
4th November 2017
10.C. - Workshop: Lighting candles, not cursing the darkness. Applications of health information across Europe

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

- **BRidging Information and Data Generation** for Evidence-based Health policy and research.

- **May 2015 - October 2017 (30 months)**

- **Aim:** To prepare the transition towards a sustainable, comprehensive and integrated EU health information system to support evidence-based health policy and research for the EU and Member States.

- **Benefits:** efficient resource allocation through better prioritization, reduced duplication of activities, and the identification of gaps in information

My Focus:

Children and Young People (aged 0-24)

1. Identify the extent and value of possible data sources across Europe

2. Recommendations on how to make more effective use of data
Study One: Health Information Needs

This study is being run by Sara McQuinn and Anthony Staines from Dublin City University, Ireland, on behalf of the European Commission funded BRIDGE HEALTH project.

BRIDGE health stands for Bridging Information and Data Generation for Evidence-based Health policy and research. Our overall aim is to create a comprehensive, integrated and sustainable health information system, to support evidence-based health policy and research, for health for Member States, and for citizens.

Our focus here is on the health and well-being of children and young people from conception to the age of 16 across Europe.

We have two main tasks:

1. Review the nature and extent of a range of possible sources of routine data on child and young people health across Europe.
2. Identify ways of making more effective use of routine data in order to examine the health and well-being of children and young people in Europe.

Your responses in this questionnaire and your work will help us to better understand the needs for information on the lives of children and young people in the EU.

Please only complete this survey once.
Study One: Health Information Needs

- January-February 2016
- Health Professionals working with children and young people’s health and well-being
- 294 Respondents, 37 Countries
- Health information sources utility, availability, recommendations

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Recommendations on how to make health information sources more effective

“to use comparable data systems for collection of data and, of course, to have standardized data available”

“We require a defined suite of universally agreed indicators for comparisons between groups/regions/countries”

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“The inability to adequately describe and compare child health and well-being across Europe in a standard and valid way”
(Cattaneo et al., 2012)
“It is international comparison that can show what is achievable in the real world, highlight strengths and weaknesses in individual countries, and demonstrate that child well-being is policy-susceptible” (UNICEF Innocenti Research Centre, 2013).
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• “International comparisons are an important means to raise awareness, stimulate research and drive investment” (Wolfe, 2014).


Study Two
Objective

To identify a holistic set of indicators to be used to monitor children and young people’s health and well-being to increase data comparability across Europe.
The Delphi Process

Recruitment of healthcare professionals
Scoping literature search
Development of first questionnaire

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The Delphi Process

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Multi-Dimensional Approach

94 Indicators

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Multi-Dimensional Approach

94 Indicators

Demographic and Socio-Economic

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Multi-Dimensional Approach

94 Indicators

Demographic and Socio-Economic

Education and Employment
Multi-Dimensional Approach

94 Indicators

Demographic and Socio-Economic

Education and Employment

Health-Related Behaviours

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Multi-Dimensional Approach

94 Indicators

- Demographic and Socio-Economic
- Education and Employment
- Health System and Policy
- Health-Related Behaviours

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## Outline of Indicators for Round One (n=94)

<table>
<thead>
<tr>
<th>Demographic and Socio-Economic</th>
<th>Education and Employment</th>
<th>Health-Related Behaviours</th>
<th>Health System and Policy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortality and Morbidity (6)</td>
<td>Education (9)</td>
<td>Lifestyle Determinants (10)</td>
<td>Health and Social Policy (6)</td>
</tr>
<tr>
<td>Poverty (4)</td>
<td>Employment (4)</td>
<td>Disability and Injury (2)</td>
<td>Disability (4)</td>
</tr>
<tr>
<td>Crime and Protection (8)</td>
<td></td>
<td>Mental Health (6)</td>
<td>Environment (6)</td>
</tr>
<tr>
<td>Social Indicators (7)</td>
<td></td>
<td>Parental Determinants and Relationships (7)</td>
<td>Health System Quality (3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reproductive and Sexual Health (8)</td>
<td>Participation and Engagement (4)</td>
</tr>
</tbody>
</table>
The Delphi Process

- Recruitment of healthcare professionals
  - Scoping literature search
  - Development of first questionnaire

Round One
- Feb/March 2017
- Analysis (n=179)
- Development of 2nd Round Questionnaire

Round Two
- March/April 2017
- Analysis (n=69)
- Development of 3rd Round Questionnaire

Round Three
- May/June 2017
- Analysis (n=55)
- Record consensus items

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The Delphi Process

Recruitment of healthcare professionals
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Round Three
May/June 2017
Analysis (n=55)
Record consensus items

✓ Importance Scale (1-5)
✓ Ranking (per domain and dimension)
✓ Availability
✓ Potential to be measured
✓ Agreement on consensus
✓ Balance/Coherence
✓ Open-ended feedback
## The Delphi Process

<table>
<thead>
<tr>
<th>Evaluation Criteria</th>
<th>Delphi Rounds</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Round One (n=94)</td>
</tr>
<tr>
<td>Indicators</td>
<td></td>
</tr>
<tr>
<td>Importance (5-point scale)</td>
<td>√</td>
</tr>
<tr>
<td>Ranking (indicators within domains)</td>
<td>□√</td>
</tr>
<tr>
<td>Availability</td>
<td></td>
</tr>
<tr>
<td>Potential to be measured</td>
<td>□√</td>
</tr>
<tr>
<td>Agreement on consensus (indicators per domain)</td>
<td></td>
</tr>
<tr>
<td>Ranking (indicators within dimensions)</td>
<td></td>
</tr>
<tr>
<td>Domains and Dimensions</td>
<td></td>
</tr>
<tr>
<td>Indicators present a balanced and coherent picture of each dimension in the EU</td>
<td>√</td>
</tr>
<tr>
<td>Open ended feedback after each dimension</td>
<td>√</td>
</tr>
<tr>
<td>Open ended feedback after each domain</td>
<td></td>
</tr>
</tbody>
</table>
Results

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## Demographics

<table>
<thead>
<tr>
<th>Completed questionnaires returned (n)</th>
<th>Round One</th>
<th>Round Two</th>
<th>Round Three</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>179</td>
<td>69</td>
<td>55</td>
</tr>
<tr>
<td>Response Rate</td>
<td>Unknown</td>
<td>69/98 = 70.4%</td>
<td>55/98 = 56.1%</td>
</tr>
<tr>
<td>Location: Europe</td>
<td>92.6%</td>
<td>96.8%</td>
<td>97.9%</td>
</tr>
</tbody>
</table>

### Country

1. Ireland (19.5%)
2. UK (10.7%)
3. Germany (8.1%)

1. Ireland (29%)
2. Germany (9.7%)
3. Malta (9.7%)

1. Ireland (25%)
2. Germany (8.3%)
3. UK (8.3%)

### Occupation/Role

1. Researcher (36.2%)
2. Epidemiologist (14.8%)
3. Other (13.4%)

1. Researcher (41.9%)
2. Epidemiologist (11.3%)
3. Health policy advisor (9.7%)

1. Researcher (47.9%)
2. Epi (14.6%)
3. Other (12.5%)

### Organization

1. University/Third Level (52.3%)
2. National Government (20.8%)
3. Healthcare provider (12.1%)

1. University/Third Level (43.5%)
2. National Government (27.4%)
3. Health care provider (9.7%)

1. University/Third Level (54.2%)
2. National Government (20.8%)
3. Health Care Provider (10.4%)
Transition of Indicators

Round One

94

Feedback

96

53

32

Round Three

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Transition of Indicators

'Widely Available' = 75%

'Consensus' = 70%

94

96

53

32

21

11

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Final Consensus - ‘Widely Available’ Indicators (total n=21)

<table>
<thead>
<tr>
<th>A: Demographic and Socio-Economic</th>
<th>B: Education and Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Mortality Rates</td>
<td>Education Completion Rate</td>
</tr>
<tr>
<td>Selected Cause-Specific Mortality</td>
<td>School Drop-out Rate</td>
</tr>
<tr>
<td>Poverty (National)</td>
<td>Early Childhood Education Rate</td>
</tr>
<tr>
<td>Jobless Households</td>
<td>% NEET (Not in Education, Employment or Training)</td>
</tr>
<tr>
<td>Socio-Economic Circumstances</td>
<td>Unemployment Rate</td>
</tr>
<tr>
<td>Income</td>
<td></td>
</tr>
<tr>
<td>Children in Care</td>
<td></td>
</tr>
</tbody>
</table>
**Final Consensus - ‘Widely Available’ Indicators (total n=21)**

<table>
<thead>
<tr>
<th>C: Health-Related Behaviour</th>
<th>D: Health System and Policy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attempted Suicide</td>
<td>Education Facilities</td>
</tr>
<tr>
<td>Adolescent Birth Rate</td>
<td>Integration of People with Disabilities into Employment</td>
</tr>
<tr>
<td>Sexually Transmitted Infections (STIs)</td>
<td>Environmental Tobacco Smoke</td>
</tr>
<tr>
<td></td>
<td>Transportation Safety</td>
</tr>
<tr>
<td></td>
<td>Immunisation Coverage</td>
</tr>
<tr>
<td></td>
<td>Leukaemia 5-year Survival</td>
</tr>
</tbody>
</table>
Final Consensus - ‘Non-Widely Available’ Indicators (total n=11)

<table>
<thead>
<tr>
<th>A: Demographic and Socio-Economic</th>
<th>C: Health-Related Behaviour</th>
<th>D: Health System and Policy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abnormal BMI</td>
<td>Prevalence of Depression &amp; Anxiety</td>
<td>Mental Health Policy</td>
</tr>
<tr>
<td>Disability Rate</td>
<td>Life Satisfaction</td>
<td>Integration of People with Disabilities in Schools</td>
</tr>
<tr>
<td>Child Abuse</td>
<td>Contraceptive Use</td>
<td>Exposure to Air Pollution</td>
</tr>
<tr>
<td>Access to Services</td>
<td></td>
<td>Participation in Decisions</td>
</tr>
</tbody>
</table>

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Conclusions
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• There is a need for a **sustainable, integrated and comprehensive** EU-Health information structure, supporting evidence-based health policy and research for the EU and Member States.
Conclusions

• There is a need for a **sustainable, integrated and comprehensive** EU-Health information structure, supporting evidence-based health policy and research for the EU and Member States.

• Information is key for healthy public policy and practice.

  ✓ Accessible
  ✓ **Comparable**
  ✓ Up-to-date/Timely
  ✓ Reliable/High quality
An agreed set of common EU indicators measuring children and young people’s health and well-being allows health professionals, policy-makers, member states, and citizens, to compare data in a standard and valid way.
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I WANT ANSWERS
CALL THE DATA SCIENTIST.
RIGHT NOW!
Study Limitations

• Small-scale study. Literature search, representative 0-24?

• English language questionnaires

• Limitations to using the Delphi technique
Future Actions

- Wider variety of disciplinary backgrounds (increase number of experts involved)
- Include views of children and young people
- Setting up of a working group at EU Level
- ‘Not Widely’ available reported indicators used as a guide, i.e. addressing the gaps
This is not a finalised list - This research could be used as a starting point for future European work.
Thank You For Listening!

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