Morbidity Statistics in the EU – key results from pilot studies in sixteen Member States.

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Abstract This article focuses on pilot studies on diagnosis-specific morbidity statistics conducted by sixteen EU Member States from 2005 to 2011 in view of establishing European Union (EU) morbidity statistics. The Eurostat 'Morbidity Task Force' analysed the results of the pilot studies and formulated a set of recommendations on the feasibility of a regular EU morbidity statistics data collection, based on a multi-source approach and best national estimates on incidence and prevalence for a selected list of diseases. This paper presents some examples of the main findings, problematic aspects and proposed solutions that the Task Force reported on potential sources and best estimates with regard to accessibility, usefulness, overall quality and comparability.

Key words: Morbidity Statistics, Administrative data, Incidence of diseases, Prevalence of diseases, Data linkage.

1 Introduction

The lack of systematic and official data on morbidity has severely hampered the development of public health indicators at EU level for supporting health policies. The recent Commission staff working document “Investing in health”¹ (which is an accompanying document to the ‘Social Investment Package’) defines the role of health as part of the Europe 2020 policy framework and points out that an improvement in health data collection is needed, in particular in developing tools to better assess the efficiency of health systems. In addition, the statistical information on specific chronic diseases is a key component in underpinning and addressing policies to improve the labour market participation, risk of social exclusion and risk of poverty.

Eurostat’s commitment in developing the conceptual and methodological framework for establishing a regular data collection on morbidity has a long-standing tradition. The legal basis for such data collection is provided by Regulation No 1338/2008 establishing a framework for “Community statistics on public health and health and safety at work”[1].

Establishing morbidity statistics is an extremely complex exercise from a methodological and operational point of view, in particular with regards to comparability of data across countries.

The demand for statistical data on diagnosis-based morbidity is increasing; however, the capability to respond to this increasing demand is constrained by limited data availability, quality, and use.

The paradox for Europe is that sometimes there is a wealth of information available for specific diseases, but this information is often scattered, sparse, not representative for the total population, not collected systematically and not

addressing the multidimensional characteristics of health. For many other diseases there are only scarce examples at national level. The result is a fragmented picture concerning the occurrence of diseases in the EU, often driven by the needs of a single disease program or ad-hoc data collection, information on incidence or prevalence only - where both indicators should be advisable - or an inefficient use of the available sources, of information collected, and resources allocation.

Lastly, the national legal framework for accessing and processing the available data from different sources poses obstacles that need to be addressed and solved. It is desirable that a future revision of the statistical law (COM (2012) 0167) will allow the partners of the European Statistical System (ESS) to reduce those constraints.

The pilot studies in 16 Member States (MS) showed the feasibility of the proposed methodology for many of the 105 indicators (both for incidence and prevalence) that are included in the Eurostat Morbidity Short List.

2 The current framework in developing diagnosis-specific statistics: the example of costs

The responsibility for the organisation and delivery of health services and healthcare is largely held by the Member States at national and sub-national level. However, the Commission is asked for actions whenever there is a need to complement Member States’ health policies, in particular in areas such as health promotion, prevention, research or dissemination of information by public health data collections within the ESS (European Statistical System).

The 2012 report on ageing from ECFIN clearly highlights the lack of comparable data on health status (morbidity) as a prerequisite for estimating projections of health care costs in the EU [3].

On average health spending per capita across EU MS increased by 4.6% per year in real terms between 2000 and 2009. This was followed by a reduction of 0.6% in 2010, as a consequence of to the economic crisis [4]. Given the significant reduction in health care expenditure in some European countries, the importance of morbidity statistics will be even greater for monitoring the resulting impact on Public Health.

On the other hand more effective prevention influences incidence and/or prevalence of diseases over time with an impact on health expenditure.

An example of how the problem could be addressed is provided by The Netherlands by an analysis of the cost of illness conducted by the National Institute of Public Health and the Environment (RIVM) in cooperation with Statistics Netherlands [5]. The main reasons for the increase in costs are: 1. ageing of the population (explains about 15% of the cost rise over the entire period 1999-2010); 2. price inflation (explains about 35%); 3. interrelated set of causes such as policy changes, easier access to services, the growth of the number of patients treated, more intensive treatment and the implementation of new medical technology (explains about 50%). In spite of ageing, the largest increase in costs over 2005-2010 occurred in young people (ages 1-24). A higher use of youth care and a change in the rules for admittance to care for the people with disabilities explain a steady increase.

Although women use more health care than men, since 2005 the costs increased faster for men than for women. This is partially due to improved male health: they live longer, and therefore use more health care, particularly at older ages.

3 The importance of morbidity statistics at National level

The benefits for MS to collect and report a set of morbidity data that are comparable at EU level should not to be underestimated. On the one hand morbidity statistics at
national level are cornerstones for monitoring and evaluation of morbidity developments in general and specific programmes in particular. On the other hand morbidity statistics that are comparable among EU-28 are the basis for comprehensive planning, e.g. in view of monitoring specific health and welfare programmes needs of human and physical resources, insurance costs and expenditures for health care activities.

A specific example for the needs for internationally comparable morbidity data is represented by issues on cross-border health care provisions, an increasing phenomenon and burden in several MS. The EU morbidity pilot studies showed that for several diseases coverage of the total of the population is far from being achieved in all MS. Coverage by existing data is sometimes missing substantial numbers of cases. If mainly data from hospitals are used, then patients whose diseases are treated by general practitioners may not be adequately represented in the national data collection system. Such lack of information may distort the national estimates on the incidence and prevalence of diseases, as well as the allocation of resources.

4 Characteristics of the pilot studies and of the Eurostat Task Force on Morbidity Statistics

Two waves of pilots have been carried out with the following common objectives:

a. Inventory of potential national sources for diagnosis-specific morbidity data

The aim of this part of the methodological approach was to identify, describe and evaluate potential national sources for diagnosis-specific morbidity statistics.

b. Elaboration of a methodology for producing best national estimates on incidence and prevalence, according to the short list MORB and the existing guidelines

The emphasis was on providing the best national estimates through a well described and valid procedure that had been developed by the Morbidity Statistics Development Group (MSDG) in 2007 [6].

c. Pilot data collection

The proposed methodology was subsequently tested by pilot projects, using the same data reference year (2005).

Countries participating in the pilots were:

- Wave I (2005-2006). In the context of the Transition Facility Programme 2005, 9 new MS - Cyprus, the Czech Republic, Estonia, Hungary, Lithuania, Latvia, Malta, Slovenia and Slovakia – assessed the overall practicality and feasibility of the methodology proposed by the MSDG.
- Wave II (2007, 2009). The projects covering years 2007-2009 involved, Austria, Belgium, Finland, Germany (participated to both calls of wave II), Poland, The Netherlands, and Romania. The final reports from this second wave were completed and made available for analysis in 2011.

In the second half of 2011 when the Task Force on Morbidity (TF MORB) was agreed by all MS at the Working Group on Public Health Statistics (WGPH) meeting. The TF MORB assisted Eurostat in analysing the estimates produced during the pilot studies by assessing the quality and comparability of the pilot results, and to produce the report “Morbidity statistics in the EU - Report on pilot studies - 2014 edition” [7].
5  Results - Selected examples from the pilots

The European Statistical System (ESS) is undergoing a process of modernisation. One of the pillars is the improved use of administrative sources. From this standpoint, the pilots performed in 16 MS show encouraging results and methodological challenges that need to be addressed in order to establish an EU data collection on morbidity.

One of the most relevant features of morbidity statistics is to have the possibility of linking data from different sources. Some pilot countries reported best national estimates by linking individual data from different sources. In other cases data were available based on one national data source. The high potential of health insurance data was explored for several diseases. The estimates reported showed that the proposed methodology allows comparisons across countries. For a complete overview of the methods and results please refer to the report and annexes [7], or papers at the Eurostat website [8, 9].

5.1 The importance of unambiguous diagnosis and definition: the case of schizophrenia

The detailed analysis of the pilot studies shows the importance of clear, univocal diagnostic criteria for the selected disease and suitable national sources for obtaining comparable estimates across countries. This is the case for schizophrenia (F20-F29), where estimates for age-standardised rates for period prevalence have been made available by nine countries. Only 2 countries have no data for schizophrenia. Eight countries used health insurance data (CZ only provided crude rates; DE not shown), whereby PL and FI used a combination of insurance and hospitals data and RO DRG-based data. The case of Latvia is interesting because a specific "Register of patients of the State Mental Health Agency" exists and provides results of the same scale as those derived from the insurance datasets. However, full comparability of these figures is missing because some of the identified sources are episode-based (HU) and some others are clearly stated as person-based (PL).

Figure 1: Schizophrenia (period prevalence)

The example on schizophrenia shows that comparable estimates can be obtained: 1. in the case of clear case definition and diagnostic criteria; 2. when suitable, even if different types of sources are available and used alone (Diseases-specific register for LV, or insurance data for EE, HU, LT, PL, or ambulatory care providers data for SK) or in combination (FI: linkage of Hospital Discharge Register for health
institutions and Social Insurance Institution data on disability allowances). On the other hand purely administrative data such as hospital in-patient based data (SI and RO) do not provide realistic estimates for schizophrenia. 3. In the case of schizophrenia, the treatment requires the use of specific medicines and the prescriptions are recorded by health insurance data, which are therefore a suitable source, as identified by some pilot countries in their national contexts. 4. As prevalence of schizophrenia is more or less the same across populations (around 1%), the systems in place in several counties seem to provide similar information.

5.2 What we could gain from low-prevalence diseases: the case of multiple sclerosis

The case of multiple sclerosis is relevant in the sense that the estimates are derived from several different sources and show a consistent higher prevalence in females, in accordance with the scientific literature.

Figure 2: Multiple sclerosis (period prevalence)

The example on multiple sclerosis prevalence shows that: 1. different population-based sources could be used for estimating multiple sclerosis prevalence. 2. The gender pattern of higher prevalence in females compared to males is consistently observed in all of the reporting countries. Despite this evidence, other problems such as under coverage or similar biases cannot be ruled out, but it confirms a general pattern known from the literature, and upon which some methodological refinements could be built. 3. The proposed approach could represent a considerable improvement compared to the traditional tools such as HIS surveys, particularly for a disease with such a relatively low rate of prevalence. In fact, for low-prevalence neurodegenerative diseases such as Parkinson's disease or multiple sclerosis, substantially large sample sizes are required, with considerably higher costs for performing the data collection.

5.3 When data linkage seems to be the solution: the case of Dementia (including Alzheimer)

Prevalence estimates for dementia including Alzheimer disease were requested in the morbidity shortlist. The importance of linkages can be clearly seen in the following example from the Finnish pilot study. The numbers of patients with dementia
(including Alzheimer’s disease) were similar in the hospital discharge register covering health and social welfare institutions (79.656) and in the disability allowance register (80.612). However, merging these data sources with ID number gave a significantly higher number of people with dementia (134.284) which increased the estimates based on a single source by 69% and 67%, respectively. As reported in the graph below the estimates from FI are much higher compared to those of other pilot countries regardless of the type of source used.

In some other countries linkage of individual records is not feasible due to legal restrictions, high costs or time-consuming linkage processes.

### Figure 3: Dementia (including Alzheimer disease) (period prevalence)

The example on dementia shows that: 1. The possibility of linking relevant data sources has a high potential for the establishment of an EU data collection on diagnosis-specific morbidity. 2. Similar approaches, such as merging of aggregated data should be further investigated, as these could be feasible in other EU countries.

### 6 Conclusions

The pilot studies in 16 MS indicate the potential for developing diagnosis-specific morbidity statistics that fit the requirements of the European Statistical System (ESS) in general and of the European public health statistics system in particular.

The approach based on best national estimates, as identified and described in the existing guidelines, proved to be feasible in different MS with different health and information systems. At the same time study results indicate caveats at different levels that prevented reaching complete data sets for all participating countries.

Despite the current limits in the pilot data collections and its quality, the final result is promising. Eurostat recently launched a restricted call for proposals to National Statistical Authorities in order to proceed in establishing diagnosis-specific morbidity statistics.

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8 References

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