



National Institute for Public Health
and the Environment
Ministry of Health, Welfare and Sport

It's all about the data!

Round table session how to
bring public health to all
policies, EUPHA conference,
Copenhagen

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It's all about the data; information pyramid



The ability to make sound judgements and decisions

Wisdom

Integrated information, from different sources, different fields

Knowledge

Data and explanation, meta-data

Information

Statistics; demographics, registries, HIS/HES etc.

Data



Usability of routinely collected health data

- A lot is out there (e.g. hospital discharge data, electronic patient records, health insurance data)
- BUT.... often hard to use for public health purposes because of:
 - Ownership
 - Lack of uniform or useful coding practices
 - Legislation/regulation (e.g. data protection)
 - Lack of knowledge/insight/mutual understanding, e.g. ;
 - › fear of abuse;
 - › not clear why public health experts want to use and combine certain data, what is needed to achieve 'knowledge' (pyramid);
 - › no insight into costs (high costs of large HIS/HES surveys vs. low costs of using existing data).

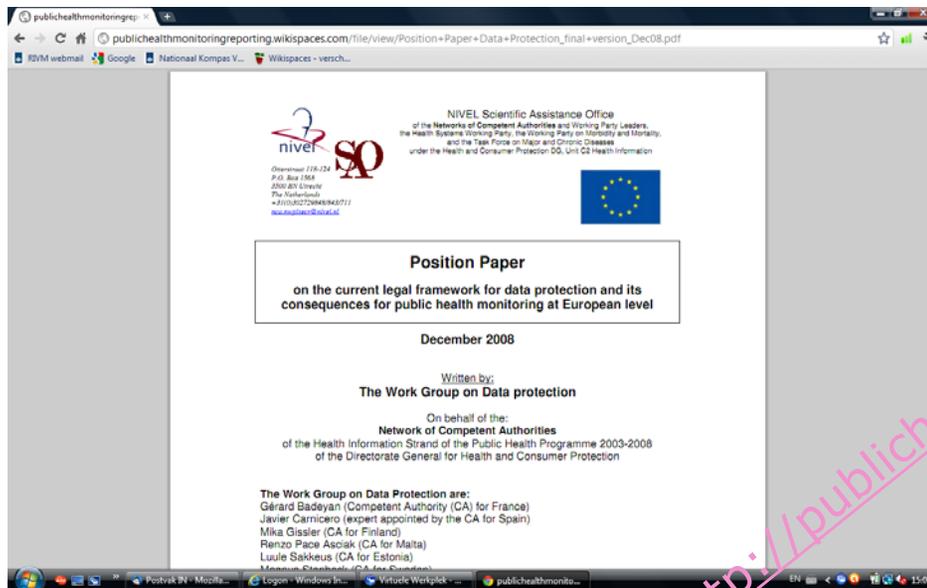




Value of data linkage

Linkage of different data sources at subject level; different purposes:

- Validation (prevent double counts, prevent missing values)
- Better risk group identification
- Comprehensive information (e.g. follow certain health care pathways)



<http://publichealthmonitoringreporting.wikispaces.com>



ECHI example: Acute Myocardial Infarction

European Community Health Indicators (ECHI): core set of 88 general public health indicators, EU health information system

Indicator: attack rate of Acute Myocardial Infarction (non-fatal and fatal) and coronary death per 100,000 population

Calculation: Age-standardized attack rate by sex in age group 35-74 in the population in a given calendar year, **based on combined hospital discharge (HDD) and mortality data (CoD)**. Attack rate counts first & recurrent events (at least 28 days between onsets events)

Why: About 30-40% of cardiac attacks are fatal and patients die before reaching the hospital → only combination of HDD and CoD can provide a complete picture.

Linkage → prevent double counts, distinguish separate events.

E.g. person who dies 4 days after hospital discharge; 1 event



What is possible in practice?

- 2010/2011: ECHI data collection pilot. EU MS (27) asked to provide AMI data (ECHI definition)
- Outcomes; 12 MS provided data:
 - only HDD: ES → no combination/linkage possible (several reasons)
 - Combined HDD and CoD data, but no linkage at subject level:
 - > DE → data protection, federal system, > 100 Gov. Health Insurances
 - > HU
 - > IE → absence of unique identifier, legal restrictions
 - > CZ → Linkage technically possible (PIN), but still legislative problems
 - > probably LV (metadata not completely clear)
 - IT, FI: CVD registries, MT PIN linkage, NL probabilistic linkage
 - No meta-data from PL, UK
- Problems data linkage reported also by Lithuania, Austria, Portugal, Estonia

NB: Failure to deliver data also due to lack of resources. The above should be seen as illustration, not as exhaustive overview of linkage possibilities in MS.



Countries experience limitations

- ECHI example shows that MS experience problems with linking routine databases at the subject level.
- Other problems reported as well by MS related to using routine health data for ECHIM/public health purposes;
 - Lack of support from government, conflicting views (e.g. Malta → health expenditure deemed unimportant)
 - Scattered ownership (e.g. Denmark, Belgium)
 - Lack of central strategy, guidance (e.g. Norway, the Netherlands)
 - Problems with quality registries (e.g. Poland, The Netherlands → poor coverage hospital data)
 - Lack of access to data from private sector (e.g. Portugal, Cyprus)



The potential of routinely collected health data

[PLoS Med.](#) 2010 Jan 26;7(1):e1000223.

Meeting the demand for results and accountability: a call for action on health data from eight global health agencies.

[Chan M](#), [Kazatchkine M](#), [Lob-Levyt J](#), [Obaid T](#), [Schweizer J](#), [Sidibe M](#), [Veneman A](#), [Yamada T](#).

World Health Organization, Geneva, Switzerland.

'Better access to data and statistics in the public domain could generate important benefits at country and global levels by fostering collaboration and innovation in statistical and analytic methods, both for new data collection and for better use of existing data.'



Routine health data should be used & usable!

- **Use them**



One could say it is even unethical not to use them; they are there, and should be used for purposes of evaluation, governance and policy development. Patients/citizens may expect that the data are used to their full potential in order to improve health care.

- **Make them usable**

At national and supra/international level actions should be taken to facilitate use routine health data collections for public health purposes; focus of Health Information systems should not only be on variables/indicators, but also on underlying coding practices, linkage possibilities, data exchange, metadata standards, etc. (foundation!)

→ This also applies to common European EC/WHO HI system!

