# Diagnosis-specific morbidity statistics in Europe

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# Diagnosis-specific morbidity statistics: Key elements

- The aim of diagnosis-specific morbidity statistics is to have a comprehensive overview and an adequate summary on the occurrence of diseases at population level

- through regular and sustainable data provision within the European Statistical System (ESS) for a selected set of diseases (Eurostat Shortlist MORB)

- The methodological approach for diagnosis-specific morbidity statistics goes beyond the use of single sources towards using information from several sources (if needed) for making best national estimates. The main emphasis is on a common output at EU level, irrespective of the national sources

- The main precondition for including a data source is that it has to be as far as possible statistically robust on the main relevant data quality parameters and hence permit reliable inter country comparisons. Whenever necessary any suitable source may be adapted in order to improve the quality of the measure

- Like many EU statistics, the compilation of diagnosis-specific morbidity statistics is output driven and not source oriented

# Why EU Morbidity Statistics are not yet in place?

- "European paradox": many sources exist, information is/can be available for specific diseases
- Each country operates in own Institutional environment, shows differences in the available sources and health systems
- In some cases the progresses have been halted by restrictive interpretation of Laws and regulations, and sense of "data ownership"
- In many cases the lack or unavailability of patient unique identifier poses barriers to data linkage for statistical purposes

**However…**

- The factual development and implementation of integration of sources and/or outputs is growing in many statistical domains in recent years
- The new EU Statistical Regulation **759-2015** (amending Regulation 223-2009) clarifies the role of NSA (National Statistical Authorities) in accessing and using administrative data for statistical purposes

# Morbidity statistics in EU so far

- 2003: London seminar on Morbidity Statistics
- 2007: Eurostat MORB guidelines and shortlist of 67 diseases/ext. causes
- Regulation 1338/2008 on Public Health Statistics
- 2005-2011: Pilot studies in 16 Member States
- 2012-2013: Task Force MORB – In-depth analysis of pilots
- Dec. 2013: TF MORB report adopted by Member States
- 2014-16: New EU project on National inventories

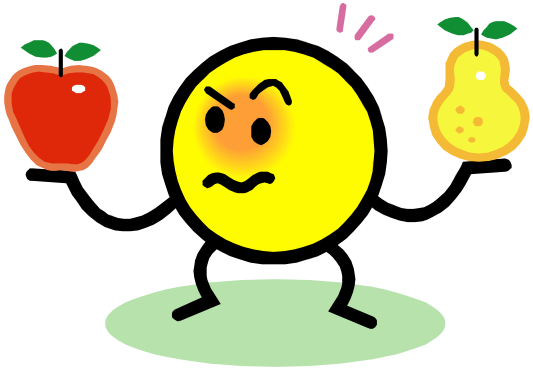
# Morbidity statistics in the EU: is it feasible?

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

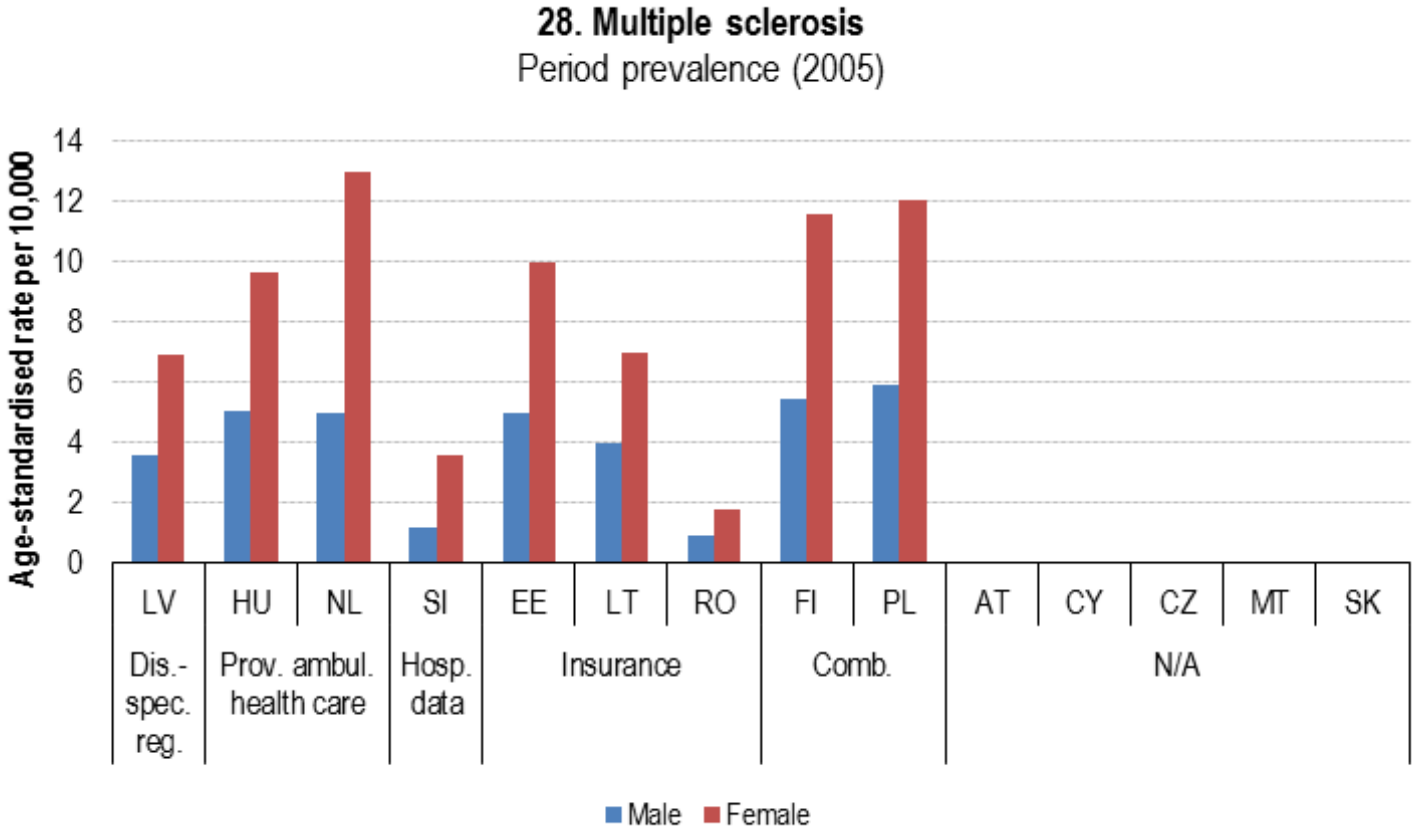
- Successful results on best national estimates on incidence and prevalence are strongly related to the possibility of accessing, and processing information from different sources, implying a good level of inter-institutions collaboration

- The pilot studies in 16 Member States showed the feasibility of the proposed methodology for many of the 103 indicators (both for incidence and prevalence) that are included in the Eurostat Morbidity Short List (SL MORB)

- The Eurostat Task Force on  Morbidiy recommended to go ahead, agreement by MS at the Working Group on Public Health Statistics on December 2013

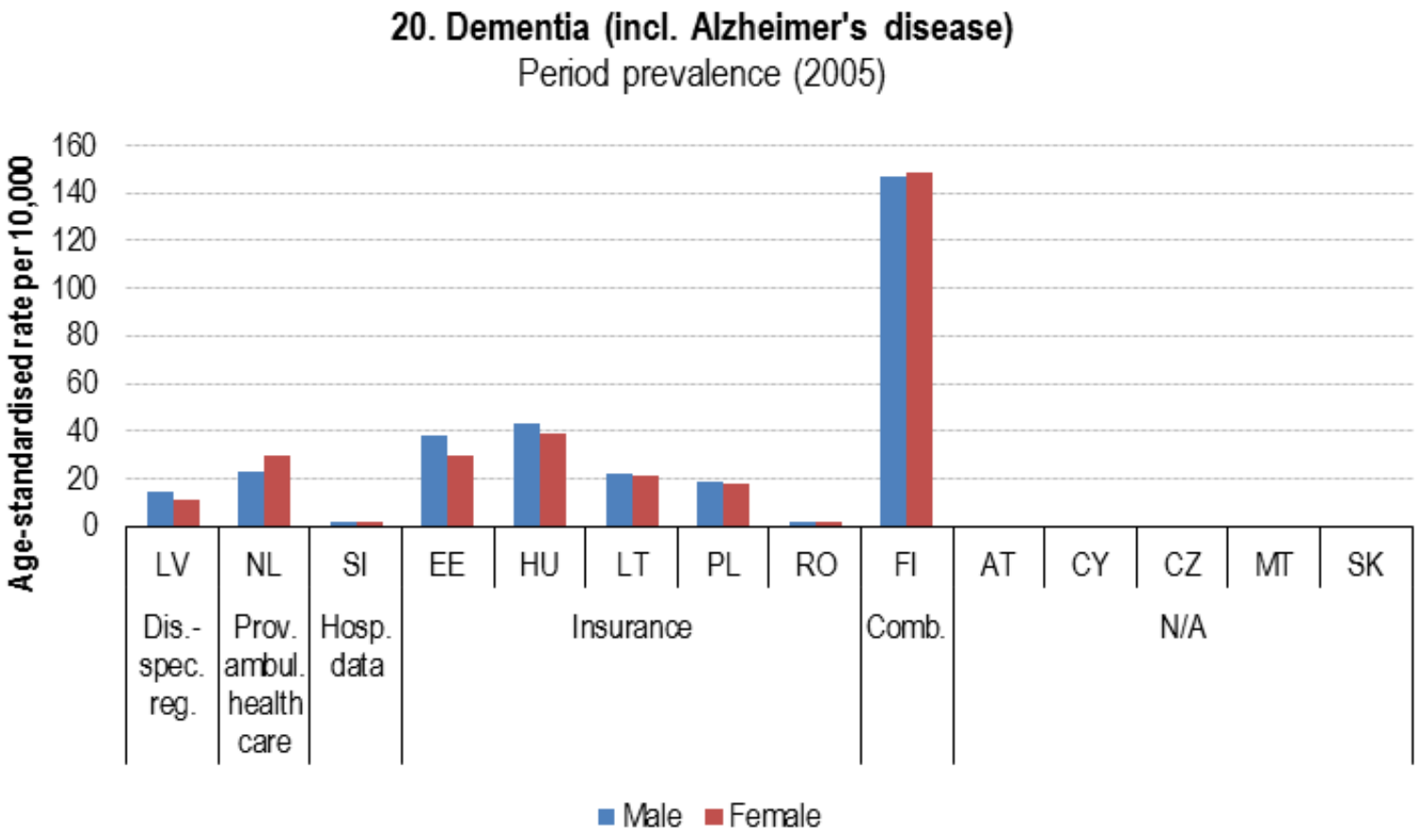


# Examples from the pilots – Low-prevalence diseases




For Romania the data refers only to DRG hospital data.
Combined sources: FI: Registers on Social Benefits under the National Sickness Insurance Scheme: special reimbursements of medicine + Registers on Social Benefits under the National Sickness Insurance Scheme: disability allowances; PL: National Health Fund – inpatient care + National Health Fund – ambulatory specialist care

# Examples from the pilots –When data linkage seems to be the solution: Dementia




Combined sources - FI: Hospital Discharge Register + Registers on Social Benefits under the National Sickness Insurance Scheme: for disability allowances

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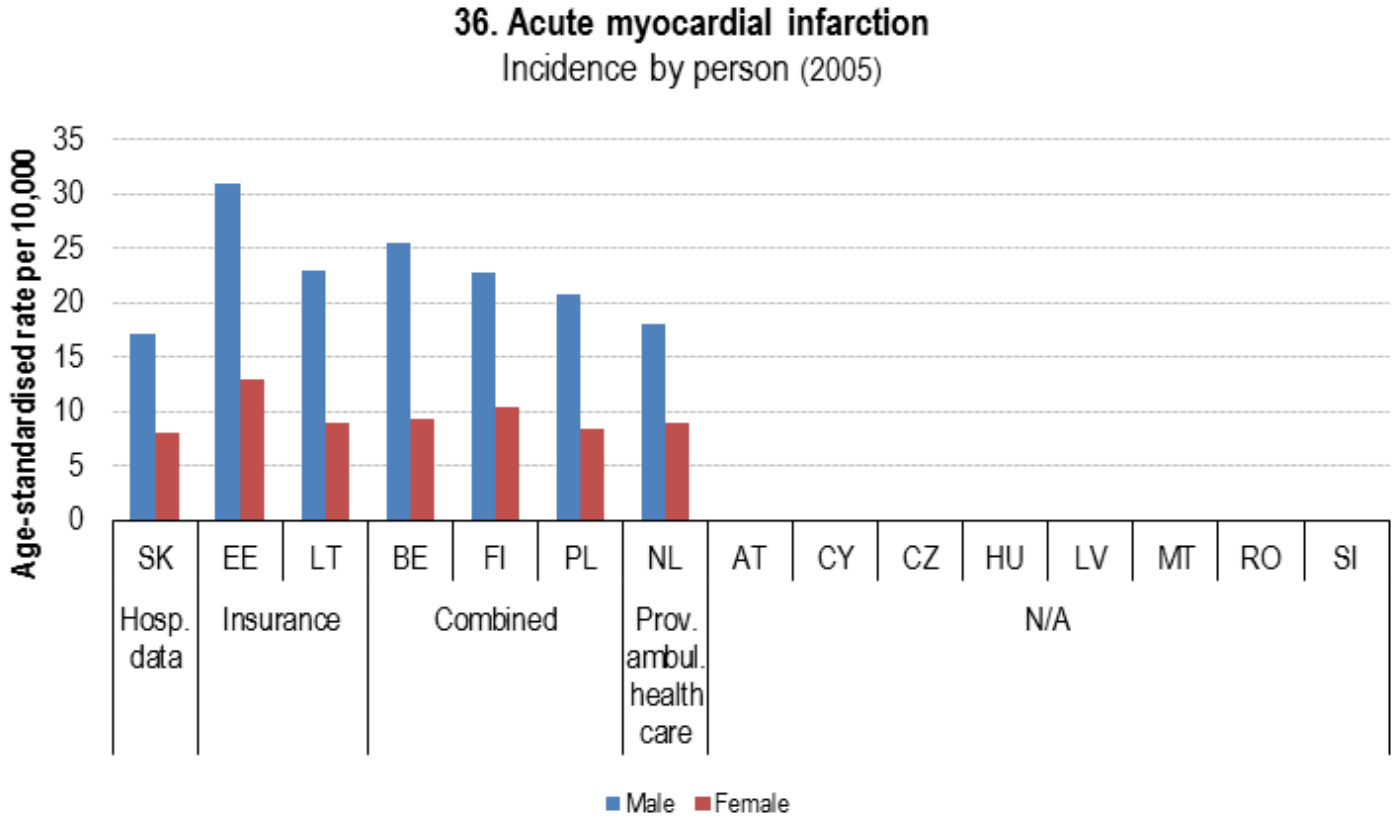
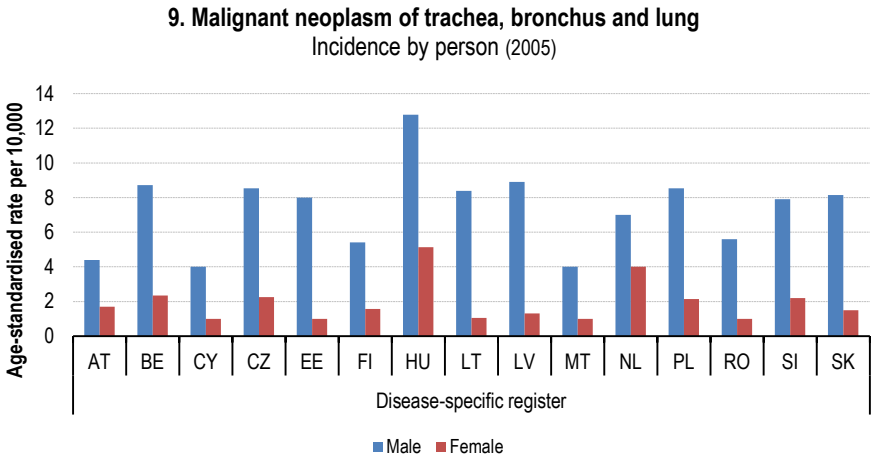
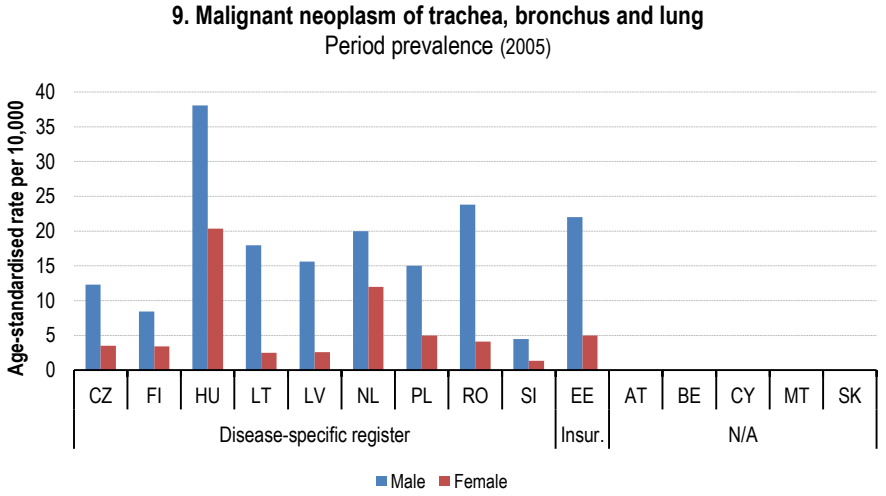
# Examples from the pilots – the case of acute myocardial infarction (AMI)



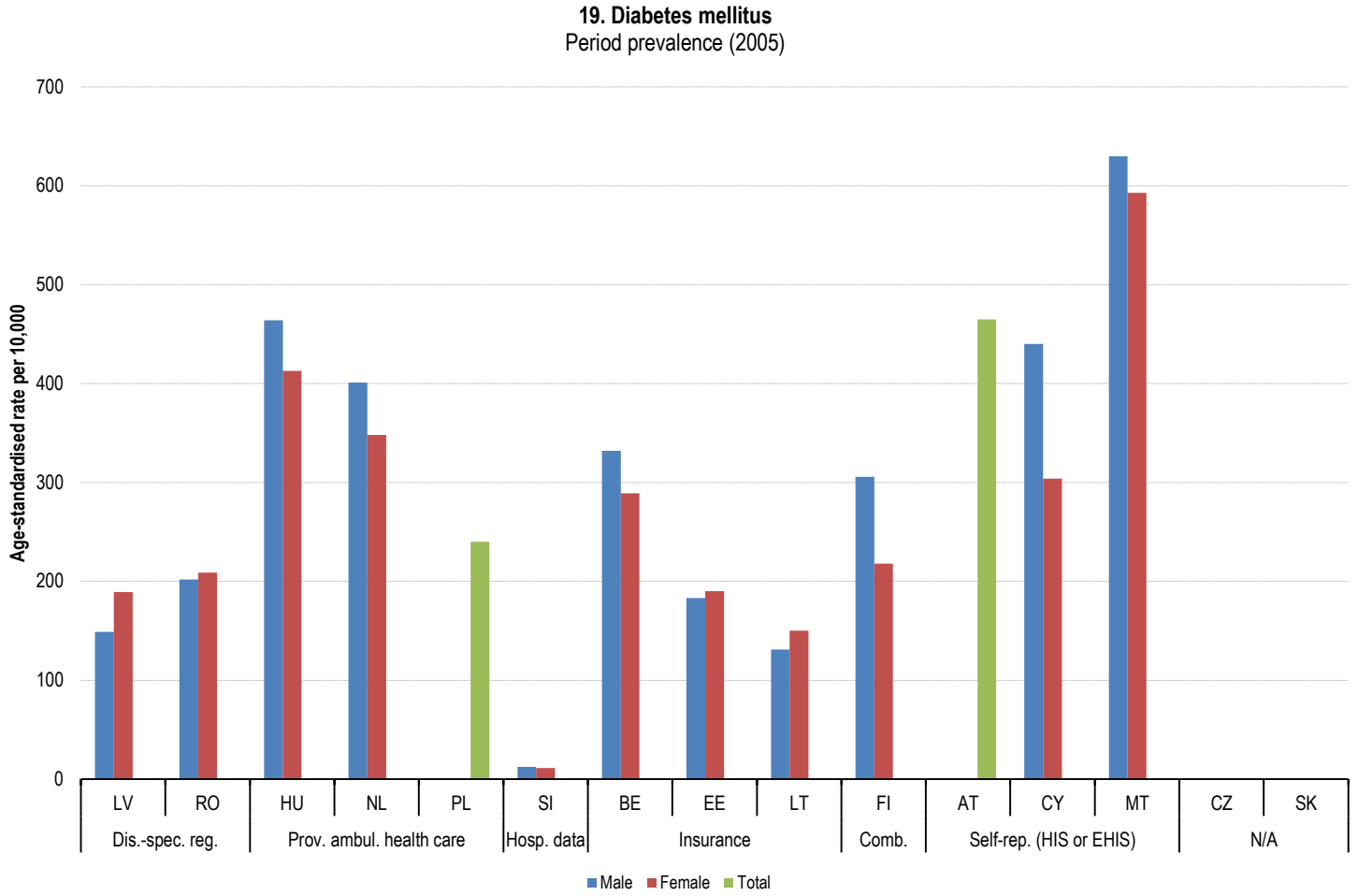

Combined sources: BE: Hospital discharges + Mortality Registry; FI: Hospital Discharge Register + Registers on Social Benefits under the National Sickness Insurance Scheme: special reimbursements of medicine + Registers on Social Benefits under the National Sickness Insurance Scheme: disability allowances; PL: Hospital Morbidity Study + Statistical Survey of the Mortality

# Examples from the pilots – Malignant neoplasm of trachea, bronchus and lung



# Examples from the pilots – Diabetes mellitus




Combined sources: FI: Registers on Social Benefits under the National Sickness Insurance Scheme: special reimbursements of medicine + Registers on Social Benefits under the National Sickness Insurance Scheme: disability allowances.

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# Lesson learned towards integration of Morbidity Statistics in the ESS

- 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)

- 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, results are promising and MS are willing to continue

- The ongoing EPIMS Project (European Project of Inventories on Morbidity Statistics) will provide an up-to date information and provide the evidences for next steps

# Morbidity statistics in the EU: Action Plan


## 1st step up to 2017

- National Statistical Authorities to provide National inventories on current situation
- Analysis by 2017 – basis for Member States to decide on continuation of the process

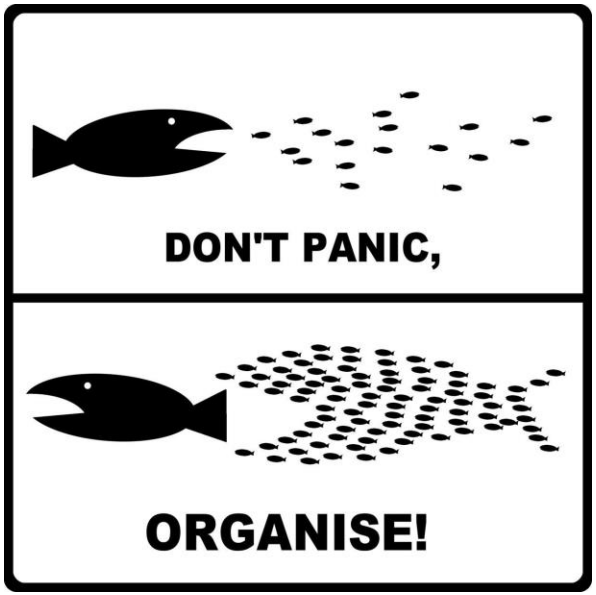
## 2nd step (Based on agreement to integrate MORB into the ESS)

- 2018-2019 pilots based on gentlemen's agreement with Member States
- 2020 implementing Regulation on diagnosis-specific morbidity Statistics

# Where do we go from here?

Some of the challenges may be overcome in the coming years

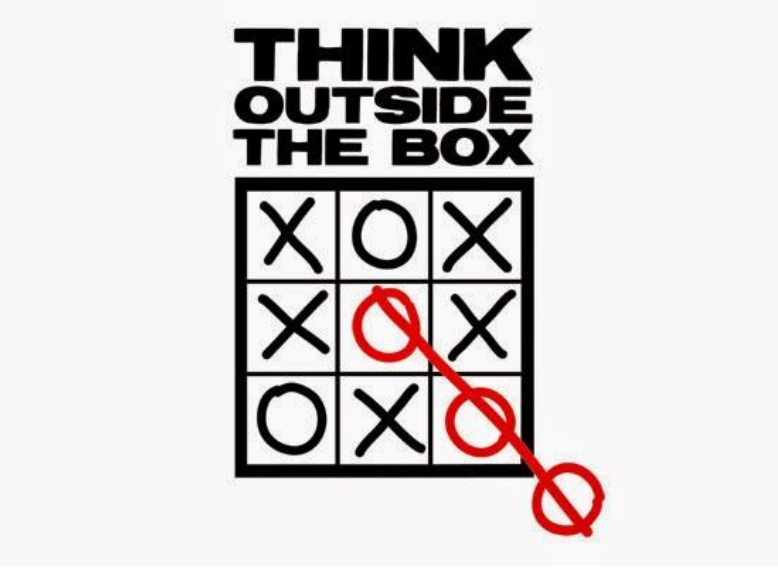
- Availability of data for consecutive years
- Improved access to (administrative) data for statistical purposes
- Implementation of unique patient identifiers




Other difficulties may be harder to overcome

- Lack of resources
- Changes in data protection regulations

# The challenges Official Statistics faces in a changing world




- Comply with quality requirements and EU code of Practice
- To be: wider, deeper, quicker, better, cheaper, less burdersome, more relevant*
- Think „outside the box“ !
- Identify/integrate data sources and models that address the underlying information need rather than worked for an *a priori* concept of what tools are appropriate*

* C. Citro, 2014 - modified

Thank you for your attention

Questions?

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# Further reading


- The Eurostat  Task Force Report on the Morbidity Statistics pilot studies: http://ec.europa.eu/eurostat/web/products-statistical-working-papers/-/KS-TC-14-003
- From multiple modes for surveys to multiple data sources for estimates. C.F. Citro; Statistics Canada, Dec. 2014. http://www.statcan.gc.ca/pub/12-001-x/2014002/article/14128-eng.pdf
- Access to Sensitive Data: Satisfying Objectives Rather than Constraints. F Ritchie; J. Off. Stat, Vol. 30, No. 3, 2014. http://dx.doi.org/10.2478/JOS-2014-0033
- Evaluating administrative data quality as input of the statistical production process. F. Cerroni, G. Di Bella, L Galiè. Riv. Stat. Ufficiale, 1-2, 2014. (Progetto BLUE-ETS)
- Statistical matching: a model based approach for data integration. Eurostat, Methodologies and Working papers, 2013. http://ec.europa.eu/eurostat/web/products-statistical-working-papers/-/KS-RA-13-020
- Utilizzo epidemiologico di archivi sanitari elettronici correnti. A cura di L. Simonato, C. Canova et al. Epidem. & Prev. Anno 32 (3) 2008 Suppl.
- The European Statistical System – Vision 2020. http://ec.europa.eu/eurostat/documents/10186/756730/ESS-Vision-2020.pdf/8d97506b-b802-439e-9ea4-303e905f4255
- Codice delle Statistiche Europee http://ec.europa.eu/eurostat/documents/3859598/5922217/10425-IT-IT.PDF
- European Core Health Indicators Monitoring (ECHIM) http://www.echim.org/index.html

# Eurostat Work plan – 2014 (adapted)

| Objective Title (defined in the ESP 2013-2017 annex) | P&P Title + Description (project and process description of Eurostat's activities aiming at producing the desired output(s)) | Outputs Title (what Eurostat plans to deliver in 2014) |
|---|---|---|
| 04.2 Provide key macroeconomic and social indicators | Project on efficiency of health systems:<br><br>1) **Morbidity statistics**: in the area of public health statistics, development of the final methodology for a regular data collection on best estimates for diagnosis-specific morbidity statistics<br><br>2) **Health Expenditures by Diseases and Conditions (HEDiC)**: in the area of public health statistics, development of a methodology and guidance for a systematic monitoring of transactions for specific diseases within the health systems at EU level | 1) Launching a feasibility study on diagnosed morbidity statistics based on recommendations by the Technical Group Morbidity statistics and the Working Group Public Health statistics<br><br>2) Submission to the WGPH of a progress report of a new 3 year project: inventory on possibilities and problems associated with breaking down health expenditures by diseases, age and gender at EU level, with recommendations for a minimum data set of diseases /disease categories for piloting |

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# Grouping of sources in the graphs

| Category | Sources included in the category |
|---|---|
| **Disease-specific register** | Includes administrative public health registries and different kinds of administrative reports. |
| **Hospital data** | Includes data from hospitals discharges both for inpatients and day cases. For Finland: Data on hospitals includes inpatient care, day cases and outpatient care excluding groups related to external causes of injuries and accidents (groups 57-60 and A-G) which only include inpatient care and day cases. |
| **Providers of ambulatory health care** | Includes data from General Practitioners' information systems, such as reports on GPs activities, primary care information systems, prescriptions from information systems, data for outpatients and data from specialists (providing care outside a hospital). |
| **Insurance (reimbursemnt-driven source)** | Includes data from compulsory health insurances and from voluntary ones. For Romania insurance data source refers to hospital data. For Latvia there are two possible mutually exclusive options - data can refer to out-patient or in-patient data set. |
| **Self-reported (HIS or EHIS)** | Data from HIS and EHIS surveys. |
| **Combined** | Includes linked/merged information from different data sources. |
| **N/A** | Non available data. This may include situations where the pilot countries did not provide the standardized rates, but only the crude ones. This was mainly due to a certain level of uncertainty about the estimates. |

From the Eurostat Task Force Report on the Morbidity Statistics pilot studies (Annex 1):
http://ec.europa.eu/eurostat/web/products-statistical-working-papers/-/KS-TC-14-003