Principles and guidelines for diagnosis-specific morbidity statistics

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- Version 1.1 -

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Preliminary remark

The present 'Principles and guidelines for diagnosis-specific morbidity statistics' aim to provide an overall description of the process for producing best national estimates for diagnosis-specific morbidity statistics. However, the overall practicability and feasibility of the proposed methodology needs to be assessed. In order to test the approach, the proposed guidelines are intended mainly to be used for trial purposes and pilot data collection, e.g. in the context of the pilot projects on morbidity statistics funded by the Transition Facility Programme 2005 or by a grant funded by the Eurostat 2007 financing decision. The experiences and results of national pilot projects will be analysed by Eurostat, and the information will also be used to elaborate and improve these guidelines in order to produce a final set of methodological guidelines for regular data compilation.

At the European level, it is planned to make diagnosis-specific morbidity statistics available for a predetermined list of diseases set out in a shortlist. While the guidelines are in principle applicable for each entry in the recommended shortlist, it is acknowledged that in the context of the pilot projects it might not be feasible to test the proposed approach for all diseases mentioned in the shortlist. There may be several reasons for this, including lack of availability of reliable data or resource constraints. In such circumstances, countries should concentrate their efforts on selected (rather than all) diseases.
Chapter 1 Background and purpose

This chapter provides information about European public health statistics in general focusing on how diagnosis-specific morbidity statistics are located within this framework and why diagnosis-specific morbidity statistics are required at EU-level. The work of Eurostat towards meeting these requirements is outlined and the overall approach for creating diagnosis-specific morbidity statistics is introduced.

1.1 Public health statistics – the national and the European dimension

In the realm of health statistics a comprehensive description of the status of health of populations is rare. The most common method used is a description on the basis of health indicators. The majority of health indicators comprise selected causes of death (COD), some data from health interview surveys (HIS) and data on selected diseases. Such lists of indicators give a first impression of the status of the population’s health but rarely lead to firm conclusions related to all or major diseases. At the national level, most studies of morbidity combine results from epidemiological studies, for example, health interview surveys (HIS), causes of death data (COD) with a myriad of other sources. This last composite category includes a multitude of national administrative sources, e.g. accidents at work and road traffic accidents; disease registrations, (e.g. cancer); data from health care providers, (e.g. hospital patients); legal notifications, (e.g. infectious diseases); and specific research findings. Such studies vary between countries, mainly because the data used are dependent on the organisation of their national health care systems. As a consequence there are little or no similarities between the national studies. Nevertheless, at a national level, these studies have great value.

At the international level the efforts for comparable statistics on morbidity mostly are limited to lists of indicators. Those on COD and on HIS are considered as the core elements for international statistics. However, the necessary, complementary information on incidence and prevalence of diseases remains a major problem because of the variety of national sources and the fact that most data sources for morbidity are derived from health care systems which are country-specific. As a result, statistical descriptions of the status of health at international level are limited and biased. In this context, the most well-known endeavour was the WHO study on the burden of diseases¹ which was conducted in 2000.

At the EU level a major challenge for health statistics was to agree on an EU system of public health statistics in general and, more specifically, on some core health statistics. This development was regarded as establishing a sound basis for the description of the status of health of the European population as well as of other elements of public health in general and for comparisons between Member States (MS). The system was agreed in 1998 and the components were developed gradually. The production of COD and HIS statistics at EU level have been major achievements. However, problems in the development of diagnosis-specific morbidity statistics for the statistical description of the status of health at population level still need to be solved, and these principles and guidelines propose a methodological approach for filling the gap in the data.

¹ See http://www.who.int/topics/global_burden_of_disease/en/
1.2 Diagnosis-specific morbidity statistics in the EU system of public health statistics

An **EU system of public health statistics** was approved by the Statistical Programme Committee (SPC) in 1998. The system consists of **three major pillars**: one on the status of health, one on the health care resources and one on health determinants. The last pillar was developed partly by including variables in data collections of the two other pillars, mainly in HIS, and partly by making use of other data sources. The pillar on the status of health is composed of HIS, COD, disability data and diagnosis-specific data. **Data from health interview surveys and diagnosis-specific data are complementary sources.** HIS provide data on health as perceived by the individuals whereas diagnosis-specific statistics are intended to provide data on health as observed by medical professionals. It has to be born in mind that this difference also has an impact on the data produced and their interpretation.

In order to implement the European system of public health statistics, an **organisational structure** called "**Partnership on health statistics**"\(^2\) was created. Up to 2006, the work was structured into three strands: causes of death statistics (COD), health care statistics (CARE) and health interview surveys (HIS). Diagnosis-specific morbidity statistics (together with disability statistics) were included into the HIS strand. In 2007, a separate (fourth) strand of the Partnership on health statistics was introduced for diagnosis-specific morbidity statistics (MORB). The reason for creating this fourth strand was that the collection of morbidity statistics cuts across all three existing strands, requiring expert input from HIS, CARE and compatibility with classifications used in COD, as well as coordination with other EU or international agencies (European Centre for Disease Prevention and Control\(^3\), International Agency for Research on Cancer\(^4\) of WHO).

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**. In health statistics the measurement of morbidity utilises the same methodology as that for descriptive epidemiology. A methodologically sound monitoring of morbidity, along with the contribution of specific epidemiological studies, will provide the foundation for exploring patterns in and causes for occurrence of diseases. This, in turn, might lead to arranging better ways for effective prevention and treatment of diseases.

1.3 Why diagnosis-specific statistics are difficult to produce whilst becoming more important at international level

Some major changes in mortality patterns took place in the last decades. This raises the question of which factors are responsible for these changes in incidence of diseases and in case fatality ratios\(^5\). In the latter case one can ask what is the dominant factor. Such questions are of great importance for public health policy.

One of the **major reasons for the change in the mortality patterns** was the result of improved treatment indicated by **lower case fatality ratios** although its quantitative impact is


\(^3\) [http://www.ecdc.eu.int/](http://www.ecdc.eu.int/)

\(^4\) [www.iarc.fr](http://www.iarc.fr)

\(^5\) Case fatality ratios are used to describe the severity of a disease. It is the proportion of persons diagnosed with a disease who actually die from this disease during the period of observation.
difficult to measure. For a long time case fatality ratios for the major killing diseases – in particular cardio-vascular diseases and cancers, covering together about 65 to 70% of all deaths – were very high, sometimes 100%. It was these diseases that, together with traffic accidents and some communicable diseases, attracted the major attention in public health. For relatively short spells of time, e.g. for one year, mortality rates reflected reasonably well the occurrence of major diseases. Therefore annual trend data of cause specific mortality were a good reflection of the course of these categories of diseases and, to a lesser extent, highlighted regional and country specific differences. The picture on morbidity was completed with information from the compulsory notifications of communicable diseases and from some other population-wide data collections, e.g. on traffic accidents and accidents at work. A combination of mortality data and data from some specific registrations gave a fairly adequate picture of the occurrence of major diseases, mainly in terms of incidence.

**Decreasing case fatality and ageing** has led to a situation whereby other diseases have become more prominent. Improved medical knowledge, better diagnostic facilities and public awareness have also contributed to a change in the demand for data: Eurostat receives more and more requests for data on chronic diseases, as well as for data on some aspects of disability, e.g. activity limitations. Many of the emerging new requirements are partly covered by information coming from population surveys, e.g. health interview surveys (HIS). These data sources allow cross-tabulations of data on self-reported health with other variables such as utilisation of medical care or socio-economic variables such as income, level of education or activity status. However, HIS data can cover only one part of the statistical information required for describing the evolution of health status and for determining the need and demand for health care. Beyond that, statistical information as determined by medical professionals (i.e. diagnosis-specific data) is indispensable.

The recent requirements from users for diagnosis-specific information can be classified in a few broad categories. First, there is the demand for data about traditional groups of non-communicable and chronic diseases, such as specific types of cancer, chronic obstructive pulmonary disease (COPD), cardio-vascular diseases or diabetes. The second category relates to ageing, with requirements for data on dementia and degenerative diseases of the locomotive system. The third category concerns diseases caused by health behaviour, such as food and drinking patterns (e.g. food borne diseases) or by lifestyles (e.g. AIDS). Sometimes there are questions on rare diseases. More and more there are also questions about the impact of diseases on the health care system, not only in terms of cure, but also in terms of prevention, i.e. occupational diseases. The emphasis is now more often on diseases calling for substantial efforts of manpower or involving heavy costs with respect to cure and care. This makes hospital records and other registration in health services an important source for disease-specific morbidity.

It could be argued that existing diagnosis-specific morbidity data gradually have become less adequate for determining the need and demand for health care services and for developing preventive measures while on the other hand the pressure on the health care services has increased. The pressure for making priorities in public health has probably never been so strong but the availability of appropriate morbidity data has not increased proportionately. Moreover, for international comparability the national sources have become less adequate because most of them have been created around the organisation of the national health care services.
So there are several reasons to reflect on diagnosis-specific morbidity statistics at European level. Innovative ways have been explored by the WHO under the projects called ‘burden of diseases’; however, this approach also requires inputs of reliable morbidity data from different sources. The WHO approach also relies heavily on estimates and assumptions around the measurement of burden expressed in Disability Adjusted Life Years (DALY), Disability Free Life Expectancy (DFLE), etc.

1.4 Requirements for diagnosis-specific statistics at European level

Requirements for morbidity statistics can be derived from various programmes of the Commission such as from the Community action programme on public health and from the Environment action programme. Although a need for sustainable data provision has been recognised – in particular for the European Core Health Indicators (ECHI), but also for other European indicator sets – this need has yet to be met.

1.5 Eurostat's activities related to diagnosis-specific morbidity statistics

First, it seems to be useful to make a distinction between health information and health statistics. **Health information** covers a wide range of quantitative and qualitative information related to health issues; information can be available on a regular or ad-hoc basis, through a variety of sources. **Health statistics** are understood here as a basic set of (official) statistics which are provided on a regular and sustainable basis and which are comparable over time and across countries.

Within the overall framework of European public health statistics, Eurostat's overall aim is to provide a **general picture of diagnosis-specific morbidity at population level** through regular and sustainable data provision within the European Statistical System (ESS) for a selected set of diseases. In order to realise this, further methodological work – based on the present *Principles and guidelines for diagnosis-specific morbidity statistics* – as well as pilot data collections are deemed necessary.

The present *Principles and guidelines for diagnosis-specific morbidity statistics* build on several activities which were launched by Eurostat towards establishing diagnosis-specific morbidity statistics at European level. These were:

- **Methods of collecting morbidity statistics – A Eurostat working paper (1998):** A study carried out by ONS-UK on major methodological issues, proposing a step-wise approach for establishing comparable statistics on morbidity. In parallel, a first inventory of data sources was created.

- **The London Morbidity Seminar (2003):** This meeting discussed issues such as inclusion and exclusion of diseases, categorisation, case definition, co-morbidity, variables and sources, and drew up recommendations on further work: the use of a matrix approach for identifying best sources for a shortlist of diseases, and the need for pilot projects.

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6 In line with the overall objective of the European Statistical System (ESS) to provide reliable and comparable statistics at EU level.

7 See 1.2 above.

8 The ESS comprises Eurostat and the statistical offices, ministries, agencies and central banks that collect official statistics in EU Member States, Iceland, Norway, Switzerland and Liechtenstein.

9 Final reports of EUMIP 1 and EUMIP 2 – Methodologies for producing EU-wide comparable disease-specific morbidity data, see also chapter 4 Sources.
- *The ad-hoc Task Force Morbidity List (2003):* Based on the conclusions of the London Seminar, this Task Force worked out recommendations on data collection, the use of HIS/HES and data linkage but could not agree on a shortlist to be used for diagnosis-specific morbidity statistics at European level.

- *Special meeting of the Partnership on Health Statistics (May 2005):* This meeting finalised a first proposal for a European shortlist for diagnosis-specific morbidity to be used in a matrix approach. The proposed shortlist was a list for dissemination of consistent diagnosis-specific morbidity statistics, i.e. setting the framework for regular dissemination of statistical results at EU level.

- *Pilot project on morbidity statistics (2005/06):* A first pilot project jointly carried out by Estonia (leader), Germany and Lithuania, testing the feasibility of the proposed shortlist and different data sources, in particular insurance data. The final report was submitted end November 2006.

- *Morbidity Statistics Development Group – MSDG (2006/07):* This group was established to bring forward the methodological framework and to prepare for a new strand on diagnosis-specific morbidity statistics within the Partnership on health statistics. The group further developed the European shortlist for diagnosis-specific morbidity statistics (resulting in the version 6 March 2007) and prepared the present principles and guidelines for the production of diagnosis-specific morbidity statistics.

In the organisational structure of the Partnership on health statistics, a Core Group for diagnosis-specific morbidity statistics (CG MORB) is being established in 2007 to steer the work in this area towards the ultimate goal of regular data compilation. At the same time, national pilot projects are being co-financed in order to gather practical experiences.

### 1.6 General approach for diagnosis-specific morbidity statistics

As already outlined above, in complementing COD and HIS, data on diagnosis-specific morbidity (MORB) are considered to be indispensable for providing a comprehensive description of the status of health of European populations by means of statistics.

At European level, it is planned to make diagnosis-specific morbidity statistics available by means of a shortlist. The focus is on regular data compilation for a selected set of diseases within the European Statistical System (ESS) in order to provide a general picture of diagnosis-specific morbidity at population level. Such a description is at a high level of aggregation for general use by politicians and health managers, the public and media, industry and insurance, and research. Depending on specific purposes the statistical description by means of data from HIS, MORB and COD will need to be complemented by results from specific research.

In 2003, a matrix approach was recommended for the establishment of diagnosis-specific morbidity statistics at EU level. The original idea of the matrix approach was that for an agreed shortlist of diagnosis (i.e. a list of selected diseases) a list of best possible sources should be established. It was assumed that for each disease of the shortlist a single data source could be found for incidence and / or prevalence data while at the same time, data sources could differ for different diseases. However, this assumption on the availability of single sources turned out to be unrealistic. Therefore, the methodological approach for diagnosis-

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10 E.g. the pilot projects which started 2007 in the new Member States, funded by the Transition Facility Programme, or grants funded in the framework of the Eurostat 2007 financing decision.

11 See also 1.5 – London morbidity seminar.
specific morbidity statistics as outlined in chapter 5 further develops the original matrix approach 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.

For each entry in the recommended shortlist the appropriate measures for data delivery are indicated: incidence, prevalence, etc. Each country has to find appropriate sources which can be used for the production of best national estimates. 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. In some cases where no reliable data at national level are available, regional data or survey results can be recalculated in order to obtain reliable estimates at national level. Methods of imputation may also yield better results. This also implies that special attention is to be given to the metadata in order to keep the estimation processes transparent. Countries need to clearly document and explain how the best national estimates were achieved (see chapters 5 and 6).

Hence, like many Eurostat statistics, the compilation of diagnosis-specific morbidity statistics is output driven and not source oriented. This means that the purpose of the shortlist for diagnosis-specific morbidity is primarily for dissemination by Eurostat. The output for dissemination according to the shortlist is largely based on data delivered by Member States but the data from the countries are based on the most appropriate (national) sources. These sources will not be fully identical for all Member States, although some sources can be identical, e.g. on communicable diseases. The reason for this is that most sources in Member States are strongly influenced by the organisation of the health care services. For instance data from general practitioners are not fully comparable between Member States because in some Member States patients can go directly to medical specialists whereas in other Member States they have to go first to a general practitioner who may or may not refer them to a specialist.

On the basis of these guidelines each Member State should gradually develop a reporting system of diagnosis-specific morbidity data using the most appropriate national data sources together with statistical and other scientific methods to improve results of a given source.

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12 Diagnosis-specific morbidity – European shortlist, version 6 March 2007
13 For (groups of) diagnosis, existing international data sources could also be the data provider; this needs to be investigated together with the countries.
14 This means that there are some similarities with the approach used to produce data for the System of Health Accounts (SHA).
Chapter 2 Selected diseases

This chapter provides information about the rationale behind the selection of diseases for the shortlist of diagnosis-specific morbidity statistics. It also covers the definition of those diagnoses and highlights some key issues relating to particular diseases. The chapter concludes by describing the analytical approach focusing on the main condition.

2.1 Rationale for the selection of diseases

In the first chapter the reasons why a comprehensive description of the total morbidity of a population is very difficult to achieve were presented and hence why diagnosis-specific morbidity statistics have only been published internationally for selected conditions. To overcome some of these problems, a list of selected diagnoses (referred to as a shortlist) was recommended. This list comprises a sufficient number of conditions in order to give a good reflection of morbidity at population level.

Several criteria have been used in order to arrive at such a shortlist. The diseases should be clearly defined without ambiguity in their descriptions. The list should include conditions with an impact on society and cover important elements of the total morbidity of the population. The significance of the conditions included may imply big demands on the health services through magnitude in numbers and / or high costs for cure and treatment. Diseases that constitute a burden to society mainly due to disability and personal suffering should also be represented. Rare diseases have not been included but some less common conditions are to be found in the list because of public health importance and possibilities for prevention. Furthermore, it is desirable that the list is compatible with other shortlists for health statistics such as the European Shortlist for Causes of Death and the International Shortlist for Hospital Morbidity Tabulation (ISHMT)\(^\text{15}\). Other sources have also been considered in the construction of the present list such as the list of European Core Health Indicators (ECHI).

The availability of data sources has not been a primary concern for the selection of diseases. The existence of special registers for certain diseases varies among countries and the organisation of health services is country-specific and influences the availability of information on diseases diagnosed by medical professionals.

2.2 Definitions of the selected diagnoses

ICD-10\(^\text{16}\) has been the framework and reference for the definition of the conditions on the list. No specific attempts have been made to adapt the list also to ICD-9 or other classifications that may be used for possible sources such as the International Classification for Primary Care (ICPC). However, most of the conditions in the list can easily be defined also by these other classifications.

With a few exceptions ICD-10 does not give specified criteria for the diagnoses in the classification. Formal definitions of this type are left to the medical textbooks. ICD-10 helps in defining the categories on the list, however, through the numerous inclusion and exclusion notes in the tabular list and in the alphabetic index that encompasses many synonyms and

\(^\text{15}\) Both shortlists are available at the Eurostat classification server RAMON \url{http://ec.europa.eu/eurostat/ramon/}.

alternative terms. As an exception, the chapter for mental disorders has short clinical descriptions and diagnostic guidelines.

ICD-10 can be applied at different levels of detail. The core classification of ICD-10 is the three-character code which is the mandatory level of coding for international reporting to the WHO mortality database and for general international comparisons. The four-character subcategories, which are extensively used in clinical applications, may not be available at national level. The definitions in the morbidity shortlist have been limited to the three-character codes, which allow enough specificity to the list.

An alternative suggestion for grouping of diagnoses is the use of the 21 chapters of ICD-10. Adopting such a suggestion would result in less specific diagnostic information but, more importantly, such an approach requires coding of all conditions in all chapters. This is not practical for general morbidity statistics using many different data sources nor is it compatible with the chosen approach to use selected specific diagnoses that can be reported with reasonable data quality.

Some of the chosen groups in the shortlist correspond to a single three-character code in ICD-10 and thus represent quite high specificity. In many other cases it is more natural to bring together closely related codes. In certain cases the structure and content of ICD-10 makes it necessary to combine codes. This may also reduce the effect of minor differences in coding and registration.

There are many categories in ICD-10 for which comparable reporting can not be expected. Obvious examples are tobacco dependence syndrome (F17) and non-organic sleep disorders (F51). Some other possible diagnoses have been left out of the list because of well known problems in reporting and coding.

In epidemiological studies and clinical research it is common to use very specific diagnostic criteria, more rigid and concise than what the ICD-10 codes imply. Internationally accepted definitions are available for, e.g., acute myocardial infarction, hypertension, diabetes mellitus, asthma, chronic obstructive pulmonary disease and rheumatoid arthritis and the ideal situation would be that these are adhered to. The extent to which such criteria based definitions and nationally recommended professional standards are followed certainly varies in the national sources for disease-specific morbidity statistics considered here. The potential impact of this variation will be described in chapter 4.

2.3 Selection of entries in the proposed shortlist by ICD chapter

Only a few of the diseases in Chapter I of ICD-10 are selected for the general morbidity list. The compulsory notification of communicable diseases is another and important source for information on the incidence of these diseases. Tuberculosis and AIDS/HIV are relatively small groups but constitute emerging public health problems in several European countries and for which also prevalence data are of interest. The code for late effects of tuberculosis (B90) is included in the definition but will only seldom turn up as a main diagnosis. The code for asymptomatic HIV infection status (Z21) is included because treatment has become available for these cases. Sexually transmitted diseases and viral hepatitis (including hepatitis B) are diseases of growing concern in many countries.

In *Chapter II, Neoplasms*, the whole group of malignant neoplasms is included as one broad summary group although most of the common cancers are represented with entries of their own. Cancer incidence data are best studied in special cancer registries existing in most countries, but malignant tumours also constitute a heavy burden to the health services. This is a reason for including them in a list for general morbidity statistics for which data on prevalence and use of health services will also be gathered. Mesothelioma is an uncommon cancer of special interest for occupational medicine due to its relation to exposure to asbestos.

Diabetes mellitus is the only disease from *Chapter IV*. This group combines diabetes type 1 and type 2, partly because there is also a code for diabetes not specified as to type (E14).

The mental and behavioural disorders, *Chapter V* of ICD-10, are well represented with seven entries in the list, reflecting their importance for morbidity statistics. Alzheimer’s disease (also codable to *Chapter VI* as G30) is grouped here together with other dementias. Alcohol and drug dependence are important groups just as depression and other affective disorders. Eating disorders, covering anorexia and bulimia, constitute a small group judged to be of special interest.

The entries from *Chapter VI* are three chronic diseases of the nervous system as well as migraine and other specific headache syndromes. The latter group does not include common, unspecified headache.

Among diseases of the eye (*Chapter VII*) only cataracts and glaucoma are specified in the list and from *Chapter VIII* only hearing loss, which includes different degrees of deafness, has been selected.

Diseases of the circulatory system (*Chapter IX*) is represented with five entries of which one, acute myocardial infarction, is also included in the broader group of ischaemic heart diseases, commonly represented in other health statistics and therefore also included here. Hypertensive diseases are important as risk factors for other diseases that might be prevented, among them heart failure and cerebrovascular diseases. The latter group includes what is commonly called stroke, mainly intracerebral haemorrhage and cerebral infarction. Stroke is not separated as an entry of its own because of difficulties in differentiating stroke from other cerebrovascular diseases. Hypertension and heart failure are examples of diagnoses which will be underreported if the statistics is based only on main diagnoses, since these are often registered as secondary diagnoses.

*Chapter X*, diseases of the respiratory system, is represented by four entries, two of them of chronic type. Acute upper respiratory infections (other than influenza) are not included despite their high frequency owing to the obvious difficulties in getting reliable data on their occurrence.

In *Chapter XI* alcoholic liver disease is specified but this group has to be analysed in relation to the group of other diseases of the liver. There are well known difficulties in getting reliable figures for alcoholic liver disease but this group is of public health importance.

Among diseases of the skin (*Chapter XII*) only two groups are in the list, dermatitis and eczema, and psoriasis.
Diseases of the musculoskeletal system and connective tissue (Chapter XIII) constitute an important section of general morbidity. Here five common groups of chronic disorders are specified in the list.

From Chapter XIV, diseases of the genitourinary system, three groups are selected, among them renal failure, which constitutes an important chronic disease problem.

No entries are selected from the chapters for pregnancy and childbirth (XV), perinatal conditions (XVI) and congenital malformations (XVII). Neither are there any entries from Chapter XVIII to which symptoms and signs are classified. Symptoms do not qualify for a shortlist of diagnosis-specific morbidity due to their lack of specificity.

Chapter XXI refers to factors influencing health status and contact with health services. This mainly implies circumstances other than actual disease, such as examinations and investigations, visits for certain procedures or psychosocial problems. Generally, these situations do not fit in a diagnosis-specific list anyhow. An additional problem is that the extent to which this chapter of ICD-10 is used in clinical coding differs considerably among countries. Therefore it has not been used for the shortlist (with the exception of Z21 mentioned above).

ICD-10 contains two alternative and complementing sub-classifications for injury and poisoning. Chapter XIX specifies the nature of injury and Chapter XX the external cause of injury. Both aspects are of interest from a morbidity point of view, but codes specifying the nature of injury describe these conditions in diagnostic terms (fractures, wounds, poisoning) and, therefore, constitute the natural approach for defining groups in a diagnosis-specific morbidity shortlist.

Injury and poisoning represent an important section of morbidity in the population but the whole group is very heterogeneous with respect to the nature of injury. ICD-10 classifies nature of injury primarily according to body region, which brings together different types of injuries in the same block. The use of body region blocks for the morbidity list was considered but discarded. A group such as injuries to the head will include all types of injuries – from superficial wounds to open fractures and severe crush injuries and all injuries to the eye – which makes it a less meaningful group from the statistical point of view. Instead, two common, more specific conditions have been selected for separate presentation, i.e. intracranial injury and fracture of femur. In addition, a group for poisoning by drugs, medicaments and biological substances has been selected from this chapter. In order to illustrate the great importance of injuries and poisonings for total morbidity it is suggested, however, to include the whole chapter XIX in the list as one summary group to which the other three may be seen as subgroups. It is suggested that countries participating in pilot projects using the diagnosis-specific morbidity list will consider if there are other specific injuries or injury groups that should be considered for later inclusion in the list.

Statistics on the external causes of injury (Chapter XX) are very relevant for accident prevention and are usually collected through special surveys, but they may not be seen as a natural part of a diagnosis-specific morbidity shortlist. However, a special part of the shortlist provides for additional tabulation of external causes in six selected broad groups (B-G). These are meant for tabulating cases that have been registered with a diagnostic code for injury or poisoning, i.e. all cases referable to chapter XIX. The total of such cases (group A) is also
included in the list. The number of cases in this group should thus correspond to the number of cases in the summary group for nature of injury (group 57).

It is well known that information on external causes of injury is difficult to get from routine registration of contacts with medical professionals. External cause codes are not always included in hospital data registration as shown by the EU Hospital Data Project (HDP 1)\textsuperscript{18}. Furthermore, in countries that do register this information, there is often considerable underreporting of external causes. This is due to the fact that hospital staff have difficulties in acquiring the relevant information.

2.4 Analysis by main condition or all diagnoses

For practical reasons all diseases a person may suffer from cannot be registered at each contact with medical professionals. Both at physician visits and at hospital in-patient care only a limited number of diagnoses, relevant for the contact, will be registered. Current chronic conditions, not needing special attention, may not be registered at a contact for an acute, unrelated disease. This has to be kept in mind when analysing morbidity statistics based on health care contacts.

In the rules and guidelines for the use of ICD-10 for morbidity coding, WHO has established the concept of \textit{main condition} to be used for morbidity analysis. An excerpt from these guidelines follows here\textsuperscript{19}.

“The condition to be used for single-condition morbidity analysis is the main condition treated or investigated during the relevant episode of health care. The main condition is defined as the condition, diagnosed at the end of the episode of health care, primarily responsible for the patient’s need for treatment or investigation. If there is more than one such condition, the one held most responsible for the greatest use of resources should be selected. If no diagnosis was made, the main symptom, abnormal finding or problem should be selected as the main condition.

In addition to the main condition, the record should, whenever possible, also list separately other conditions and problems dealt with during the episode of health care. Other conditions are defined as those conditions that coexist or develop during the episode of health care and affect the management of the patient. Conditions related to an earlier episode that have no bearing on the current episode should not be recorded.

By limiting analysis to a single condition for each episode, some available information may be lost. It is therefore recommended, where practical, to carry out multiple condition coding and analysis to supplement the routine data. This should be done according to local rules, since no international rules have been established. However, experience in other areas could be useful in developing local schemes.”

It is clear that routine diagnosis statistics from hospital in-patient care or physician visits cannot be expected to give a complete picture of the existing morbidity in the patient population. Even if other diagnoses than a main condition are registered, one cannot expect comparable

\textsuperscript{18} For additional information about HDP 1 see\textsuperscript{19}
\url{http://ec.europa.eu/health/ph_information/indicators/project_indicators_en.htm}
practice for this registration. Therefore, diagnosis-specific morbidity data from routine reporting of physician or hospital care can be expected to provide more comparable statistics only if based on main conditions. This may be sufficient for the management, monitoring and evaluation of health care programmes, but does not give a complete picture of morbidity in the population, not even in the part of the population that has been in contact with the health services.

In hospital in-patient discharge statistics the recommendation of selecting a main condition or a main diagnosis is usually applied, even if there may be minor differences in how this is defined nationally. Other sources, such as diagnostic information from general practitioners, may not specify a main diagnosis if more than one is registered. One conclusion is that it might be advisable to collect and analyse morbidity data from health services contacts based not only on main conditions but, separately, also on all conditions being recorded. Pilot data collection and analysis may help in better understanding the difference between statistics based on main condition and those based on all conditions registered.
Chapter 3 Data requirements

This chapter provides a summary description of the requirements for diagnosis-specific morbidity statistics. It also presents the definitions of the requested measures (incidence, prevalence) as well as information about standardisation and the reference population.

3.1 Current requirements

The basic, current requirement is to produce (estimates of) absolute numbers, crude rates and age-standardised rates of national, diagnosis-specific morbidity by sex for as many items as possible in the shortlist. These estimates are incidence and prevalence as specified in Annex II for each disease or group of diseases\(^{20}\). The final aim is to have (estimates of) age-standardised rates for incidence and prevalence. However, (estimates of) absolute numbers or crude rates by 5 year age groups and sex should also be produced if the data are available. The specific requirements for data submission to Eurostat are described in chapter 7.

For some chronic diseases (e.g. glaucoma, chronic obstructive pulmonary disease and rheumatoid arthritis) only 12 month prevalence is conceptually and statistically meaningful. For other diseases (e.g. HIV/AIDS) there is a need for incidence and prevalence data. The definition of these terms is given in section 3.3.

It is envisaged that data for diagnosis-specific morbidity should be produced at regular intervals, such as every five years, preferably for the same reference year, starting in 2005. For small countries, several year averages (e.g. 3-years averages) could be more appropriate.

The quality of data to be entered in the tables is of utmost importance. Chapter 6 describes the general quality criteria as well as recommended standards.

3.2 Potential future requirements

Having produced data on incidence or prevalence of a particular disease, it may be possible to break this down further by geographical variables (e.g. regional breakdown by NUTS\(^{21}\)) and other socio-demographic and socio-economic characteristics (educational level, occupation, income level etc). Standard European classifications should be used for all the additional future requirements. The work of the Eurostat Task Force on Core Social Variables\(^{22}\) also has to be taken into account once additional breakdowns are considered.

3.3 Measures of morbidity – incidence and prevalence

There are two measures which are commonly used to measure morbidity: incidence and prevalence. Prevalence can be subdivided into point prevalence and period prevalence. The specifications for this data compilation exercise require data on one or more of these measures depending on their appropriateness and usefulness for epidemiological purposes.

\(^{20}\) Annex II Diagnosis-specific morbidity - European shortlist, Version 6 March 2007, sheet 'measures'.
\(^{21}\) See [http://ec.europa.eu/eurostat/ramon/nuts/splash_regions.html](http://ec.europa.eu/eurostat/ramon/nuts/splash_regions.html)
Incidence

The incidence of a disease is the rate at which new cases occur in a population in a given time period, usually in the past 12 months. The numerator is number of new cases; the denominator is the population at risk\(^{23}\) at the time when the cases were ascertained.

For example, for a specific tumour and population, the incidence is calculated simply by dividing the number of new cancer cases observed during a given time period by the corresponding number of people in the population at risk. For cancer, the result is usually expressed as an annual rate per 100,000 persons at risk.

However, one individual may experience the same pathological event on more than one occasion in the specified time period. For example, a person may have several myocardial infarctions in the study period. In these circumstances, the definition of incidence by person is restricted to the first event.

In some cases, for example, in calculating the incidence of influenza or sexually transmitted diseases (STDs), it is more important to count all episodes in the given time period. The request is therefore to include incidence by episode.

By collecting incidence by person and incidence by episode, it is possible to determine if, for example, the rate of STDs is increasing because more people are getting infected or the same people are getting infected more often.

Prevalence

Prevalence is a rate which is calculated by dividing the number of individuals with a disease by the size of the population under consideration at a specific point in time (point prevalence).

Prevalence is an appropriate measure for chronic diseases / disorders, only in relatively stable conditions, and it is unsuitable for acute disorders.

A prevalence measure can also be relevant to cases occurring during a specified period of time (e.g. in a particular year). This is relevant even in chronic conditions, where the manifestations are intermittent. In consequence, a 'point' prevalence, based on a single examination, at one point in time, tends to underestimate the condition's total frequency. If repeated or continuous assessments of the same individuals are possible, a better measure is the period prevalence defined as the individuals with a disease at any time (within a specified time period) as proportion of the population under consideration. It is common practice to use 12 months as the study period.

For chronic diseases / disorders (e.g. some cardiovascular conditions, diabetes, senile dementia), both 'point' and 'period' measures of prevalence are appropriate. The same is true also for many cancers, even if incidence may be a more relevant measure for them. However, for short-term diseases (e.g. influenza) or those with intermittent episodes (e.g. some mental health problems, back pain), period prevalence measures are more likely to identify all relevant cases.

\(^{23}\) Population at risk are the individuals at risk developing the disease during the given time period.
For prevalence statistics from different studies to be comparable, the length of period asked about must be the same.

### 3.4 Reducing error owing to double-counting

First of all, it is necessary to define a case. A person is classified as a case if he or she is affected by a specific disease according to diagnostic criteria. People or cases can have several occurrences of the same disease and these are called spells, episodes or events.

As a general rule, the aim of most data requirements is to avoid double counting. These are most likely to occur when considering infections, cancers and injuries.

The diseases in the shortlist include cancers. There is a request for rates of all cancers as a group and for particular types of cancer, e.g. breast cancer or colon cancer. If a person has had two types of cancer in the study period, normally the last twelve months, then they are represented in each of the specific cancer categories yet just once in the any cancer category (group 5).

For infections, we are asking for incidence by person and incidence by episode. Let us say for example that a person has had two spells of influenza in the past twelve months. In terms of incidence by person, that person is counted once. In terms of incidence by episode (or event), they are quite correctly counted twice.

Another example where the same pathological event happens more than once to the same individual in the course of the reference period is myocardial infarction. An individual may have several episodes of myocardial infarction in the past 12 months. In these circumstances the definition of incidence by person is restricted to the first event, although sometimes it is more appropriate to count all episodes, used when calculating incidence by episode.

### 3.5 Standardisation

Making comparisons between countries with different age structures requires some form of statistical adjustment of incidence or prevalence rates to take account of this. Trend analysis also requires some form of standardisation as changes in age structures may be different among countries. Furthermore, diseases do not affect the population uniformly. Some arise during childhood; others are more prominent in middle age whilst others are associated with advancing years. Similarly, certain diseases are more frequent among one sex than the other.

The presentation of data by age and sex is rather cumbersome so it is helpful to derive a single statistic that summarises the comparisons across groups taking account for differences in their different age and sex structures. There are two methods of doing this termed direct and indirect standardisation.

Direct standardisation by age entails comparisons of weighted averages of age-specific disease rates, the weights being equal to the proportion of people in each age group in a standard population.

In compiling the data for diagnosis-specific morbidity the recommended approach is direct standardisation by age for men and women separately. However, it has one drawback. Direct standardisation is inadvisable if the number of cases in any of the cells of the cross-
classification of the variables used to standardise is small with annual fluctuations. Thus if one is standardising for age and sex and there is a possibility of very low numbers in any combination of age and sex categories, direct standardisation should be avoided. If there is a possibility that there are no cases in any of the cells of classification (zero cells) then direct standardisation needs to be regarded with great caution. In order to overcome these problems, age groups or data for several reference years (e.g. 3-years averages) could be combined. Indirect standardisation is highly robust in the context of small cell numbers but has serious limitations for international comparability of disease specific morbidity.

**Direct standardisation**

In the direct standardisation method the number of cases "expected" in each age group is calculated as if all the populations compared would have the same age distribution of the standard and it is obtained by applying the age-specific rates to the corresponding categories of the standard population. The standardized rate \( R_{STD} \) is obtained by dividing the total of expected cases by the total population of standard.

\[
R_{STD} = \sum_i R_i \times w_i \times 10^n; \quad w_i = \frac{P_i}{P_S}; \quad \sum_i w_i = 1
\]

Where

\( R_i \) = the age-specific rate for the \( i^{th} \) age category,
\( P_{Si} \) = the number of individuals of the standard population for the \( i^{th} \) age category,
\( P_S = \sum_i P_{Si} \) is the total population of standard.

The standardised rate is also expressed per 10,000.

The standard population to be used as the basis for comparison is the 1976 WHO European population; it is presented in Annex IV.

**Indirect standardisation**

Indirect standardisation is different in both method and interpretation. It is used when the numbers in the age-specific cells are very small and fluctuate and it can also be used when age-specific data are not available.

The indirect standardisation, instead of using the structure of the standard population, utilises its specific rates and applies them to the populations under comparison, previously stratified by the variable to be controlled (sex and age). The total of expected cases is obtained this way. The standardised ratio is then calculated by dividing the total of observed cases by the total of expected cases. This ratio allows comparing each population under study to the standard population: a standardised ratio higher than one (or 100 if expressed in percentage) indicates that the risk of a specific disease in the observed population is higher than what would be expected if it had the same experience or risk than the standard population. The ratio can also be applied as a multiplier to the crude rates to obtain an indirect standardised rate.
However the indirect standardisation method requires the specific rates of the standard population, which are not yet available for diagnosis-specific morbidity statistics.

3.6 Reference population

A central purpose of epidemiology is the measurement of disease in relation to a population at risk. Making a disease measure relative to a population size more strongly emphasizes a change in a small group over the same change in a larger group and produces a numeric value that reflects the risks.

The population at risk is the group of people, healthy or sick, who would be counted as cases if they had the disease being studied. It is defined on the basis of demographic data, such as place of residence, sex, age group, etc.

In order to avoid very common logical errors in the conclusions, it is very important to consider the appropriate reference population.

Implicit in any epidemiological investigation is the notion of a target population about which conclusions are to be drawn. Occasionally measurements can be made on the full target population. More often observations can only be made on a study sample, which is selected in some way from the target population.

Often the selection of a study sample is partially random. Within the target population an accessible subset, the study population, is defined. The study sample is then chosen at random from the study population.

\[ \text{Target population} \Rightarrow \text{study population} \Rightarrow \text{study sample} \]

This approach is appropriate where a suitable study population can be identified but is larger than the investigation requires.

According to the general aim of diagnosis-specific morbidity statistics at European level “to have a comprehensive overview or an adequate summary on the occurrence of diseases at population level”, for the majority of the diseases included in the shortlist, the \textbf{reference population should be represented by the total resident population} in a specified country at time t. Within this broad definition appropriate breakdowns may be specified – for example in age range or sex.

The accuracy of the total population counting also affects the quality of the measures of disease. A measure of coverage should be provided as metadata. See chapters 5 and 6.
Chapter 4 Sources

This chapter provides a general description of major potential sources for diagnosis-specific morbidity data (mainly at national level). A distinction is made between sources which directly qualify to be a main source for diagnosis-specific morbidity statistics, and sources which can only provide additional information to be used in the preparation of best national estimates.

The extent to which these sources exist in countries varies, and it has to be kept in mind that the national output may need adjustments in order to meet the requirements of diagnosis-specific morbidity statistics. In any case, the quality criteria outlined in chapters 5 and 6 are to be considered when using data sources.

Furthermore, special attention should be paid to the variety of sources and networks producing data which exist at international level (WHO; projects funded by the European Commission). National data submitted for international compilation should be reviewed for their use in the production of diagnosis-specific morbidity statistics as defined in these guidelines.

For additional information, please see also "Methods of collecting morbidity statistics". Eurostat Working Papers, Population and social conditions 3/1998/E/no.924 and the final reports of EUMIP 1 and EUMIP 225. For first experiences with health insurance databases, see the final technical report of the 2004 pilot project on morbidity statistics26.

4.1 Main sources for diagnosis-specific morbidity statistics

The sources mentioned below exist in most countries as routine data collection systems, and potentially they provide good population coverage, have a history of data collection with recognised quality criteria and produce information on diagnoses as provided by a health care professional.

Disease-specific registers

Such registers are primarily a source of incidence data; methods exist to estimate prevalence. While being labour-intensive and costly to maintain, their usefulness and quality depends on many criteria such as

- which diseases are covered;
- coverage of cases (voluntary vs. mandatory reporting, regional vs. national coverage);
- data protection laws (possibility to link up with other registers such as causes of death registers, population registers, etc.);
- reporting episode based vs. person based; double counting, etc.;
- available background information about individuals (age, sex, level of education, occupation etc.).

Nationwide personal-level identifiable medical registries with established quality control systems with the possibility to link to other sources could be considered to be an ideal source for diagnosis-specific morbidity statistics.

25 http://ec.europa.eu/health/ph_projects/monitoring_project_en.htm; EUMIP 1 was funded in 1999 and EUMIP 2 in 2001.
**Administrative notifications (routine surveillance systems)**

These exist mainly for infectious diseases for which mandatory notification systems are in place in all EU countries. At EU level, the surveillance of infectious diseases is carried out by the European Centre for Disease Prevention and Control (ECDC). Other notification systems, e.g. on road traffic victims or suicides, are generally not harmonised in the EU.

**Hospital records and registrations**

- Hospital in-patients (national registers on in-patients exist in most countries)
- Hospital out-patients (ambulatory care)

These data can contribute to diagnosis-specific incidence data but only to a limited extent. In-patient data only qualify to be the main source for diseases where hospitalisation is likely to occur. Recently there is substantial progress in harmonising data at international level but still much remains to be done in order to use this source for population based diagnoses-specific morbidity statistics. Hospital records are mainly used in conjunction with other sources.

**General practice (GP) records (primary care)**

GP records include information on consultations, diagnosis, prescriptions, treatments and test results. Often access to these records is not possible due to data confidentiality. GP data provide a medical diagnosis but differences in coding have to be considered (similar to diagnoses provided through insurance data). GP records are also limited by the different national roles of general practitioners. This affects mainly the population covered. In some Member States persons have free and direct access to medical specialists, some of them not necessarily working in an out-patient department of a hospital. In other countries a referral of a general practitioner to a specialist is mandatory.

**Sentinel practice networks**

In many countries primary care based sentinel networks are operational on a continuous basis. These networks collect information about disease indicators in the population at a regional or national level and include only primary care based physicians with direct access for the population. This infrastructure is particularly well suited for the provision of information on the distribution of diseases in the community with the advantage of professionally defined morbidity. For additional information see the final report of the project "Health monitoring in sentinel practice networks".

**Health insurance databases**

The utilisation of health insurance data (public and private) can represent a valuable (and cost-effective) data source, and often this can even be the only available source of information. Studies indicate that diagnoses in health insurance databases are not necessarily validated for all cases because health insurance systems are driven by reimbursement of medical acts. Before the data can be used for statistics, a validation of the diagnoses that are found in the health insurance records has to be performed for each diagnosis. Differences in coding quality, coding habits, coding incentives etc. need to be considered. The influence of the different national health care systems also has to be taken into account (at least through description in the metadata).

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27 See also [http://www.ecdc.eu.int/](http://www.ecdc.eu.int/)
International data sources
Potential data sources for diagnosis-specific morbidity statistics can also exist at the international level, e.g. the network of cancer registries under the aegis of IARC-WHO (Lyon, France)\textsuperscript{29}, or through projects funded by DG SANCO\textsuperscript{30}. National data available through international sources should be considered but their quality needs to be evaluated analogously to national sources.

4.2 Additional information sources

The following sources do not qualify as main source for diagnosis-specific morbidity statistics. However, they can provide information which could be used in the preparation of best national estimates (according to the methodology explained in chapter 5). They can also be useful to compare data from different sources.

Causes of death registers
This source can – in absence of other sources – be used to estimate the incidence of certain diseases, i.e. diseases with low recovery rates and high mortality such as some cancers. In most countries, only the underlying cause of death is reported in the COD database. However, more and more countries record multiple causes; exploring the potential of this information is in an early stage.

Health interview surveys (HIS)
Population-based survey data tend to be used for prevalence estimates. HIS ask for self-reported health, i.e. there is no direct link to the diagnosis as provided by a health care professional. Nevertheless, for some long-standing, chronic diseases with low fatality as well as for health problems such as overweight and smoking, HIS could be a valuable source for population based estimates. In the context of diagnosis-specific morbidity statistics, this source is suitable for providing additional information to be used in imputation procedures.

Health examination surveys (HES)
Health examination surveys provide information on health status through physical examination (e.g. hearing test, vision test, blood pressure, body weight and height) and through various laboratory tests (e.g. blood and urine analyses). A feasibility study for a European health examination survey\textsuperscript{31} is currently being carried out; final recommendations are expected by March 2008. While there is no direct link to the diagnoses provided by a health care professional, this source could provide additional information.

Epidemiological and public health studies
While not being a routine source, for specific diseases epidemiological studies can provide additional information which can be used to supplement routine sources and improve estimation procedures from routine sources. Some EU projects, e.g. funded under the Programme of Community action in the field of public health\textsuperscript{32} or under the Framework Programmes of the European Community for research and technological development\textsuperscript{33}, can provide valuable information for adjusting national sources and for improving comparability.

\textsuperscript{29} \url{www.iarc.fr}
\textsuperscript{30} Information about projects funded by DG SANCO is available at \url{http://ec.europa.eu/health/ph_programme/programme_en.htm}
\textsuperscript{31} \url{http://www.ktl.fi/fehes/}
\textsuperscript{32} See \url{http://ec.europa.eu/health/ph_programme/programme_en.htm}
\textsuperscript{33} See \url{http://ec.europa.eu/research/}
at EU level. If these projects carry on, they may ultimately lead to a harmonised EU-wide data source for one or a group of specific diseases. Examples are the network on drug-related diseases, on mental diseases, on rare diseases, etc. However, each source has to be investigated in the light of the quality criteria set out in chapters 5 and 6.

Research databases
In some countries, research databases containing data on patients might exist. For example in Italy, Health Search\textsuperscript{34} is a research database where "a sample of General Practitioners provides data using a common software. The sample is not statistically selected. GPs participate on a voluntary basis but Health Search tried to guarantee representativeness at regional level. In the database there are demographic variables, clinical information (diagnosis, lab tests and results, admission in hospital), prescriptions and information on prevention (BMI, smoking habits, blood pressure, etc.). Many variables are registered using international or national classifications (for pharmaceuticals, diagnosis, tests)."

Data from patient organisations
For various diseases, patient organisations exist at national level. These might also be considered to gather additional information. However, special attention needs to be paid to the reliability of such sources.

\textsuperscript{34} http://www.healthsearch.it/
Chapter 5 How to use sources to meet data requirements

Many potential sources for diagnosis-specific morbidity statistics can exist in each Member State. With the exception of information collected for some selected diseases, e.g. notifiable diseases or occupational diseases, existing data sources for certain diseases are not necessarily the same in all Member States and/or they do not always cover the same population at risk. The main reason for the differences is that most sources on diagnoses are bound to categories of health care providers and that the patient coverage of these providers is determined by differences of the health care organisation in the country. Other important reasons are the variety of insurance systems and the multitude and diversity of national epidemiological studies. Therefore for most of the diseases there is not one and the same ‘single’ provider source available for all countries. Nevertheless some ‘single’ provider sources, e.g. hospital discharge statistics, are available in all Member States and deserve more attention even if the national output might need adjustments in order to meet the requirements of diagnosis-specific morbidity statistics as determined in chapter 3.

There might be important differences in terms of coverage and quality between data sources. However, it should nevertheless be possible to achieve comprehensive and sustainable diagnosis-specific morbidity statistics at EU level based on the reliable outputs at national level according to a common reporting standard to Eurostat. The output is harmonised but not necessarily the input.

Recommendations are provided here for a stepwise approach for making best national estimates for the different entries in the shortlist for diagnosis-specific morbidity (Annex II).

The stepwise approach for the production of the national estimates for reporting is divided in three steps leading to three outputs:

1. **Step 1**: list and describe all potential national sources for each 'cell', i.e. each entry of the shortlist and the required measures (incidence, prevalence). This is the national meta information (output 1).

2. **Step 2**: decide on the most appropriate method for estimating the national data for each disease. This is the national plan of operations (output 2).

3. **Step 3**: calculate the estimates for submission of tables to Eurostat according to the methods described in step 2 using the sources of step 1. This is the national implementation plan (output 3).

The quality criteria of clarity (see chapter 6) plays an important role during the estimation process; special attention should be paid to the metadata, i.e. to the appropriate documentation of the methods used.

5.1 Step 1: National meta information

The aim of this part of the methodological approach is to (a) identify and (b) describe and evaluate the potential main national sources and – whenever adequate – additional sources for diagnosis-specific statistics.36

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35 For data submission tables see Annex III.
36 For main and additional sources see chapter 4.
First, for every entry (cell\textsuperscript{37}) in the shortlist (table) the available sources should be identified and listed.

Second, for each source \textit{a description and an evaluation} should be made according to the criteria set out below. Since some sources (such as hospital discharge statistics, insurance data) could be used for several diseases, at first a general description and evaluation of the source should be given without looking at its validity for every entry in the list (this can be done at a later stage).

A clear distinction should be made between main sources and additional information sources. Particular attention should be paid to the potential of administrative sources.

It should be noted that in this step the focus is on main sources. However, also other important sources which might be relevant for several diagnoses should already be considered here. In step 2 the need for additional information sources and their potential contribution for calculating reliable national estimates play a role. (Whenever possible) a description and (in any case) an evaluation of these additional sources has to be made later in step 2.

Output 1 is an inventory of all potential sources per disease of the shortlist for each of its measures (incidence, prevalence). Each source covered in this output is complemented with an evaluation\textsuperscript{38}.

\textbf{Criteria for description and evaluation of sources}

The following set of criteria should be considered as the minimum criteria for describing national sources, their coverage, potential biases and their overall quality. This information is also necessary in order to define appropriate estimation methods when data from a specific source are to be grossed up to the national total or when several sources are used for producing the national estimates (see section 5.2 on step 2 below).

\textbf{Purpose of the source}: What is the rationale for data collection and what is the link to the objectives of diagnosis-specific morbidity statistics? To what extent can expected biases be taken into account or eliminated when using data of this source?

\textbf{Owner}: Who is the owner of the data source? Are there copyright restrictions in using the data? Can the reliability of the source, sustainability of data provision, etc. be guaranteed?

\textbf{Type of data collection}: Is it a sample or a census? Is reporting voluntary, mandatory or statutory?

\textbf{Updating mechanisms}: How often are the data collected and how often are data updated?

\textbf{Breakdowns}: What breakdowns and what level of detail are available in the source (e.g. sex, age, geographical information)?

\textbf{Computerised}: Is the information available in an electronic form?

\textsuperscript{37} Each cell is defined by the disease and its respective measure(s), e.g. 'dementia and period prevalence', 'asthma and incidence by person' or 'asthma and period prevalence'.

\textsuperscript{38} The description and evaluation of the sources used during the estimation process form also part of the metadata.
**Diagnosis:** Has the diagnostic information been generated by a health care professional? Which classification has been used (ICD-9, ICD-10, ICPC, others)? Are all diagnoses recorded or only the main diagnosis? Is the diagnosis validated – if not, how could this be done? What information is available about coding rules and procedures?

**Person or episode related information:** Is the information available in the source person-related or does it refer to episodes (spells, events), i.e. when one person can be counted as having several episodes during a given period?

**Incidence and / or prevalence:** What type of information can be derived from the source – incidence (by person or by episode) or prevalence (point or period), or both?

**Coverage:**
- What population is covered by the source – the total (resident) population or only parts thereof? If not – how can this be taken into account?
- All ages or only specific age groups?
- Does the source cover in-patients and / or out-patients?
- Are all health care providers covered (public and private)?
- Does the source cover all diagnoses in the shortlist or does it only refer to selected diseases in the shortlist?
- Does the source have national coverage or does it only cover some regions?

**Impact of the national organisation of the health care system:** To what extent is the source influenced by the national health care system and how the system is structured for use by the population (e.g. registrations of referrals, access to specialists)? What can be done to take account of the potential biases originating from the original data collection when estimating morbidity statistics from this source?

To aid evaluation of the national data and their potential for international comparability the results of the different EUCOMP projects are indispensable background material. The EUCOMP could be very helpful in understanding the relevance of the potential provider sources and in the description of administrative sources because EUCOMP takes into account the impact of the health care organisation on its sources for EU comparable diagnosis-specific morbidity statistics.

### 5.2 Step 2: Using the available sources to come to the national estimate (the national plan of operations)

The aim of this part of the approach for diagnosis-specific morbidity statistics is to describe in detail how the sources identified in step 1 are (or will) be used for filling the data submission tables. In step 2 the emphasis is on methodology. For each entry in the shortlist the different sources should be looked at and a decision has to be made on their usefulness for the measures required for that entry (incidence, prevalence). Different scenarios might occur as described below. For detailed examples, see Annex I.

- In some cases there is a one to one relation between the existing information source in national statistics and the data requirements for a particular cell. So the ‘perfect

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39 Annex III.
source’ is found with the ‘perfect figure’ meaning that there is a direct relation between source and cell (see example 1).

- In other situations the results of a given source might require adjustments for approaching the ‘perfect figure’. In many cases this can be done according to information which is readily available in the source, or certain rules have to be applied for allocation of the data to different cells. In other cases, estimations have to be made for filling the cells and this can be done according to different methods (see examples 2 and 3).

- In some cases data from different sources have to be brought together either by synthesising at aggregated level or by direct record linkage if regulations allow this (example 4). In such cases not only main sources are used but also additional information sources.

Whatever procedures are used should be documented. If data are deficient or if any relevant information is missing a strategy has to be defined how these problems should or could be solved (output 2) (see also description of step 3).

Sound statistical methodologies should be explored in order to make the best possible estimate, ‘according to available knowledge’. Here, the common problems for making national estimates from incomplete data sources are faced. For instance: can national estimates be made from one or two regional registrations? Other sources, e.g. epidemiological studies or insurance data can be helpful in this respect.

Another example may be the adjustment of incomplete data for some notifiable diseases by making use of findings of specific epidemiological studies. For example, it may be possible to eliminate double counting from hospital discharges and general practitioner data on acute myocardial infarction by using personalised insurance data.

This step of the methodological approach for diagnosis-specific morbidity statistics requires the utilisation of (sophisticated) statistical methods in combination with epidemiological and clinical expertise.

The documentation produced during the implementation of step 2 should represent a summary of the problems that a country’s team faced when filling the tables required for diagnosis-specific morbidity.

- For each cell in the table identify the areas where difficulties or gaps exist.
- Methodological problems (e.g. elimination of double counting, splitting procedures used for aggregate data, choice between information sources that deliver data with different values, etc.).
- Other deficiencies / problems.

In order to keep the estimation process transparent, relevant elements of this documentation will feed into the metadata.

The particular types of deficiencies / problems faced during preparation of the steps 1 and 2 should also be documented. Some of the problems may be relatively easy to solve; others may need further consideration.

40 An example will be added to a later version of the document.
If some information is confidential and has to remain confidential, this fact has to be indicated for the information in question.

5.3 Step 3: The national implementation

The aim of step 3 is to turn the outputs of steps 1 and 2 into practice by using the data available in the relevant sources (step 1) according to the methods defined and described in step 2. This implementation procedure should result in an (estimated) figure for each cell of the tables for diagnosis-specific morbidity statistics. During the production process the cross-classification table filled with (final) data is based on the so-called documentary tables (i.e. tables which contain additional information and calculations on which the final estimates are based). This is output 3.

While doing this exercise (step 3) it is worthwhile revisiting the procedures carried out and the decisions made during steps 1 and/or step 2. Producing output 3 may contribute to a better understanding of the whole process.

The following points require attention for the purpose of making the final output 3 (diagnosis-specific morbidity statistics).

1. What are the implications of the imperfections of different data used for the quality of the reported diagnoses figures, mainly in terms of underestimation or overestimation of these values?
2. Which problems are anticipated to persist in the near future and how can these problems be overcome?
Chapter 6 Statistical quality

6.1 General quality framework of the European Statistical System

Within the European Statistical System (ESS), the overall approach for high-quality statistics is set in the European Statistics Code of Practice for national and Community statistical authorities. The Code of Practice is based on 15 principles, and statistical authorities within the EU commit themselves to adhere to these principles.

The principles concern:
- Professional independence
- Mandate for data collection
- Adequacy of resources
- Quality commitment
- Statistical confidentiality
- Impartiality and objectivity
- Sound methodology
- Appropriate statistical procedures
- Non-excessive burden on respondents
- Cost effectiveness
- Relevance
- Accuracy and reliability
- Timeliness and punctuality
- Coherence and comparability
- Accessibility and clarity

The Code of Practice as well as further information are available at http://ec.europa.eu/eurostat/quality.

6.2 Eurostat's quality definition

Quality of statistics is defined by Eurostat with reference to the following six criteria:
- relevance;
- accuracy;
- timeliness and punctuality;
- accessibility and clarity;
- comparability; and
- coherence.

Although not a measure of quality, the costs involved in the production of statistics as well as the burden on respondents act as a constraint on quality.

The ultimate goal of the Eurostat quality framework is the production of standard quality reports. At this stage of development of diagnosis-specific morbidity statistics such quality reports are not required. However, the existing basic guidelines for quality reports⁴¹, the

⁴¹ http://epp.eurostat.ec.europa.eu/pls/portal/docs/PAGE/PGP_DS_QUALITY/TAB47143233/STANDARD_QUALITY_REPORT_0.PDF
checklists\textsuperscript{42} and the quality indicators\textsuperscript{43} should provide guidance for ensuring a high-quality of the estimates of diagnosis-specific morbidity.

A short description of the six quality criteria is presented below. Although all criteria are important, those of particular interest for the proposed methodological approach for diagnosis-specific morbidity statistics are highlighted.

\textbf{Relevance}

Relevance is the degree to which statistics meet current and potential users’ needs. It refers to the extent to which concepts used (definitions, classifications etc.) reflect user needs.

\textbf{Accuracy}

Accuracy in the general statistical sense denotes the closeness of computations or estimates to the exact or true values. The purpose of each survey / data collection is to produce statistics, i.e. to estimate the (usually) unknown values of quantifiable characteristics of a target population. Statistics do not represent true values because of variability (the statistics change from implementation to implementation of a survey due to random effects) and bias (the average of the possible values of the statistics from implementation to implementation is not equal to the true value due to systematic effects).

A certain typology of errors has nowadays been adopted in statistics. \textit{Sampling errors} affect only sample surveys; they are simply due to the fact that only a subset of the population, usually randomly selected, is enumerated. \textit{Non-sampling errors} affect sample surveys and complete enumerations alike and comprise:

- Coverage errors \textit[e.g. coverage of a source];
- Measurement errors \textit[e.g. ICD codes given by the health care professional];
- Processing errors;
- Non response errors; and
- Model assumption errors \textit[e.g. errors in step 2 of the methodological approach, chapter 5].

For diagnosis-specific morbidity statistics, and in particular with regard to the potential sources, the non-sampling errors are of particular importance. The Eurostat guidelines for quality reports provide additional information\textsuperscript{44}.

\textbf{Timeliness and punctuality}

\textit{Timeliness} of statistics reflects the length of time between their availability and the events or phenomena that they describe. \textit{Punctuality} refers to the time lag between the release date of data and the target date when it should have been delivered, for instance, with reference to dates announced in some official release calendar, laid down by Regulations or previously agreed among partners.

\begin{itemize}
\item \textsuperscript{42} http://epp.eurostat.ec.europa.eu/pls/portal/docs/PAGE/PGP_DS_QUALITY/TAB47143233/STANDARD_QUALITY_REPORT_0.PDF
\item \textsuperscript{43} http://epp.eurostat.ec.europa.eu/pls/portal/docs/PAGE/PGP_DS_QUALITY/TAB47143233/STANDARD_QUALITY%20INDICATORS.PDF
\item \textsuperscript{44} http://epp.eurostat.ec.europa.eu/pls/portal/docs/PAGE/PGP_DS_QUALITY/TAB47143233/STANDARD_QUALITY_REPORT_0.PDF
\end{itemize}
**Accessibility and clarity**

*Accessibility* refers to the physical conditions in which users can obtain data: where to go, how to order, delivery time, clear pricing policy, convenient marketing conditions (copyright, etc.), availability of micro or macro data, various formats (paper, files, CD-ROM, Internet…), etc.

*Clarity* refers to the data’s information environment whether data are accompanied with appropriate metadata, illustrations such as graphs and maps, whether information on their quality is also available (including limitation in use…) and the extent to which additional assistance is provided by the NSI for their comprehension. In the context of diagnosis-specific morbidity, special attention should be given to the *metadata*, i.e. how the best national estimates were achieved needs to be well explained and transparent.

**Comparability**

Comparability aims at measuring the impact of differences in applied statistical concepts and measurement tools / procedures when statistics are compared between geographical areas, non-geographical domains, or over time. We can say it is the extent to which differences between statistics are attributed to differences between the true values of the statistical characteristics.

There are three main approaches under which comparability of statistics is normally addressed:

- *Comparability over time* refers to comparison of results, derived normally from the same statistical operation, at different times.
- *Geographic comparability* emphasises the comparison of statistics between countries and / or regions in order to ascertain, for instance, the meaning of aggregated statistics at European level. Geographic comparability is not of course limited to the comparability within EU. The EU statistics can be compared with other international statistics, for example with Japan and USA.
- *Comparability between domains* refers to non-geographical domains, for instance between industrial sectors, between different types of households, etc.

For diagnosis-specific morbidity statistics, both geographic comparability (between Member States) and comparability between domains (i.e. different diagnoses) are of particular interest.

**Coherence**

Coherence of statistics is their adequacy to be reliably combined in different ways and for various uses. It is, however, generally easier to show cases of incoherence than to prove coherence.

When originating from a single source, statistics are normally coherent in the sense that elementary results derived from the concerned survey can be reliably combined in numerous ways to produce more complex results.

When originating from *different sources*, and in particular from statistical surveys of different nature and / or frequencies, statistics may not be completely coherent in the sense that they may be based on different approaches, classifications and methodological standards.

For diagnosis-specific morbidity statistics, several sources might exist for specific diagnoses; the best national estimate might come from one of several sources, or might be produced
using different sources. Therefore, expected incoherence between data sources needs to be well described.

For further information about the Eurostat quality concept please see http://ec.europa.eu/eurostat/quality.
Chapter 7 Submitting data to Eurostat

The general requirements for submitting data to Eurostat are outlined in chapter 3, and the methodology how to produce the data is given in chapter 5. Quality criteria for the production of data are presented in chapters 5 and 6. Based on this, tables for the submission of diagnosis-specific morbidity data are provided in Annex III.

Data are to be provided for data year 2005. If 2005 data are not available, those for the closest year available are to be provided, specifying the year that the data refer to. Small countries might use averages over several years (e.g. 3-years averages), stating which years’ data have been used. Averaging over several years makes the statistics more robust, especially for small frequencies, and may overcome confidentiality restrictions.

Sex: data are to be provided for males and females.

Diagnosis: Ideally, data are to be provided for all entries of the shortlist.

Please note: the final goal is the provision of data for all entries of the shortlist. However, it is acknowledged that this is very ambitious. Pilot projects and feasibility studies might therefore not test the proposed approach and provide data for all entries of the shortlist but rather for selected diseases only.

Measures: The requested measures (incidence, prevalence) are also given in the shortlist. Definitions of the measures are presented in chapter 3. Data submission tables (Annex III) are based on these requirements.

Core data: For each measure, absolute number (all ages) and crude rates (all ages, per 10,000 population) are requested (mandatory). Age-standardised rates by the direct standardisation method (per 10,000 population, using 1976 WHO European population45) are also mandatory. However, this depends on having rates by age group. Whenever possible and appropriate, data by age group (either for absolute number or – if absolute number is not available – for crude rates) are also to be given (voluntary).

Please note: owing to anticipated difficulties of standardisation, only the provision of crude rates might be feasible for some countries and diseases.

In some cases, rates according to age groups may be based on estimates (from one source or from an amalgamation of multiple sources). These can be used for calculation of age-specific crude rates but are less appropriate for general use. In such cases there may be standardised rates without submission of age-specific data. Such reliable standardised rates can be very useful.

Rounding: Age-standardised rates and crude rates should be rounded (no decimals – e.g. an age-standardised rate of 25.7 per 10,000 should be entered as 26 in the tables of Annex III).

Calculation of rates: For the calculation of rates, national population data held by Eurostat are to be used. Data are available on-line at the Eurostat website46. For the measures incidence by episode, incidence by person and period prevalence, the annual average population is to be applied, and for point prevalence the population on 1st of January. If point prevalence is

45 See chapter 3.
46 http://europa.eu.int/comm/eurostat, under the title 'data' – 'Population and social conditions'
reported for the 31st of December, the population 1st of January of the following year is to be used.

**Metadata:** This metadata is needed for comparative analysis among Member States and its interpretation. Descriptive information should be provided on the sources used and the methods applied to estimate the national figure (according to the three steps described in chapter 5). For the time being, there is no template for metadata reporting. Templates for metadata presentation will be developed based on experiences from pilot data collections.

**Missing data and empty cells:** There are several reasons why data may not be entered in the cells. First, data may not be available at all. Second, data may be available or even created but are of insufficient quality for dissemination. Third, data may become available in the future after some problems are solved. Fourth, the data are available and of good quality but there are no cases to report. Last, owing to confidentiality restrictions there may be a need to suppress the data.
Chapter 8 Dissemination and access to data
To be drafted

Chapter 9 Useful contacts
To be drafted

Index
To be drafted
Annex I Examples

Example 1
Cancer incidence as taken from a national cancer registry.

Example 2
A source might not cover the complete reference population but the structure of the undercoverage might be known. For example, in Germany, 90% of the population are covered by the statutory health insurance, i.e. this source does not cover the total population. In addition, it is known that some professional groups and people with higher income can choose private insurance. It is also known that – due to the historical development of the statutory health insurance with so called primary and mutual funds – in some statutory health insurance schemes (mostly in the primary funds) the insured persons have lower income, are older and show higher risks for health problems. With appropriate assumptions and additional information, this bias can be taken into account when estimating diagnosis-specific morbidity data from this source.

Example 3
Health insurance data are a possible source for diagnosis-specific morbidity statistics. However, the coding of a diagnosis is for remuneration purposes and the diagnosis is not validated in the health insurance databases. Therefore, strategies for internal validation have to be developed, i.e. rules have to be defined in order to identify the ‘case’.

The following example of an algorithm for Diabetes mellitus for the German health insurance database (sample of insurees) is taken from the final report of the pilot project on morbidity statistics47:

"To define an insuree as diabetic, at least one of the following three criteria must be fulfilled for continually insured persons in the year 2002 (cf. Hauner et al. 2003). For persons who died during 2002 the criteria are to be applied for the last four quarterly periods of their life.

- at least two prescriptions of anti-diabetic drugs,
- if only one prescription is documented, the diagnosis for diabetes E10–E14 without modifier A and V must be coded at least once,
- for insurees without an anti-diabetic drug prescription, the diagnosis for diabetes (E10–E14, without modifier A and V) must be coded for at least three of four quarterly periods."

Example 4
In Sweden personal identification numbers are used regularly in health services. In a study, diabetes prevalence was estimated for a defined local population through linking records on hospital discharges and physician visits with a diabetes diagnosis with data on prescriptions of diabetes drugs filled by the pharmacists in the same area. While there is an obvious overlap between the three sources, through linking data from the three sources, one could arrive at a better estimate of diabetes prevalence than basing the estimate on the separate data sources.

Annex II Diagnosis-specific morbidity - European shortlist, Version 6 March 2007

See file Diagnosis-specific morbidity (European shortlist 6 March 2007).xls
Annex III Diagnosis-specific morbidity statistics – tables for data submission to Eurostat

See file Morbidity tables (23-04-2007).xls
Annex IV 1976 WHO European standard population

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