Introduction of problems and needs of an EU health information system

Pre-conference EPH Conference 2016

Petronille Bogaert
Herman Van Oyen
Scientific Institute of Public Health, Belgium

www.bridge-health.eu
Outline

- Overview BRIDGE Health
- Definition EU health information system
- Context and problem definition
  - The current situation
  - Political context
- Challenges
- Needs
Overview BRIDGE Health
... 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 **concept paper** describing the scope, tasks, activities and governance structure of a EU health information system (EU HIS);

- **Structural and institutional option** of such a EU HIS and support the transition towards it; and

- Develop blueprints for **specific actions** (tasks) of a EU HIS.
This project is funded by the Health Programme of the European Union.

Bridge Health constitution

- 31 institutions
- 12 WPs and 7 HAs
- 16 EU countries
Vertical activities: work packages

WP 1-3 • Coordination, Dissemination, Evaluation

WP 4 • European Core Health Indicators Monitoring (ECHIM)

WP 5 • Harmonized population based health examination surveys

WP 6 • Impacts of environmental chemicals on health

WP 7 • Reproductive, maternal, newborn, child and adolescent health (RMNCAH)

WP 8 • Platform for population based registries

WP 9 • Platform for Injury Surveillance

WP 10 • Building a platform for administrative data on Health Care

WP 11 • Integration of approaches in EU information system for health monitoring and reporting

WP 12 • Evaluation of health care systems

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

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

An EU health information system is an integrated effort to collect, process, analyse, report, communicate and use comparable health information and knowledge covering all Member States to understand the dynamics of the health of the European citizens and populations in order to support policy and decision-making, programme action, individual and public health outcomes, health system functioning, outputs and research in the European Union.
Context and problem definition
- Health and health care are major policy area that draw intense political attention
  - Healthy population is prerequisite for economic growth
  - National health expenditures are increasing
  - Nations of equity, social justice and concerns to respond to needs of citizens
Context

- Member States are facing common challenges
  - Demographic changes with ageing populations, multi-morbidity and disability
  - Chronic diseases rising
  - Growing healthcare needs
  - High patient expectations
  - Expensive technologies and pharmaceuticals

→ Need for high-performing equitable health systems
Context

- This needs to be guided by
  
  Best available data, research and evidence
  • Up-to-date data and high-quality data
  • Relevant research
  • Good practices

- Policies and interventions need to be evaluated for their outcomes, costs and priority-setting
- Trends in health and determinants should be timely provided
- Closer cooperation between Member States in this context of increasing interdependence and common challenges.
The current EU health information situation

- EU health information research and evidence for policy has been taken forward through
  - The work of the European Commission
  - Individual and independent EU projects
  - And international organisations OECD and WHO
The current EU health information situation

- 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
The current EU health information situation

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 (ENRIEICO)
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)
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
The current EU health information situation

- Projects demonstrated
  - Diversity of health information structures in Europe
  - Fragmentation of databases and registries
  - Health information inequalities regarding the availability and quality of data
  - Lack of the sustainability of health information activities.
Political context

- In 2011:
  - EU parliament resolution\(^1\) 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 Conclusions\(^2\) 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.”

- In 2012:
  - Joint letter of NPHIs to Commissioner Dalli asking to find sustainable mechanism
    for health monitoring and reporting.

---

Political context

- In 2013:
  - The Council of the EU\(^1\) 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”.

- Health Ministers\(^1\) 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.”

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. “

Challenges in health information
Challenges in health information

1. Much of the gathered evidence and knowledge is still dispersed, incomplete and difficult to access.
   - Diversity of health information (infra)structures in Europe
   - Fragmentation of databases and registries
   - Huge area were no health data exist or indicators of comparable quality

2. Large differences can be found in terms of quality and, as a consequence, in comparability of health information between and within EU Member States.
   - Health information inequalities

This project is funded by the Health Programme of the European Union
3. Health information activities are often funded through ad hoc projects rather than through sustainable structures.

- Lack of sustainability of health information activities
- Health information activities often focus on vertical approaches
  - No holistic approach
  - Fragmentation leads to internal competition in health information domains
  - Lack of coherence and balance
  - Less efficient use of existing data
Needs in health information
Needs in health information

- BRIDGE Health organised a consultation meeting with the National Public Health Institutes (NPHIs) on 16th of March 2016
- Questionnaire were send out and filled in before the meeting and elaborated in focus groups.
  - 10 NPHIs replied to the questionnaire before the meeting: Belgium, Bulgaria, Finland, France, Germany, Ireland, Italy, Netherlands, Norway, Slovenia.
  - 12 NPHIs participated in the focus groups (total of 14 participants): Belgium, England, Finland, France, Germany, Ireland, Italy, Netherlands, Norway, Portugal, Slovenia, Spain
- Is there a need for an EU health information system? What are those needs?
Needs in health information

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
Needs in health information

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.
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.
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.
Needs in health information

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/informed policy making, monitoring and planning.
Conclusion

This calls for some form of central governance which can accommodate for the current challenges and needs in health information.
www.bridge-health.eu

Contact: bridge.coordination@wiv-isp.be