N.3. Workshop: Diagnose-based morbidity statistics for the European Union

Chairpersons: Marieke Verschuuren, The Netherlands, Monica Pace, Eurostat and Iveta Nagyova, Slovakia

Accessible, high quality and sustainable health care is an important objective of the European Union (EU) and indicators on morbidity are an essential element of every comprehensive public health monitoring effort. Several EU policy frameworks request quantifiable and comparable morbidity statistics for all EU-28 Member States as a basis of evidence informed decisions. Most importantly, these are the Council request for adequate representation of health in the framework of the Europe 2020 Strategy (Council Conclusions on sustainable health information systems, 10 December 2013), and the invitation to continue the monitoring exercise for the uptake of the health theme in the European Semester process. Moreover, there is a need to improve the coordination on health systems performance and to develop concrete EU action towards reducing the burden of chronic diseases. However, morbidity figures are notoriously difficult to measure, and up until now, solid estimates have been lacking at the European level. Eurostat, the statistical office of the EU, acknowledges the importance of high quality, regular data collections on disease incidence and prevalence. Therefore, in 2007, they proposed a methodology and guidelines for a Eurostat morbidity strand, which was followed by pilot data collections in 16 countries. This workshop will inform the participants about the latest state of play of Eurostat's activities on morbidity statistics. Both process and content will be addressed. First, the leader of the project at Eurostat will explain the history of the morbidity strand activities, the current status and the plans for the future. Next, the results of the pilot data collections from one of the participating Member States (Lithuania) will be presented, followed by a presentation on the situation in a country that is presently not yet fit for starting morbidity statistics, but is already working towards such data collection, not only for international, but in particular also for national use (Ireland). After that, there will be ample time to discuss issues such as (problems with and solutions for) data quality and comparability. The added value of this workshop is that it provides an overview of the state of affairs of an important new health information activity in the EU. It is targeted at everyone with an interest in general public health and/or chronic diseases monitoring. The workshop is a joint activity of the EUPHA sections on Public Health Monitoring and Reporting and Chronic Diseases, and Eurostat.

Key messages
- Eurostat morbidity statistics will fill in a major health information gap in the EU trough the provision of regular diagnose-based estimates of incidence and prevalence for a shortlist of 60 diseases.
- The workshop will inform the participants on the latest state of affairs of Eurostat's activities on morbidity statistics. Both process and content (data availability and quality) will be addressed.

Morbidity statistics at EU level
Hartmut Buchow

H Buchow, M Pace, M Domingues De Carvalho
European Commission, DG Eurostat, Unit F5, Luxembourg, Luxembourg
Contact: Hartmut.Buchow@ec.europa.eu

Background
Eurostat's commitment in developing morbidity statistics reaches back to the mid-90s. However, while the domain of health status and health determinants are currently covered by surveys, the core activity on diagnosis-specific morbidity data with incidence and prevalence rates is still missing. A legal basis for such data collection is provided by Regulation No 1338/2008 establishing a framework for Community statistics on public health.

Methods
In 2007, the Morbidity Statistics Development Group (MSDG) presented a methodological framework for diagnosis-specific morbidity statistics including a shortlist of diseases with

about 100 indicators for a minimum data set. Up to 201 116 Member States tested that methodology by national pilot studies. Countries were requested to find appropriate sources for producing best estimates. In 2011, Eurostat established the Task Force on Morbidity Statistics (TF) for analyzing the pilots' results, especially in view of sources and best estimates.

Results

The TF concluded that the study results indicate the feasibility of the approach to report best national estimates from MS with different health and information systems. At the same time, it emphasized the caveats at different levels that prevented the study from reaching complete data sets for all participating countries. Some adaptations in view of indicators and the shortlist of diseases were recommended.

Conclusion

Based on the TF recommendations Eurostat and Member States agreed to go ahead. Eurostat will follow a two-steps approach: first step will be an in-depth inventory by Member States in view of preparedness for reporting high quality estimates on morbidity indicators as requested. In case of promising results, methodology and guidelines will be adapted for the second step: pilot studies in all Member States and subsequent inclusion of morbidity statistics into the European Statistical System.

Comparison of data sources revealed some problems with reporting for widely used communicable and mental disease surveillance systems and limitations of sample surveys, especially problems with sample size and response rate.

Conclusion

Good quality disease-specific registers are still the best morbidity data source but such registers exist only for limited number of diseases. The Compulsory Health Insurance Information System is reliable enough to use it for diagnosis-specific morbidity statistics. This source allows for calculating morbidity of any indicator and disease including rare diseases, avoiding the creation of expensive disease-specific registers, and reducing the burden of data collection on respondents. Sample surveys could be used as a complementary data source for population morbidity for a limited number of diseases or symptoms.

Morbidity statistics in Lithuania
Rita Gaidelyte

R Gaidelyte
Institute of Hygiene, Health Information Centre, Department of Health Statistics, Vilnius, Lithuania
Contact: rita.gaidelyte@hi.lt

Background

Lithuania has long history of collection of diagnosis-based morbidity statistics using registries and summary annual reports from health care institutions. The introduction of new computer technologies and a Compulsory Health Insurance System gave the possibility in 2003 to start using the administrative data source of the Compulsory Health Insurance Information System for health statistics purposes including morbidity statistics.

Methods

During the years 2005-2008, Lithuania has participated in two Eurostat projects on morbidity statistics. During the projects, an inventory of available data source for morbidity statistics was performed. Data sources were evaluated. The methods of data calculation (operational definitions of indicators for every disease) from the Compulsory Health Insurance Information System or combined data sources were developed. Morbidity indicators using the European diagnosis-specific morbidity shortlist were calculated from sources of acceptable quality, and were compared.

Results

The comparison of the data from the Compulsory Health Insurance Information System and other data sources showed that insurance data and high quality diseases-specific registers (cancer and tuberculosis) is comparable; estimates based on data from two different health sample surveys was much higher for hypertension and diabetes as was expected.

Challenges in the Development of a Regular Morbidity Statistics Data Collection
Gráinne Cosgrove

G Cosgrove
Department of Health, Dublin, Ireland
Contact: Grainne_Cosgrove@health.gov.ie

Background
The need for comparable morbidity statistics at both national and EU level is well recognised, however there are significant challenges and barriers to achieving this goal. This is the case in a number of EU Member States including Ireland.

Methods
The Task Force on Morbidity Statistics analysed the data and the reports from the 16 pilot countries. A number of common difficulties among the pilot countries were identified. These included the lack of available data sources, lack of a unique patient identifier, restrictions on data linkage and issues of quality and completeness of data sources. In addition, among countries with relatively comprehensive data on morbidity, other issues including differences in interpretation of guidelines and methodology, difficulties with access to data, and comparability of the resulting estimates were identified.

Results
The work of the Task Force showed that while the future development of a regular morbidity statistics data collection is feasible, this will be more difficult in some countries than in others. Although Ireland did not participate in the pilot project, it is known that many of the difficulties encountered by the pilot countries may also apply in Ireland. This is also likely to be the case in other Member States.

Conclusion
There are many challenges and barriers to achieving comparable morbidity statistics at a national and EU level. It is hoped that developments in the coming years in Ireland including the implementation of individual health identifiers and proposed health information legislation will improve the availability of morbidity statistics, although other barriers such as a lack of available data sources will be more problematic to overcome in order to achieve the goal of a regular morbidity statistics data collection.