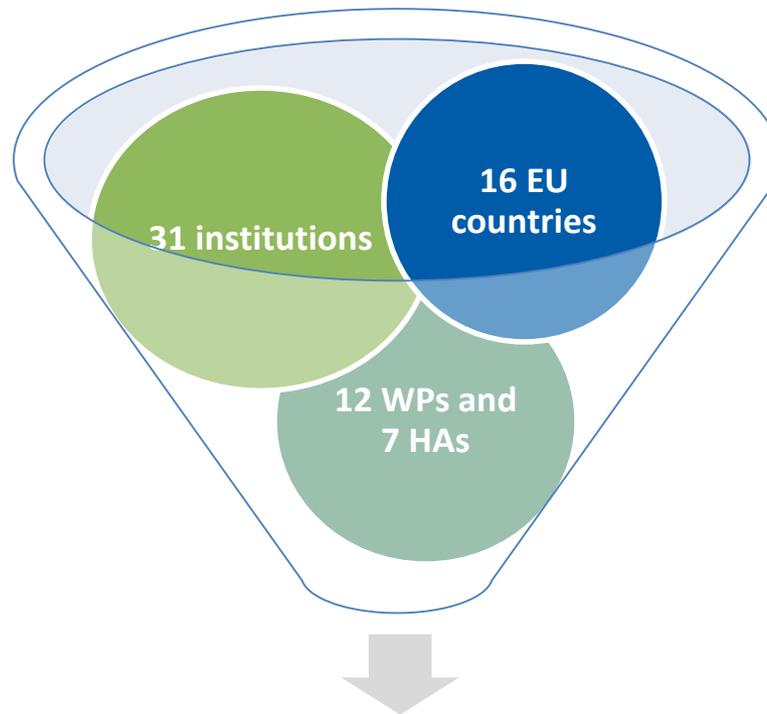
... working towards a **health information and data generation network** in the European Union covering major European health policy areas both for

- population health and
- health system performance.

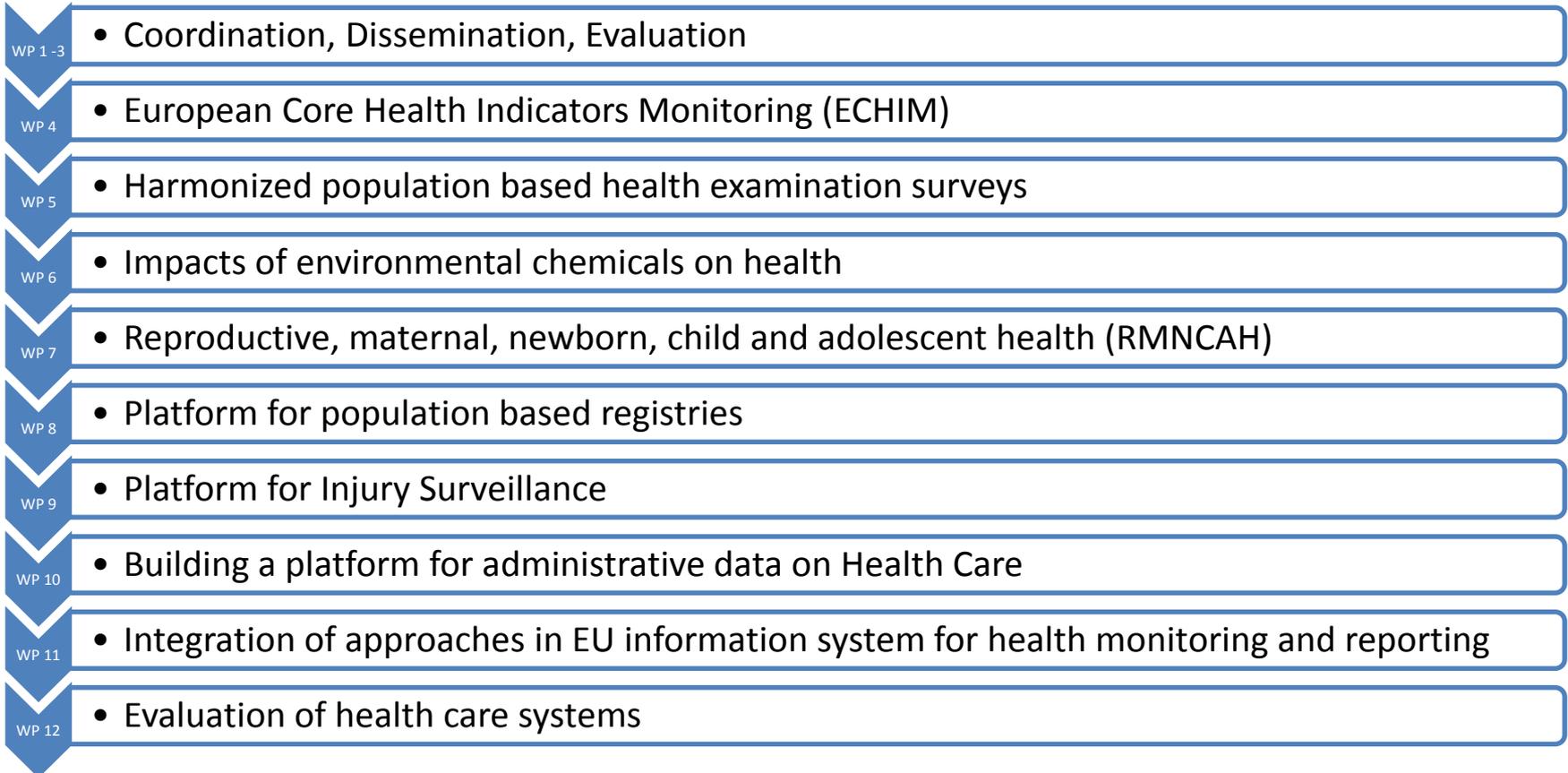
Deliver a **policy paper** describing the scope, tasks, activities and governance structure of a EU Health Information System;

- **structural and institutional options** of such a EU HIS and support the transition towards it; and
- to develop blueprints for **specific actions** (tasks) of a EU HIS = horizontal activities.

Bridge Health constitution



Vertical activities: work packages



Horizontal activities

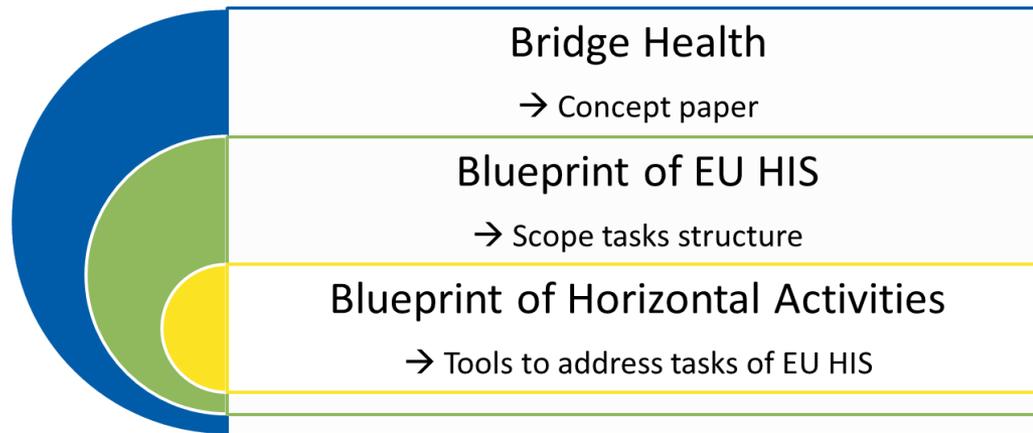
Horizontal Activities
1) Transferability of health information and data for policy
2) Health information inequality within the EU and within MS
3) Information at regional level (ECHI indicators, health inequalities) and for specific population groups
4) Standardisation methods of the collection and exchange of health information
5) Data quality methods including internal and external validation of indicators
6) Priority setting methods in health information
7) Ethical and legal issues in health information

Horizontal activities

- BRIDGE Health is working through horizontal activities that tackle generic objectives
 - Brings together expertise from different health information domains
 - Building blocks of EU HIS
- The outcome is:
 - A set of technical blueprints to get the EU HIS started

Overarching activity

- Deliver a concept paper describing the scope, tasks, activities and governance structure of a EU Health Information System.



Concept paper



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Concept paper

- Provides the context and the problem definition
- Describes the vision, mission and tasks
- Proposes different options with strengths and weaknesses to allow a healthy and informed decision by Member States
- Suggests a stepwise approach
- Illustrates the need for overarching activities
- Provides a set of recommendations

1. Context and problem definition
 - A. Problem
 - B. Political context
 - C. Where do we stand now?
 - D. Need for EU HIS
 - E. Added value of EU HIS
2. Working towards an EU HIS
 - A. Mission, B. Vision, C. Scope, D. Goal, E. Tasks
3. Selecting an EU HIS
 - A. Elements to consider
 - B. Various options
4. Engagement opportunities
5. Recommendations



1. Context and problem definition



A. Problem

- Health policy needs to be based on the best scientific evidence derived from
 - Sound and timely data
 - Relevant research
- No holistic and integrated EU Health Information System (EU HIS):
 - No EU-wide public health monitoring system for health or health systems
 - No health information system for policy oriented research or advice

B. Political context

- Discussions back in 1998¹
 - The Health Monitoring Programme (HMP) adopted in 1997 is intended to pave the way for permanent EU health monitoring.
 - A feasibility analysis resulting in proposals for the organization of EU health monitoring was carried out in 1997.



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¹Aromaa A. Health observation and health reporting in Europe. Rev Epidemiol Sante Publique 1998; 46(6): 480-90.

B. Political context

- In 2011:
 - EU parliament resolution¹ asked the EC to
 - consider and assess the possibility of **extending the remit of ECDC** to encompass non-communicable diseases and using it as a centre for data collection.
 - Council Conclusions² called the EC to
 - “consider the need for the better deployment of existing data and additional comparative data and information on unhealthy lifestyles behaviors, social health determinants and non-communicable chronic disease. This should be obtained from **sustainable health monitoring systems** already in place or which might be established at EU level.”



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¹<http://www.europarl.europa.eu/sides/getDoc.do?type=TA&language=EN&reference=P7-TA-2011-0390>

²http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/126524.pdf

B. Political context

- In 2011:
 - Council Conclusions¹ called the EC to
 - “Strengthen cooperation and make better **use of existing networks and existing public health and related institutions**, which investigate, monitor and research the impact of the health determinants.”
 - “Prioritise support for the assessment of the cost-effectiveness of activities and policies to promote health and prevent diseases and for dissemination of the results, to provide a **better information and evidence base** for implementation of policies and activities in Member States to address health inequities.”
- In 2012:
 - Joint letter of NPHIs to Commissioner Dalli asking to find sustainable mechanism for health monitoring and reporting.



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¹http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lisa/126524.pdf

B. Political context

- In 2013:
 - The Council of the EU conclusions¹ stated that “policy-making and decision-making process should be, as far as possible, **evidence-based** and supported by adequate **health information systems**”.
 - And welcomed “the further development and consolidation, while avoiding duplication of work, of a **health monitoring and information system at EU level** based on the ECHI and existing health monitoring and reporting systems”.
 - The Council invites the commission and the MSs to improve the coordination on **Health systems performance assessment** at EU level by:
 - streamlining the debate on the theoretical **HSPA framework** and identifying useful **methodologies and tools** to support policy maker in taking decisions;
 - defining criteria for selecting **priority areas** for HSPA at EU level and improving the availability and quality of relevant data and information.



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¹http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lisa/140004.pdf

B. Political context

- Health Ministers¹ invited the EC and MS “to cooperate with a view to establishing a sustainable and integrated EU health information system. This should build on what has already been achieved through different groups and projects, such as ECHI-ECHIm projects, exploring in particular the potential of a comprehensive health information research infrastructure consortium (ERIC) as a tool.”

→ Leads to the set-up of BRIDGE Health.



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¹http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lisa/140004.pdf

B. Political context

- In 2014:
 - Mission Letter of President Juncker to Commissioner Andriukaitis¹
“Developing expertise on performance assessments of health systems, drawing lessons from recent experience, and from EU-funded research projects to build up country-specific and cross-country knowledge which can inform policies at national and European level. “



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¹https://ec.europa.eu/commission/sites/cwt/files/commissioner_mission_letters/andriukaitis_en.pdf

B. Political context

- Communication of the Commission¹ on “effective, accessible and resilient health systems” calls for
 - closer cooperation in this context of increasing interdependence and common challenges.
 - eHealth in terms of information flows in the system, a type of information systems “that facilitate and support the strengthening of information knowledge systems”.
- The European Commission also points out² that
 - “data has become a key asset for the economy and our societies similar to the classic categories of human and financial resources.”
 - The use of “Big Data” including health data, at European level could be a great source of advantages in terms of productivity, research and innovation.



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¹http://ec.europa.eu/health/healthcare/docs/com2014_215_final_en.pdf

²<https://ec.europa.eu/digital-single-market/en/making-big-data-work-europe>

C. Where do we stand now?

- Under Framework Programme and EU Health Programme major investments have been made in individual and unlinked projects without a holistic view
- Successful projects:
 - Useful for EU and MS: some projects have integrated their outputs in Eurostat and JRC
 - Data collection of high number of MS
 - Building networks and capacity
 - Indicator development
 - Knowledge and tools



C. Past initiatives

European Projects associated to BRIDGE Health

1. Child health research strategy (RICHE)
2. Consortium to Perform Human Biomonitoring on a European Scale (COPHES)
3. Developing a Child Cohort Research Strategy for Europe (CHICOS)
4. Environmental Health Risk in European Birth Cohorts (ENRIECO)
5. EuroHOPE
6. European Best Information through Regional Outcomes in Diabetes (EUBIROD)
7. European Collaborative for Healthcare Optimization (ECHO)
8. European Cardiovascular Indicators Surveillance Set (EUROCISS)
9. European Community Health Indicators Monitoring (ECHIM)
10. European Health Examination Survey (EHES)
11. European Life and Health Expectancy Information System (EHLEIS)
12. Euro-peristat
13. EuroREACH A Handbook to Access Health Care Data for Cross-country Comparisons of Efficiency and Quality (EUROREACH)

→ non-exclusive list of existing EU projects in health information

D. Need for EU HIS

- National Public Health Institutes consultation meeting (16/03)
- Questionnaire
 - **Is there a need for an EU HIS? What are those needs?**
 - What could be the added value of an EU HIS?
 - How can National Public Health Institutes contribute and participate?
- Group discussion
 - What are the essential tasks of an EU HIS?
 - Evaluate the different options for an EU HIS?
 - How can your institute concretely and specifically contribute in the set-up and maintenance of an EU HIS?

D. Need for EU HIS

1. Need for European health information strategy
2. Data harmonization, collection, processing and reporting
3. Comparison and benchmarking among MS and for Europe
4. Knowledge sharing and capacity building
5. Transferability of HI and evidence-based policy making

D. Need for EU HIS

1. Need for European health information strategy

- Improved coordination between various health information activities (by different DGs, different agencies, different projects, etc.);
- Need for interdisciplinary cooperation with other policy sectors and civil society;
- Improving the link between health information activities (including research and development) and policy needs;
- Need for decisions on common issues;
- Create synergies and sustainability between projects and health information activities.

→ *Need for coordination and collaboration in health information.*



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D. Need for EU HIS

2. Data harmonization, collection, processing and reporting

- Harmonization of data definitions and indicators between countries;
- Standardised methodological approach to data collection (adapt to culture etc.);
- Facilitate sharing and exchange of harmonised data at individual and population level;
- Harmonized EU wide health reporting (including data visualizations);
- Ensure sustainable data collections and data availability for evidence-based public health;
- Better usage of collected data.

→ *Better data quality and comparability.*



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D. Need for EU HIS

3. Comparison and benchmarking among MS and for Europe
 - Assess quality and efficiency health care systems;
 - Assess inequalities in Europe;
 - A unified general picture of health situation in Europe;
 - Addressing health determinants that operate across national boundaries.

4. Knowledge sharing and capacity building
 - Diminishing the health information inequalities between countries;
 - Developing knowledge and expertise and facilitating the exchange of knowledge and expertise including good practice examples.

D. Need for EU HIS

5. Transferability of HI and evidence-based policy making
 - Developing, implementing and evaluating EU actions;
 - Effectiveness and efficiency of public health interventions;
 - Respond effectively to population health and health systems' challenges;
 - Fast health analysis for preparedness and research;
 - Efficient spending of resources.

→ *Evidence-based policy making, monitoring and planning.*

E. Added value of EU HIS

Added value for research and public health institutions

1) EU-comparative data

- Data quality
- Continuous availability
- Larger cohorts for research
- Enhanced data access flow
- Structured scientific exchange
- Produce quicker results

2) Collaboration between NPHIs

- Organize and coordination public health expertise and systems
- Create synergies between projects and health information activities
- Better access to existing knowledge and expertise

E. Added value of EU HIS

Added value for stakeholders in Member States

Decision makers	Citizens and health care providers
<ul style="list-style-type: none">- Quality information for evidenced based decisions.- Better preparedness.- International comparison: evaluate and discuss how to tackle similar challenges.- Programme evaluation.	<ul style="list-style-type: none">- Improved health and wellbeing by enhanced monitoring of health risks, health status, health determinants, and the safety and quality of healthcare services.- Evidence-based care.- Reduced health inequalities.
Administrators/ data providers	Financers
<ul style="list-style-type: none">- Reduce burden by increasing harmonization of international data collection → reduce duplication.- Assist in obligation to provide data to international sources.	<ul style="list-style-type: none">- Better value for money in international health information activities.- Optimise funds allocation.

E. Added value of EU HIS for the EU



- Insight in European health situation
 - Causes of changes of population health and health systems
 - Effectiveness and efficiency of public health interventions
 - Changes and evaluation of health system performance
- Comparison and benchmarking against other regions of the world
- Policy
 - Alignment of activities and strategy
 - Efficient spending of resources
 - Clear communication of public health developments and threats
 - Better support of EU initiatives e.g. joint procurement, inequalities, Active and Healthy Ageing, European Semester, health impact assessment,...

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 - A. Elements to consider
 - B. Various options
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2. Working towards a European Union Health Information System



A. Mission

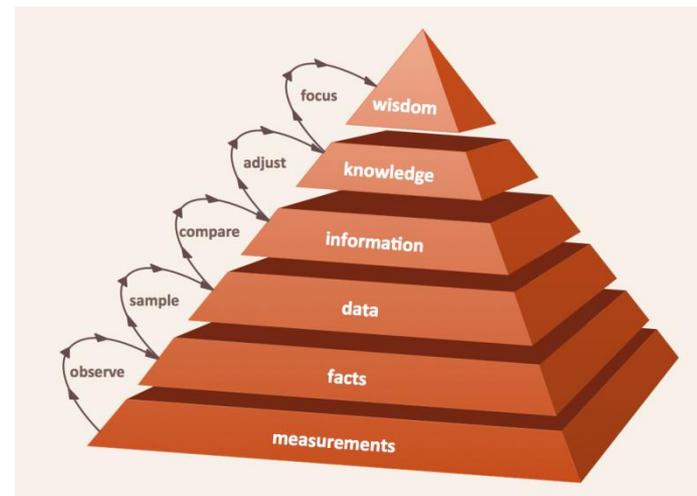
An EU Health Information System improves people's health and health system performance in the EU by data integration and analytics, knowledge generation and dissemination that supports multi-level actions.

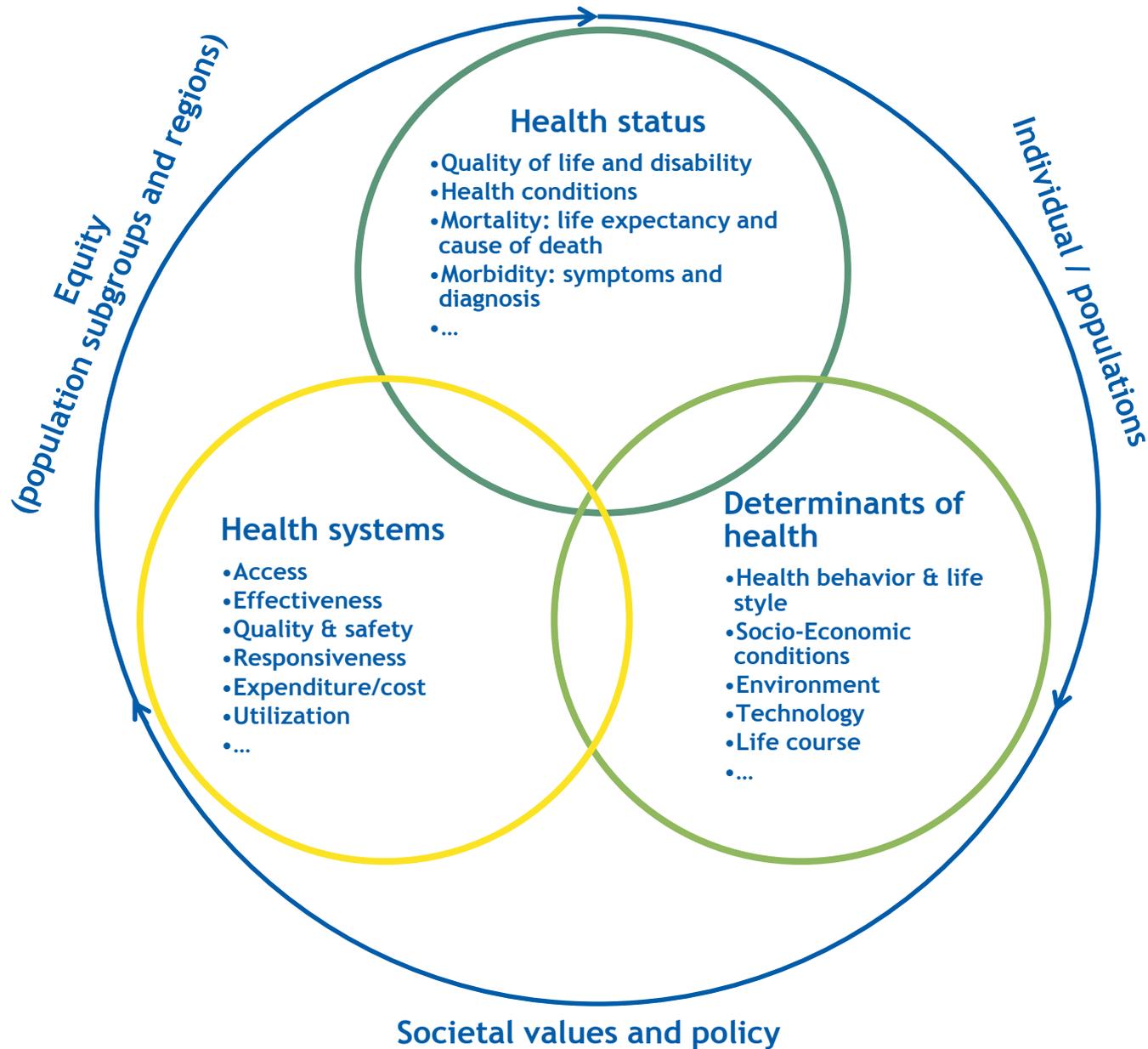


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B. Vision

An EU Health Information System provides timely the best available knowledge for decision-makers to improve EU populations' health and well-being.



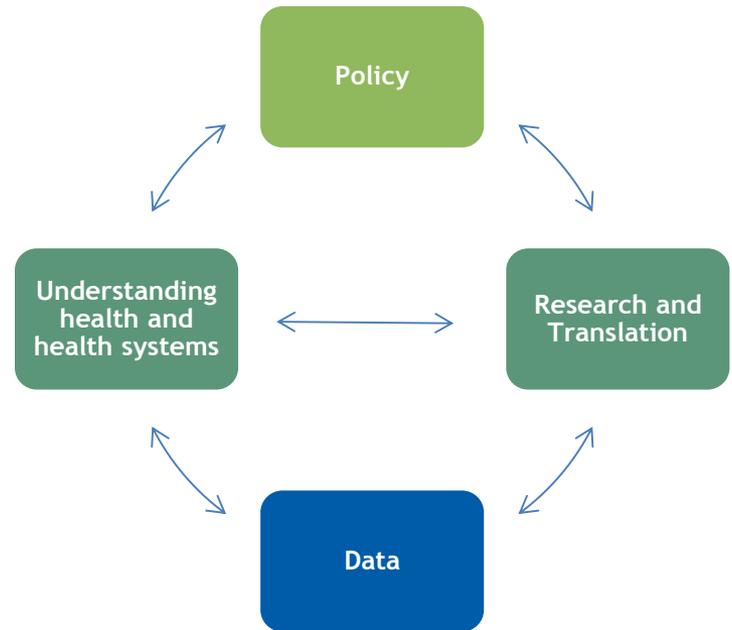


The goal of the EU HIS is to support social and health policies and health in all policies in the EU and all Member States by ensuring the collection, analysis and exchange of health information

1. With comparable data (harmonisation and standardisation);
2. Of high relevance and utility (priority setting method);
3. Of the highest possible quality (timeliness, internal and external validity);
4. For closure of knowledge gaps and addressing information needs; and
5. By addressing ethical and legal issues;
6. Covering the whole of the European Union and the Member States in a structured way.

E. Tasks: working areas

- EU HIS with four working areas:
 - (1) Policy aspects: health information strategy, communication, coordination, ..
 - (2,3) Understanding health and health systems, research and translation: translation to policy, data processing, monitoring, tools and knowledge, ..
 - (4) Data repository: data quality, comparability, collection, ..



E. Tasks

1. Involve all Member States and EU institutions to develop an EU Health Information Strategy;
2. Identify health information needs and priorities in a methodological and systematic way;
3. Map out data sources and identify data gaps;
4. Set up European data/ indicator repository;
 - Collection (standardised tools)
 - Compilation (access and/or transfer),
 - Repository
 - Integration (data extraction),
 - Transformation (harmonization and loading processes),
 - Analysis (data quality and production of outputs) and
 - Inference (conclusion reached on the basis of evidence and reasoning);

E. Tasks

5. Identify legal and ethical issues related to data ownership, sharing, access, transfer, storage, processing and reporting;
6. Linkage and exchange with stakeholders: support research-to-policy interaction, transferability of health information and data for policy and outline the information dissemination strategy and tools;
7. Ensure outputs are datasets for research purposes, information system for public health surveillance and monitoring, public reporting of health and healthcare performance indicators;
8. Guidelines for training and capacity building for Member States to reduce health information inequalities;
9. Ensure sustainable funding for the EU HIS;
10. Ensure regular evaluation of the EU HIS.

E. Tasks



E. Tasks: Horizontal activities

- The Horizontal Activities in BRIDGE Health are working on a set of technical blueprints, which
 - Work on generic objectives;
 - Bring together expertise from different health information domains; and
 - Are the building blocks of the EU HIS.
- The technical blueprints developed by BRIDGE are the essential functions of the EU HIS.
- They are made as such to get the EU HIS started.

E. Tasks: Horizontal activities

Horizontal Activities
1) Transferability of health information and data for policy
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E. Tasks: NPHIs consultation meeting

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E. Tasks: Group discussion

Question 1: What are the essential tasks of a EU Health Information System?

Common between groups: Identify and standardize core set of indicators and protocols for collection (including definition)

Different by groups:

- a) To make an inventory of existing databases and systems.
- b) To do a needs assessment of health information users.
- c) Identify methods for health information needs.
- d) Internal and external coordination.
- e) Assure quality of data.
- f) Organise capacity building.

E. Tasks: Suggestion focus

Create a common **EU strategy** on EU health information

Formulate clear objectives and focus on

1. Consolidating ECHI indicators

- Enable to set priorities
- Find common definitions for indicators
- EU-wide collection

→ *Legal framework, similar mechanism and guarantee of sustainability*

2. Capacity building health system performance assessment

- Training, skill building, exchange expertise between MSs (e.g. European Programme for Intervention Epidemiology Training)

3. Make use of existing **knowledge centres** in different domains of health information in function of the EU health information strategy

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3. Selecting structural options for an EU HIS



A. Elements to consider

Elements related to stakeholder exchange, interaction and support:

- Acceptability and support by the Member States, the European Commission, other EU institutions and, in case it is built on an existing institution, the institution itself.
- High usability of Member States and EU institutions
- Equitable participation of Member States
- Maximal coverage of Member States
- Forum for stakeholder exchange and interaction through active committed networks

A. Elements to consider

Elements related to stakeholder exchange, interaction and support:

- Links with scientific community, including researchers and health professionals
- Patient public involvement such as patient associations and civil societies
- Structure building on national infrastructures
- Support and/or performance of primary research and research with secondary sources
- Possibility for interaction with international organisations (e.g. OECD and WHO)

A. Elements to consider



- Elements related to content:
 - Scope focusses on public health
 - Set clear targets/objectives to focus efforts on priority aspects
 - Capacity to have overarching role
 - Bring together overlapping activities and other research projects (avoid duplication)
 - Potential to be recognised to have EU public health leadership
 - Efficient decision making procedure
 - Clear mandate, coordination and vision on health information (census building)
 - Providing information for decision making
 - Use pooled and harmonised data collected for research, as sources of information for population health and public health
 - Maximises probability of success → feasibility

A. Elements to consider

- Elements related to content:
 - Flexible for changes
 - Legal and technical progress
 - Economic constraints
 - Allow reduction or expansion of scope
 - Open, coordinated and transparent (access to data for researchers and public communications about data governance)
 - Establish transparent regular review and evaluation procedures to ensure continued efficiency
 - Mechanisms to secure trustworthy scientific guidance
 - Wide perspective with local/national uptake
 - Include all aspects of health information and reliable data for research

A. Elements to consider

- Elements related to sustainability:
 - Long term and short term: time necessary for its implementation:
 - of infrastructure
 - of resources (human and financial resources)
 - of content
- Elements related to legal aspects:
 - Clear legal basis
 - Clear data owner and intellectual property agreements based on common competition, ethical and data protection rules

B. Various options

- Strengthen existing, create a new structure or combination.
- Take up part or all activities.
- Overarching role by bringing together the activities.
- Short-term vs. long-term solutions.
- Some options suit better the purpose of an EU HIS, but feasibility needs to be taken into account.

B. Various options: strengthen an existing structure

- The following options can be considered, separately or combined:
 - Extension of the scope of the European Centre for Disease Prevention and Control (ECDC)
 - Reorganisation of DG Health and Food Safety (SANTÉ)
 - Expanding Eurostat's tasks
 - Extending work plan of DG Joint Research Center (JRC)
 - Outsource to the World Health Organization (WHO) Europe or the Organisation for Economic Co-operation and Development (OECD)

B. Various options: strengthen an existing structure

Strengths	Weaknesses
Infrastructure	Existing structure has divergent tasks
Administration	Strong political will to change existing structures
Legal framework	Need to find additional resources in existing frameworks
Political setting	
Existing networks	

B. Various options: Create a new structure

- The following options can be considered:
 - Independent new EU agency
 - European Research Infrastructure Consortium (ERIC)
 - Joint Action
 - Supra-European structure



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B. Various options: Create a new structure

Strengths	Weaknesses
Flexibility in activity and scope	Political support
Tailor to needs and demands	Financing mechanisms
Cover gaps of existing structures	Expertise needs to be build up
Have voice of its own	Need to build up credibility

B. Various options: Combination of new and existing structures

Strengths	Weaknesses
Flexibility in activity and scope	Challenging coordination
Not overriding existing structure	Need for good collaboration
Long term relationship	No central contact point

- It could be a combination of any of the above e.g. combine ERIC with JRC, ECDC and Eurostat

B. Various options: NPHIs consultation meeting

Group discussion:

Evaluate the different options for a EU Health Information System.

- a) What would be the ideal option?
- b) What is the most feasible option on short and long term?

B. Various options: NPHIs consultation meeting

- Ideal:
 - Group A. New EU public health information agency
 - Group B. Extending the scope of ECDC
 - Group C. New EU agency. Extending scope ECDC or Eurostat.
- Feasible:
 - Group A. Exploring **ERIC** as an instrument to develop an organisation to coordinate and to look at gaps in health information or extending the role of the ECDC.
 - Group B. Joint Action which can have the aim to build a EU Health Information System or **ERIC** which is flexible.
 - Group C. Create a new mechanism where the directors of the existing institutions can meet and collaborate. Have a central contact point with a mandate.

B. Various options: conclusion

- Not feasible in the short term to reorganise, expand or create structures dependent of the European Commission.
- BRIDGE Health recommends to create an ERIC as the vehicle of an EU HIS.

B. Various options: conclusion

- 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 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.
 - Can provide relevant information for decision makers and has the capacity to bring together different actors in health information.

B. Various options: conclusion

- Challenges for setting up ERIC:
 - 100% Member States driven
 - A balance needs to be found between monitoring and research in health and health systems
 - No guarantee for long term sustainability
 - No direct link with EU institutions

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3. Engagement opportunities



3. Engagement opportunity

- National public health institutes (NPHIs) or corresponding institutes
 - The health information knowledge centres in Member States
 - Translators of health information to policy
 - Contact points for communication of health information to international organisations with an existing network
 - In favour of maximising usage of existing knowledge (e.g. through hubs)
- Will of NPHIs to actively build on EU health information.
- Practically:
 - Use the existing network IANPHI to form a consortium;
 - Provide the content for the country knowledge (cycle); and
 - Use existing domain specific knowledge networks as hubs.

➔ Active role of NPHIs to set-up the ERIC



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4. Recommendations



Recommendations in set up of ERIC



- Member States play central role with maximal inclusion of Member States for the setup of an ERIC
- National public health institutes or corresponding institutions in Member States are drivers
- A core central structure with minimum overhead
- Use existing knowledge and experience from EU projects through hubs
- Develop roadmap with stepwise approach with basic elements:
 - Create a common EU strategy on EU health information
 - ECHI indicators used for country reports
 - Capacity training in health system performance assessment to interpret health information
- Limit the involvement of international organisations to the role of observers



TF EGHI



Outline

1. Possibility to give feedback on concept paper
2. Discussion on added value of EU HIS
3. Discussion on essential functions of EU HIS
4. Roadmap development: first steps in start up of ERIC
5. Governance model and conceptual framework of ERIC



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