

# **Information, indicators and data on the prevalence of chronic diseases in the European Union**

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# Executive summary

## Background and objectives

The European Commission called for a report on data, indicators and available information on the prevalence of major chronic diseases in the European Union (EU). This in response to a health information action that was proposed in conclusions from the EU Council <sup>1</sup>.

The present report by the RIVM (National Institute for Public Health and the Environment, the Netherlands) is the result of this call and gives an overview of existing sources of data, indicators and available information on the prevalence of major chronic diseases in the European Union. The report addresses the following chronic diseases as proposed in the call:

- cardiovascular disease (diseases that involve the heart or blood vessels): ischemic heart disease and stroke;
- cancer;
- diabetes;
- respiratory diseases (diseases of throat and lungs): chronic obstructive pulmonary disease (COPD), asthma, allergic rhinitis;
- mental disorders: depression;
- neurodegenerative disorders (diseases characterised by progressive nervous system dysfunction): dementia, Parkinson's disease and multiple sclerosis.

In addition, the report gives a short overview of the availability of data on the prevalence of chronic diseases in general.

## Methods

We gathered and reviewed existing information on data availability, quality and comparability from the following sources:

1) Relevant EU sponsored health information projects identified through the project database of the Executive Agency for Health and Consumers (including the information collected by the Joint Action for European Community Health Indicators and Monitoring (JA for ECHIM), the European Health Examination Survey Pilot Joint Action (EHES JA), and some disease-specific projects).

2) Databases containing health information, such as the database of Eurostat (the statistical office of the European Union), the Health for All database of the World Health Organization (WHO-HfA), the health database of the Organisation for Economic Cooperation and Development (OECD) and the GLOBOCAN database from the International Agency of Research on Cancer.

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<sup>1</sup> Council of the European Union (2011). Council conclusions 'Innovative approaches for chronic diseases in public health and healthcare systems' (2011/C 74/03). Official Journal of the European Union 8.3.2011.

3) European health information initiatives, such as:

- The European Health Interview Survey (EHIS);
- The Eurostat morbidity statistics pilot.

We also analysed reports from relevant international institutes, expert networks and EU funded health information and reporting projects for prevalence data. In addition, the information on chronic diseases on the website of DG SANCO (the European Commission Directorate-General Health & Consumers) was included in the analysis. We have prioritised towards data available from ready to use sources that are providing comparable information for more than one country. Finally, we searched the research databases MEDLINE, EMBASE, SciSearch and PsycINFO for reviews and comparative studies on the prevalence of the selected disease groups that were published after 2008.

For each disease (group) we collected the following information into structured tables:

- (most important) sources;
- source type: database, project report, research article or review article;
- type of data collection: register or survey using an interview and/or examination;
- geographical coverage: EU Member States, Acceding countries and Candidate Countries, and the European Free Trade Association (EFTA) Countries;
- possibilities to breakdown by gender and age groups;
- periodicity and year(s) of data collection.

## Results

### **Lack of comparable and sustainable data on chronic disease prevalence**

Based on the tabular overviews of existing data, we identified several gaps in data availability for the prevalence of the selected chronic diseases. The availability of timely data is especially problematic for cardiovascular diseases, whereas data on cancer is much more widely available than for other chronic diseases. For some diseases (e.g. multiple sclerosis, Parkinson's disease, diabetes) a wealth of local and national data exists but because these data are originating from a great variety of studies, they are still far from comparable. Furthermore, the available information on the prevalence of chronic diseases is scattered among several reports, (project) websites, research articles and international databases, with generally only the latter being a source with some form of sustainability. The availability of data varies enormously between EU Member States.

### **European Health Information Survey is important source for self-reported prevalence**

Focusing on databases, information on the self-reported prevalence of cardiovascular disease, cancer, diabetes, depression, COPD and asthma has become available from the first wave of EHIS for the majority of EU countries. Eurostat published the EHIS data for diabetes, COPD, asthma and depression in its online database. In addition, information on the self-reported prevalence of diabetes, asthma, COPD and depression is also available from the ECHIM data collection pilot for several EU countries that did not participate in the first wave of EHIS. All EU Member States will probably conduct EHIS in the second wave, which is planned for 2014.

### **Eurostat morbidity data activities are important potential source for register-based prevalence**

Register-based data on the prevalence of cardiovascular disease, cancer, depression, COPD, asthma, diabetes, Parkinson's disease, multiple sclerosis and dementia have been collected in the Eurostat morbidity statistics pilot for many EU countries, but Eurostat will not publish the data as comparable statistics. The aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. This, together with the second wave of EHIS will significantly improve the availability of prevalence data and provide possibilities to monitor trends. In addition, several projects and networks aim to improve the quality, comparability and availability of prevalence data in Europe.

### **Large differences in data availability between countries**

Availability of the data is not equally distributed among countries and this leads to large 'health information inequalities' within the EU27. Data availability is generally better in the 'old' EU15 countries and worse in the countries that became EU Member in 2004 or later. Furthermore, trend data are not always available and several studies/projects highlight the need for more age and sex-specific data collection to be able to standardise data by age and sex, which is essential for making international comparisons.

## **Conclusions and recommendations**

### **Lack of data impedes health policy development and evaluation throughout Europe**

Based on the overviews of existing data we conclude that the availability of timely and comparable chronic disease prevalence data is far from ideal in Europe. A balanced, timely and adequate picture of chronic disease prevalence is lacking. This impedes health policy development and evaluation throughout Europe. Health interview surveys, registries and epidemiological studies that include some form of health examination are important data sources. The data quality and comparability of these sources mainly depends on the methods used in each specific survey or register. Due to a lack of consensus on the methods and definitions, these methods often differ leading to problems in comparability. Still, together health interview surveys (HIS), registries and health examination surveys (HES) form a good basis for improving national and international health monitoring systems.

### **EU-wide data collections important to boost the data situation**

From the overviews of available data it is clear that EU-wide data collections such as EHIS and the Eurostat morbidity statistics activities are important future or potential sources of data on the prevalence of chronic diseases in the EU27. For this reason and because they are complementary to each other, these pilot initiatives together with EHES-related initiatives may boost the data situation in the future and therefore need to be sufficiently supported. Implementation of a harmonised European Health Examination Survey (EHES) in all EU Member States would provide an important source of comparable data on both the prevalence of chronic diseases as well as on their determinants. The implementation of an EHES could build on preliminary work that has already been done in previous EU projects like the EHES pilot project and the Feasibility of a European Health Examination Survey (FEHES).

### **Sustainable investments needed for monitoring disease trends**

In addition to benchmarking and supporting health policies, the purpose of health indicators is to monitor trends. In order for European Health Interview Survey, European Health Examination Survey and the Eurostat morbidity statistics activities to fully reach their potential for health monitoring, sustainable investments are necessary to make sure that the current pilots become a sustainable data source and provide possibilities to monitor and compare trends. Because disease registers, HIS and HES activities are expensive, it is worthwhile to further stimulate the use of existing routinely collected data as started by the Eurostat morbidity pilot and develop protocols to arrive at optimal comparability for such data sets. Regularly updating larger multicenter studies would also be important for monitoring disease trends. We mention: the European Community Respiratory Health Survey, the International Study of Asthma and Allergies in Childhood and the MONICA study (MONItoring trends and determinants in CARDiovascular disease).

### **Stimulate joint data collection and need for central coordination**

To improve the current data situation in Europe, DG SANCO should stimulate joint data collection between Eurostat, the OECD, the WHO and EU Member States by bringing them together on morbidity data and other health information topics as part of a common health information strategy. These organisations should join forces and use each others' expertise and networks to improve the availability, quality and comparability of health data in general and for chronic diseases in particular. To make investments in improving data availability, comparability and quality more sustainable, some central form of coordination is needed. Sustainable investments should, therefore, also become part of the common European health information strategy. Finally, a web-based chronic disease monitoring system can increase visibility of available information and increase Member States' commitment.

## **Acknowledgements**

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# 1 Introduction

The Council of the European Union has published a Council Conclusion paper ‘Innovative approaches for chronic diseases in public health and healthcare systems’. In this, the Council has invited the Member States and the Commission to “initiate a reflection process aiming to identify options to optimize the response to the challenges of chronic diseases, the cooperation between Member States and summarize its outcomes in a reflection paper by 2012”(1).

The Council also invited the Commission to integrate, where possible, chronic diseases as a priority in current and future European research and action programmes (1). In addition, the United Nations (UN) High Level Meeting on non-communicable diseases in New York in September 2011 confirmed that addressing chronic diseases has now become a global priority (2).

One of the four areas in which scope for action was identified by the Council was “comparable information at European level on the incidence, the prevalence, the risk factors and the outcomes concerning chronic diseases”. This should take account of “different existing mechanisms such as the EHES, the development of morbidity statistics under ESTAT, existing registries and other sources, to enable benchmarking and evidence-based policy”.

In response to this health information action the European Commission called for a report on data, indicators and available information on the prevalence of major chronic diseases in the European Union (EU). The present report is the result of this call and gives an overview of existing sources of data, indicators and available information on the prevalence of major chronic diseases in the European Union. The report addresses the following chronic diseases, as specified by the Commission:

- cardiovascular disease (diseases that involve the heart or blood vessels): ischemic heart disease and stroke (paragraph 4.2)
- cancer (4.3)
- diabetes (paragraph 4.4)
- respiratory diseases (diseases of throat and lungs): chronic obstructive pulmonary disease (COPD), asthma, allergic rhinitis (paragraph 4.5)
- mental disorders: depression (paragraph 4.6)
- neurodegenerative disorders (diseases characterised by progressive nervous system dysfunction): dementia, Parkinson’s disease and multiple sclerosis (paragraph 4.7).

In addition, the report gives a short overview of the availability of data on the prevalence of chronic diseases in general (paragraph 4.1).

For meaningful international comparisons data should not only be actually available, but also comparable and of sufficient quality. Comparability and quality are strongly dependent on the type of data collection (examination or interview survey, specific disease registry, general practice (GP) or hospital registry, epidemiological study). Based on the complex findings from the overview this report also gives proposals to improve the availability, reliability and comparability of chronic disease prevalence data (chapter 5 Conclusions and recommendations).

This report is the first in a series of four reports to be prepared by the Dutch National Institute for Public Health and the Environment (RIVM) in 2012 in response to a call by DG SANCO (Directorate-General Health and Consumers). These reports should feed into DG SANCO's work on chronic diseases and/or the reflection process described above. The other reports will give an overview of the burden of chronic diseases in the older population, their impact on economic participation and good practices related to retention and return to work interventions. In addition they will provide an analysis of the outcomes of a European-wide stakeholder consultation as part of the so-called 'chronic disease reflection process'. The current report will be an important basis for the overview of the burden of chronic diseases in the older population in Europe.

## 2 Background and context

The EU is required by its founding treaty to ensure that human health is protected as part of all its policies. The EU's current health strategy 'Together for Health' (2008-2013) aims to protect and improve human health. It is implemented, among other things, through so-called health programmes. One of the aims of these health programmes is to generate and disseminate health information and knowledge needed for improving the health of EU citizens. This is for instance reflected in separate health information strands in the first and second Action Programme on Public Health. Within these strands, various health information oriented projects have been executed.

Given the importance of health information for health policy preparation and evaluation, DG SANCO (Directorate-General Health and Consumers) has supported projects on developing and defining health indicators (such as European Community Health Indicators), piloting on data collection in specific areas, building information websites and publishing reports. Other activities include cooperating with Eurostat on harmonisation of data collections, e.g. EHIS (European Health Interview Survey) and building the so-called HEIDI wiki. This HEIDI wiki (Health in Europe: Information and Data Interface) is an internet based wiki tool for European health information and data to be launched early may, 2012.

The EU has funded numerous projects with the intention to further develop indicators in specific health areas and in that effort a central coordinating effort has been developed in the ECHI and ECHIM projects and the Joint Action for ECHIM. The goal of these European Community Health Indicators (ECHI) projects was to establish a set of health indicators for the EU health information system (to support health policies through monitoring trends and making comparisons between countries).

This ECHI shortlist has been developed as a priority list for data harmonisation among EU countries, in which 'harmonisation' refers to uniformity of indicator definition as well as of underlying data collection. The 88 shortlist indicators were selected by expert panels to represent a core set of 'the most important public health items, from a general policy maker's point of view'. The selection was also driven by national public health policy priorities (3). The list was adopted by DG SANCO as a central guide for the further implementation of health monitoring and reporting at the EU level, and mentioned as such in the EU Health Strategy 'Together for Health' (4). The ECHI shortlist also features in the framework Regulation for statistics concerning public health and safety at work, adopted by the Parliament and council in 2008 (5)

### 3 Methodology

For this report we gathered and reviewed the available information on data availability, quality and comparability as published by the following sources:

- 1) Relevant EU projects identified through the EAHC project database <sup>2</sup>. This includes:
  - a. Health information projects covering more than one chronic disease or disease group:
    - Joint Action (JA) for ECHIM: ECHIM stands for European Community Health Indicators and Monitoring. This is a three-year project to develop and implement health indicators and health monitoring for the EU and its Member States. It draws on the work of the previous ECHI and ECHIM projects, and will end at 30.6.2012. Within the JA for ECHIM data on the prevalence of several chronic diseases are collected as part of a *pilot data collection*.
    - EHES JA: The European Health Examination Survey Pilot Joint Action is a collaboration to collect nationally representative, high quality health data that are comparable between countries and over time (see textbox 1).
  - b. Health information projects focusing on specific chronic diseases:
    - Cardiovascular diseases: EUROCISS I and II;
    - Cancer: EUROCHIP, EUROPREVAL, RARECAREnet, EUNICE;
    - Diabetes: EUDIP, EUCID, BIRO, EUBIROD;
    - Respiratory diseases: ECRHS, IMCA I and II;
    - Mental disorders: MINDFUL, EU-WMH;
    - Neurodegenerative disorders: MS-ID, EUREMS, EuroCoDe, ALCOVE.
- 2) Databases containing internationally comparable health data:
  - Eurostat database;
  - WHO-HfA database (World Health Organization Health for All database);
  - OECD Health database (Organisation for Economic Cooperation and Development);
  - GLOBOCAN 2008 database (the global cancer database of the International Agency for Research on Cancer).
- 3) European health information initiatives:
  - EHIS: The European health interview survey (EHIS) is implemented and managed by Eurostat and will include information from all EU Member States (see textbox 2).
  - Eurostat morbidity statistics pilot: The aim of this pilot was to test the feasibility of the methodological approach for producing diagnosis-specific morbidity statistics required for the European Statistical System (see textbox 3).

In addition, we scanned reports from relevant international institutes (e.g. OECD, WHO and the European Commission) and expert networks (e.g. Alzheimer Europe, International Diabetes Federation, European Heart Network, European Respiratory Society) for the availability of prevalence data. For example, 'Health at a Glance: Europe 2010' (6), 'the Major and Chronic diseases report' (7), 'European cardiovascular disease statistics 2008' (8) and 'The state of mental health in the European Union' (9). We also scanned several reports on the prevention and management of chronic disease for information on relevant data sources for chronic disease prevalence (10-14).

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<sup>2</sup> <http://ec.europa.eu/eahc/projects/database.html>

### **Textbox 1: European Health Examination Survey (EHES)**

#### *Data collection:*

In the European Health Examination Survey Pilot Project (2009-2011) twelve countries piloted a standardised health examination survey (HES) in the working age population. The core measurements that were included by all countries were: actually measured weight, height, waist circumference, blood pressure, total and HDL-cholesterol, fasting glucose or HbA1c<sup>3</sup>. These are modifiable determinants of major chronic diseases that are not identified in health interview surveys. Although these determinant data are not falling within the scope of this report, data on these determinants are also very important for monitoring of chronic diseases, for example for modelling and projecting future disease trends. In addition to these core measurements, countries may include other measurements and questions into their national HES. Potential additional measurements are for example lung function tests and blood triglycerides, which are an indicator of cardiovascular risk.

#### *Future:*

The vision of the EHES project is to grow into a sustainable system of national health examination surveys in Europe as part of the European Health Survey System and covering all EU and EFTA/EEA countries.

#### *Significance for ECHI indicators:*

When EHES will be fully implemented in a majority of EU Member States, ECHIM has proposed to switch to using EHES as preferred data source for the indicators on blood pressure and BMI.

#### *Pros and cons:*

Multi-centre population-based (research) studies or health examination studies in different countries using the same methodology are probably the most reliable source for international comparisons. They would also allow the benefit from new knowledge and markers that are derived from genomics research. However, they are expensive and therefore often carried out on an ad hoc basis.

Furthermore, we scrutinised the information on the epidemiology of chronic diseases that has been gathered by the EU funded health information and reporting projects, indicated below:

- EUPHIX (EU Public Health Information & Knowledge System) has been developed as a prototype for a web-based European public health reporting and monitoring system for health professionals, policy makers and others (the website is offline now).
- EUGLOREH (Global Report on the Health Status in the European Union). The general objective of this project was the production of a 'Report on Health in the European Union' extending from 1998 until the most recently available data. This report is intended to be a reference publication providing general information on health status of the European population and on associated time trends. Its information has been included in a preliminary version of DG SANCO's HEIDI wiki website.
- DYNAMO-HIA (DYNAMIC Model for Health Impact Assessment). The aim of this project was to develop a web-based tool to assess the health impact of policies. The project collected age- and sex-specific data on the prevalence of COPD, diabetes, ischemic heart disease, stroke and cancer for as many of the 27 countries of the European Union as possible. These data serve as input for the DYNAMO-HIA model.

<sup>3</sup> For details see: <http://www.ehes.info/>

## **Textbox 2: European health interview survey (EHIS)**

### *Data collection:*

Between 2006 and 2010 the first data collection round for EHIS was carried out in the majority of EU Member States (BE, BG, CZ, DE, EE, EL, ES, FR, CY, LV, HU, MT, AT, PL, RO, SI, SK) Switzerland and Turkey<sup>4</sup>. Eurostat has published the results of the first wave for the self-reported prevalence of diabetes, depression, asthma and chronic bronchitis, emphysema, and other chronic obstructive pulmonary disease (15). EHIS could also be a source for the self-reported prevalence of myocardial infarction, coronary heart disease, stroke, cancer and allergy. It is noted that not in all countries mentioned a full scale survey has been carried out; in some countries only specific modules were applied, in others the full questionnaire was applied but only in a small pilot sample.

### *Future:*

Based on the outcomes of and experiences in the first data collection wave, the EHIS questionnaire has been thoroughly under revision<sup>5</sup>. This will lead to adaptations to the EHIS question underlying the indicators for prevalence of chronic diseases in the second wave (planned for 2014). In the January 2012 draft version of the revised questionnaire, in the EHIS question asking the respondent whether he/she has had any of the diseases listed, the part about whether the disease was diagnosed by a doctor has been deleted from the question. The approval process by the Member States has not been finalised yet, so (minor) changes in the questionnaire can still occur. The final version of the questionnaire is expected to be ready later this year. At the time of writing this report, an EHIS implementing act on EHIS is being developed. It is envisaged that this act will form the legal basis for EHIS wave II in 2014. It will not form the legal basis for possible future waves after 2014. The legal basis for future waves is not yet certain. It is expected that all EU Member States will conduct EHIS in the second wave.

### *Significance for ECHI indicators:*

As proposed by the Joint Action for ECHIM, EHIS is the preferred (interim) source for 27 ECHI shortlist indicators, and hence it is a very important data source for the proposed European indicator set. In the Joint Action for ECHIM national HIS data have been collected in the so called ECHIM pilot data collection for countries not participating in the first EHIS wave. The data will be published in the final report of the JA for ECHIM as well as in the HEIDI data tool (16).

### *Pros and cons:*

The advantage of HIS is that it is a population based survey and also includes patients that have not been in contact with the types of health care services that are covered in the register data. As it is based on self-report, the diseases are also not described in terms of ICD codes. (E)HIS-based estimates may be influenced by reporting biases and sampling related biases. Therefore, they may not be a fully adequate reflection of the current situation in a country, and other estimates may be better for this purpose. However, as a common methodology is underlying the gathering of EHIS data, they suit the purpose of international comparison and benchmarking rather well.

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<sup>4</sup> For details see:

[http://circa.europa.eu/Public/irc/dsis/health/library?!=/methodologiessandsdatasc/healthsinterviewssurvey/ehis\\_wave\\_1&vm=detailed&sb=Title](http://circa.europa.eu/Public/irc/dsis/health/library?!=/methodologiessandsdatasc/healthsinterviewssurvey/ehis_wave_1&vm=detailed&sb=Title)

<sup>5</sup> For details see:

[http://circa.europa.eu/Public/irc/dsis/health/library?!=/methodologiessandsdatasc/healthsinterviewssurvey/ehis\\_wave\\_2&vm=detailed&sb=Title](http://circa.europa.eu/Public/irc/dsis/health/library?!=/methodologiessandsdatasc/healthsinterviewssurvey/ehis_wave_2&vm=detailed&sb=Title)

Finally, we have looked at information on chronic disease on the website of DG SANCO <sup>6</sup>. We focused on data available from ready to use sources providing comparable information and for more than one country.

The analysis of the above-mentioned sources has revealed that these projects/reports mapped the availability of prevalence data only until 2008 for most disease groups. Therefore, we searched MEDLINE, EMBASE, SciSearch and PsycINFO for reviews and comparative studies performed after 2008 (see Annex 3 for search strategy).

We did not include hospital discharge data as a potential source of prevalence because they only represent the subset of patients who are admitted to hospital, often with specific complications. Therefore, they do not reflect the true prevalence for the chronic diseases at hand. Furthermore, hospital admission policies show prevalence independent trends over time. For example, currently in many countries only the most severe cases of patients with COPD will visit a hospital.

For each disease (group) we collected the following information into structured tables:

- (most important) sources;
- source type: database, project report, research article or review article;
- type of data collection: register or survey using an interview and/or examination;
- geographical coverage: EU Member States, Acceding countries and Candidate Countries, and the European Free Trade Association (EFTA) Countries;
- possibilities to breakdown by gender and age groups;
- periodicity and year(s) of data collection.

As the ECHI shortlist has been developed as a priority list for data harmonisation among EU countries, we also shortly summarise some issues related to indicator development for chronic diseases as related to the ECHI shortlist.

In addition to benchmarking and supporting health policies, the purpose of ECHI indicators is to monitor and compare trends. For monitoring trends sustainable data collections are necessary. Therefore, the overview of available data sources distinguishes between information from databases and information from project reports and research or review articles. Databases are generally sustainable data sources or have the potential to become a sustainable data source. Reports and research articles or reviews are generally presenting data that are available on an ad hoc basis.

Based on the tabular overviews of existing data, we have identified gaps in data availability and possibilities for improvement. Finally, in chapter 5 we make some realistic proposals to improve the availability, reliability and comparability of chronic disease prevalence data in the European Union based on experience from international indicator projects and networks such as the Joint Action for ECHIM.

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<sup>6</sup> [http://ec.europa.eu/health/major\\_chronic\\_diseases/diseases/index\\_en.htm](http://ec.europa.eu/health/major_chronic_diseases/diseases/index_en.htm)

### Textbox 3: Eurostat morbidity statistics pilot

#### *Data collection:*

Sixteen countries have carried out the Eurostat diagnosis-specific morbidity statistics pilot between 2007 and 2010. This pilot study aimed at providing best national estimates. The sixteen participating countries collected register-based data for a large number of diseases, which included the chronic diseases addressed in the current report <sup>7</sup>: ischemic heart diseases (including AMI), cerebrovascular disease, diabetes, cancer, COPD and asthma, depression, Parkinson's disease, multiple sclerosis and dementia.

#### *Future:*

In September 2011 Eurostat formed a Task Force on morbidity statistics. This Task Force aims to assess the data collected in 16 country pilots for their quality and comparability. The aim is to provide criteria and recommendations on how to calculate the best estimates for the measurements presented in the European shortlist including harmonised definitions for the different indicators. The final aim is to set up a regular data collection on morbidity within the European Statistical System. Eurostat will not publish the set of morbidity pilot data since they were collected to assess the feasibility of the proposed method. Countries may decide themselves whether they want to publish the data.

#### *Significance for ECHI indicators:*

Register-based data for diabetes, asthma, COPD, depression and dementia were also collected in the ECHIM data collection pilot. In this pilot each Member State also decided for itself which would be (are) the best data source(s) for calculating the estimates. The attempt to collect administrative/register-based data was less successful than the collection of national HIS based data. Only a few countries could devote enough resources or were able to provide the data according to desired ECHI dimensions and breakdowns.

#### *Pros and cons:*

Given the fact that not in all Member States the health information system is well aligned with the health care system (the latter usually providing registry-based data), there will be limitations to the comparability of national estimates resulting from registers. Small differences (between and within countries) in disease coding practices compromise data comparability even further (17). In addition, due to differences in national priorities and data protection regulations, possibilities for developing national registers vary between countries.

The advantage of register-based data is that they are routinely collected and therefore are a cheap source of data. Another advantage of registers over survey sources is that they identify diseases based on medical diagnosis. However, several chronic diseases often remain undiagnosed, because people do not always seek medical help, or consult physicians (e.g. General Practitioners) who are not specialised in the disease and do not always recognise or register their disease. This is for example often the case for mental disorders. Diabetes often remains undiagnosed as well. Therefore, epidemiological surveys using more comprehensive measurement instruments (e.g. diagnostic interviews, health examinations, biomarkers from blood) tend to find higher prevalence estimates than estimates based on registered/diagnosed cases.

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<sup>7</sup> For details see:

<http://circa.europa.eu/Public/irc/dsis/health/library?!=/methodologiessandsdatasc/diagnosis-specific&vm=detailed&sb=Title>



## 4 Results

This chapter starts with a short overview of data on the prevalence of chronic disease in general. Next, it gives for each chronic disease (group):

- a table that includes information on the identified sources for prevalence data;
- a short overview of relevant indicator development;
- a short analysis of the current data situation and an identification of main gaps (or possibilities for improvement);
- a short overview of existing initiatives to improve data availability, reliability and/or comparability in these areas.

### ***4.1 Chronic disease in general***

The ECHI indicator self-reported chronic morbidity provides information on the prevalence of any long-standing (chronic) illness or longstanding health problem, i.e. on the burden of chronic diseases in general (3, 18). The data on self-reported chronic morbidity are available for all EU countries and Iceland, Norway, Switzerland and Croatia from a question in the so called Minimum European Health Module (MEHM) in the European Union Statistics on Income and Living Conditions (EU-SILC) (19). The MEHM is also included in EHIS but data are not published (yet) by Eurostat (20). The question in the MEHM asks whether the respondent has any long-standing illness or longstanding health problem. Also SHARE includes a question on chronic or long-term health problems (21).

In addition, EHIS and SHARE include a question asking the respondents whether they have one or more of the chronic diseases listed on a show card (20, 21). The answers to these questions could be combined into a measure for the prevalence of chronic diseases in general or into a measure for the prevalence of multi-morbidity.

## 4.2 Cardiovascular diseases

Cardiovascular diseases (CVD) comprise a wide range of pathological conditions of the heart muscle and blood vessels. However this paragraph only focuses on ischemic heart disease (IHD) (including acute myocardial infarction (AMI)) and stroke because among the cardiovascular diseases they are responsible for the highest disease burden in terms of DALYs (22).

### Key messages:

- At present, routinely updated sources of Europe-wide data on the prevalence of cardiovascular diseases (CVD) are very scarce.
- According to the EUROCISS project, data on attack rate of AMI and stroke are more readily available than data on prevalence. Attack rate of AMI and stroke are both included in the ECHI shortlist.
- Information on the prevalence of cardiovascular diseases is available from the first wave of EHIS for many EU countries. Data on the prevalence of CVD have also been collected in the Eurostat morbidity statistics pilot for many EU countries, but Eurostat will not publish the data as comparable statistics.
- For several European countries information on CVD prevalence is available from epidemiological studies, but methodological differences hampered full comparability of the data.
- The aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. Furthermore, all EU Member States will probably conduct EHIS in the second wave, which is planned for 2014. Both initiatives will significantly improve the data availability for CVD prevalence and provide possibilities to monitor trends. In addition, the EuroHeart II project aims to provide the most up to date statistics on CVD in Europe.

### Indicator development

The EU funded EUROCISS project (European Cardiovascular Indicators Surveillance Set, 2000-2003) has proposed a list of indicators with the aim of improving future monitoring of CVD morbidity in Europe. These indicators have been divided into three categories: 1) already available indicators; 2) those that should be implemented in the short-term (including for instance attack rate); and 3) those recommended for long-term implementation. Among the long-term implementation indicators are the prevalence of ischemic heart disease and the prevalence of stroke. The *long-term implementation indicators* need a longer period of time to be implemented, and require, for each country, the training of a dedicated team of epidemiologists to support their development (23). Therefore, according to the EUROCISS project, data on attack rate of AMI and stroke are more readily available than data on prevalence. Attack rate includes first and recurrent event and case fatality in and out of hospital (23). The activities of the EUROCISS project have contributed to the development of indicators in the ECHI project (3). Attack rate of AMI and stroke are both included in the ECHI shortlist.

EUROCISS has provided details on sources of data on cardiovascular diseases (including population-based surveys at national and regional level, HIS, HES, longitudinal studies, GP registers and population-based registers) from 16 of the 27 EU countries plus Iceland and Norway. The EU countries included Austria, Belgium, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Italy, the Netherlands, Poland, Portugal, Spain, Sweden and the United Kingdom (23).

In addition, the project concluded that to obtain a comprehensive picture of cardiovascular diseases, many sources of information must be integrated. For example, to distinguish between hospitalisation for first occurrence of a disease or for treatment of further episodes and to correct for early readmission. Following the experience of the Nordic countries, EUROCISS recommended that all medical and death records across Europe would adopt a personal ID. This would allow an easier and more accurate record linkage among the different sources of information (23).

## **Data situation and main gaps**

Table 1 gives an overview of available data sources for cardiovascular disease. It is obvious that comparable data on the prevalence of CVD are scarce. Comparable data on morbidity from CVD are clearly more difficult to collect and less available than mortality data. At present, there is no routinely updated source of Europe-wide CVD morbidity data (8, 24).

### **Databases**

The Eurostat morbidity statistics pilot has collected data on the prevalence of ischemic heart diseases (including AMI) and cerebrovascular disease. Eurostat will not publish the morbidity pilot data because they were collected to assess the feasibility of the proposed method. Countries may decide by themselves whether they want to publish the data or not.

The European health interview survey (EHIS) has also included 12-months prevalence (self-reported) of stroke, coronary heart disease and myocardial infarction (20). Not all EU countries participated in the first wave of EHIS, however. The Survey of Health, Ageing and Retirement in Europe (SHARE) also contains a question on the prevalence of coronary heart disease, myocardial infarction and stroke, but it is limited to people aged 50 years and over and not all EU countries participate in SHARE (25).

Some countries (e.g. Finland, Germany, Italy, The Netherlands, Portugal and Spain) regularly carry out examination (HES) or interview (HIS) surveys that also include cardiovascular diseases (23, 26). However, information from periodically repeated HIS is self-reported and this may not be sufficient to assess the full amount of CVD morbidity, while the high costs of clinical examination make the HES difficult to carry out. Only a few European HIS and HES studies use properly standardised and sensitive methods to assess CVD morbidity in the best way (23).

### **Research articles and reports**

Ad hoc population based studies on CVD morbidity are usually limited to specific geographical areas (7). Truelsen et al. (2006) performed a systematic review of published population-based studies on stroke prevalence. The majority of stroke prevalence studies were from populations in Italy or the UK. There were more studies on incidence than on prevalence and there were several methodological differences that hampered full comparisons of data. The authors also compared WHO Global Burden of Disease estimates for stroke prevalence (calculated from routine mortality statistics) with estimates from 'ideal' stroke population

studies. Those estimates were in good agreement. Therefore, the authors concluded that until better and more stroke studies are available, the WHO stroke estimates may provide the best data for understanding the stroke burden in countries where no stroke data currently exist (27).

The DYNAMO-HIA project gathered age- and gender-specific data on prevalence and/or incidence and mortality of IHD and stroke in as many EU countries as possible, using existing data sources, to create an EU-wide dataset (26). The main source of data for stroke were the WHO estimates from the review of stroke prevalence and incidence in Europe by Truelsen et al. (2006). These were available for almost all of the 27 EU countries (the exceptions were Romania, Estonia and Bulgaria). The UK general practice research database<sup>8</sup> (GPRD,) and the Netherlands GP registry data were the most complete and reliable source of data for IHD and stroke. For countries for which prevalence data were missing, the DYNAMO-HIA project used DISMOD II software to estimate stroke and IHD prevalence. These estimates were based on country-specific mortality data and relative risks from the UK GPRD (26, 28). Details of the sources of data obtained for each country are described in the annex of the DYNAMO-HIA report (26).

### **Data on attack rate of AMI and stroke are more readily available**

The Joint Action for ECHIM collected age-standardised attack rate of AMI and stroke based on combined hospital discharge and mortality data as part of the ECHIM pilot data collection. Because a relatively large proportion of stroke and AMI patients die suddenly before reaching the hospital, only a combination of mortality data and hospital discharge records can provide a complete picture of the burden of these diseases. Therefore, these data should be linked to the subject level. Due to personal data protection regulations this linkage is not possible (yet) in several countries (18).

The WHO MONICA project<sup>9</sup> (MONitoring trends and determinants in Cardiovascular disease) has examined the incidence of coronary and cerebrovascular events in 37 different populations in 21 countries (including 29 populations in 16 European countries) (29, 30). Although the data from the study were collected between mid 1980s and 1990s and the study populations were not necessarily representative of the countries, it still represents the most recent Europe-wide comparable dataset on CVD morbidity, because they were all collected and validated through the same standardised methodology (8).

The EUROCISS Project also performed an inventory of AMI and stroke population-based registers in Europe. It was concluded that although population-based registers provide the best indicators for the attack rate and case-fatality of AMI and stroke, comparability is still limited because these registers cover different age groups (ranging between 25 and 74 years or more) and use different procedures for event definition (31). The EUROCISS group has also observed that no population data or registries are currently available in Europe on heart failure (31).

## **Current initiatives to improve the data situation**

Currently register-based data collected in the Eurostat morbidity statistics pilot are not available yet. However, the final aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. Furthermore, all EU Member States will probably conduct EHIS in the second wave, which is planned for

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<sup>8</sup> [www.gprd.com](http://www.gprd.com)

<sup>9</sup> [www.kti.fi/monica](http://www.kti.fi/monica)

2014. Both initiatives will significantly improve the availability of data for the prevalence of cardiovascular diseases and provide possibilities to monitor trends.

Furthermore, the EuroHeart II (European Heart Health strategy II) project of the European Heart Network will report on and analyse the current situation with regard to cardiovascular and circulatory diseases in the EU. One of its objectives is to provide the most up to date statistics on CVD in Europe (including a cost of disease study in the EU) and analysing these data (32).

**Table 1: Overview of available data on the prevalence of cardiovascular diseases.**

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
<b>Database (see annex 4 for indicator definitions)</b>						
EHIS <sup>a</sup>	European Health Interview Survey	database (data not available yet)	BE, BG, CZ, DE, EE, EL, ES, FR, CY, LV, HU, MT, AT, PL, RO, SI, SK, CH and TR conducted a first wave of EHIS between 2006 and 2010.	by sex and 8 age groups (15-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+)	first wave between 2006 and 2010. Second wave planned for 2014.	(20)
Eurostat diagnosis-specific morbidity data activities <sup>b</sup>	administrative sources (clinical records, insurance data), disease registers, etc.	database (data not available yet)	16 countries carried out the pilot (CZ, CY, EE, HU, LT, LV, MT, SI, SK, AT, DE, BE, DE, FI, NL, PL and RO)	by sex and by 18 age groups (0-4, 5-9, etc., 85+)	pilot study in 2007-2009	See info on Circa <sup>10</sup>
SHARE	interview	database	17 EU countries: 2004 (AT, BE, CH, DE, DK, ES, EL, FR, IT, NL and SE), 2006/7 (plus CZ and PL), 2008/9, 2010 (plus EE, HU, PT, SI, data for 2010 not released yet).	by sex, people aged 50 and over	4 waves: 2004, 2006/7, 2008/9, 2010 (data for 2010 not released yet)	(21, 25, 33)
<b>Reports and articles</b>						
DYNAMO-HIA	variety of sources (surveys, registries)	project report	data available for few EU-27 countries, therefore prevalence is estimated with DISMOD	age- and sex-specific data	preferably data collected since 2000	(26)

<sup>10</sup> <http://circa.europa.eu/Public/irc/dsis/health/library?l=/methodologiessandsdatasc/diagnosis-specific&vm=detailed&sb=Title>

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
Truelsen et al., 2006	1) varying population-based studies, some including physical exam; 2) WHO GBD estimates for stroke prevalence calculated from routine mortality statistics	literature review	1) prevalence studies available for ES, FI, FR, IT, NL, SE and UK; 2) WHO prevalence estimates available for all EU27 countries (except BG and RO) plus CH, IS and NO	1) by sex and different age-groups depending on study; 2) by sex and age groups (25–34, 35–44, 45–54, 55–64, 65–74, 75–84, 85+)	studies published during the period January 1993 to June 2004	(27)

<sup>a</sup> 12-months prevalence (self-reported) for coronary heart disease, myocardial infarction and stroke

<sup>b</sup> period prevalence of ischemic heart diseases (including AMI), heart failure and cerebrovascular disease

## 4.3 Cancer

There are many forms of cancer, or malignant neoplasm. In the WHO European region colorectal, breast, prostate and lung cancers are responsible for the highest disease burden in DALYs due to cancer (22). All cancers start because cells divide and grow out of control, forming malignant tumours, which can invade nearby parts of the body or spread to more distant parts of the body. Untreated cancers can cause serious illness and death.

### Key messages:

- According to the EUROCHIP project, cancer prevalence proportions, trends and projections are a high priority for which indicators are already available.
- Information on cancer is much more widely available than for other diseases. This reflects the long tradition, of population based cancer registries in most European countries. These cancer registries routinely collect epidemiological indicators such as incidence and prevalence.
- GLOBOCAN provides prevalence estimates for all EU, EFTA, Accession and (Potential) Candidate countries using a function of incidence and observed survival.
- Information on the prevalence of cancer is available from the first wave of EHIS for many EU countries. Data on the prevalence of cancer have also been collected in the Eurostat morbidity statistics pilot for many EU countries, but Eurostat will not publish the data as comparable statistics.
- The aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. Furthermore, all EU Member States will probably conduct EHIS in the second wave, which is planned for 2014. Both initiatives will significantly improve the data availability for cancer prevalence and provide possibilities to monitor trends. In addition, several projects and networks aim to improve the quality, comparability and availability of cancer data in Europe.

## Indicator development

The consecutive EU funded EUROCHIP <sup>11</sup> projects (I-III) all had the overarching aim of fighting inequalities in the field of cancer and improving information and knowledge on the disease. The EUROCHIP I project identified ‘Cancer prevalence proportions, trends and projections’ as a high priority for which indicators are already available on their list of indicators (34). EUROCHIP-II made several suggestions for cancer indicators to be included in the ECHI shortlist, including cancer incidence, survival, prevalence and cancer treatment quality. However, cancer prevalence was not included in the ECHI shortlist (35).

The cancer prevalence is the number of persons in a defined population who have been diagnosed with cancer, and who are still alive at the end of a given year. There is no unique definition of cancer prevalence. Total (or complete) prevalence represents the number or proportion of persons in the population alive at a certain point in time who previously had a

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<sup>11</sup> [www.tumori.net/eurochip/](http://www.tumori.net/eurochip/)



diagnosis of the disease, regardless of how long ago the diagnosis was, or if the patient is still under treatment or is considered cured. Patients who are still alive five years after diagnosis are usually considered cured since the death rates of such patients are generally similar to those in the general population. However, there are some exceptions, notably breast cancer. For breast cancer, the risk of death remains higher than normal for many more years.

Prevalence can also be decomposed by disease duration (i.e. 1-, 2-, 5- and 10-year prevalence). This so called partial prevalence limits the number of patients to those diagnosed during a fixed time in the past. This is a particularly useful measure for planning and allocation of resources, because it is relevant for estimating the needs for cancer services according to specific phases of cancer care. The resource requirements for treating newly-diagnosed patients are, namely, quite different from those for supporting long-term survivors.

## **Data situation and main gaps**

Table 2 gives an overview of available data sources for cancer. Information on cancer is much more widely available than for other diseases. This reflects the long tradition, of population based cancer registries in most European countries. These cancer registries routinely collect epidemiological indicators such as incidence and prevalence (36). In some countries, cancer registries cover the entire population, while in others coverage only extends to limited geographical areas.

### **Databases**

The Eurostat morbidity statistics pilot has collected data on the prevalence of all malignant neoplasms (cancer) and 13 cancer types (including malignant neoplasm of colon, rectum and anus, malignant neoplasm of trachea, bronchus and lung, malignant neoplasm of breast and malignant neoplasm of prostate). Eurostat will not publish the morbidity pilot data because they were collected to assess the feasibility of the proposed method. Countries may decide by themselves whether they want to publish the data or not.

The European health interview survey (EHIS) has also included 12-months prevalence (self-reported) of cancer (malignant tumour, also including leukaemia and lymphoma) (20). Not all EU countries participated in the first wave of EHIS, however. The Survey of Health, Ageing and Retirement in Europe (SHARE) also contains a question on the prevalence of cancer, but it is limited to people aged 50 years and over and not all EU countries participate in SHARE (25).

IARC (International Agency of Research on Cancer, part of the World Health Organization) publishes 1-, 3- and 5- year cancer prevalence estimates for the adult population (aged 15 and over) in GLOBOCAN 2008. Prevalence is based on cases diagnosed within one, three and five years because they are likely to be of relevance to the different stages of cancer therapy, namely, initial treatment (one year), clinical follow-up (three years) and cure (five years) (37, 38). Prevalence is estimated using a function of incidence and observed survival. In some countries cancer registries only cover a limited geographical area. When the information is incomplete, IARC uses statistical and mathematical models to impute the missing values and provide estimates of cancer incidence at national level.

The WHO-HfA provides the cumulative number of cancer patients (old and new cases) for 15 countries. Data are obtained from national cancer registers whenever available or from the existing routine reporting system (39).

## Research articles and reports

The EUROPREVAL project provided data for the observed total, 2-, 5-, 10 and 15-year cancer prevalence at 31 December 1992. The project estimated cancer prevalence directly in population-based cancer registries by counting the number of cases still alive and present at a specified point in time. This approach requires registration and follow-up for vital status over many years. The project used standardised data collection and validation procedures (40, 41).

Bray et al., (2012) reports 1-, 2-3- and 4-5-year prevalence for the adult population (aged 15 years or over) by world region and predefined categories of human development. The information serves as input for GLOBOCAN 2008. They updated the cancer prevalence estimates in GLOBOCAN 2000 and 2002 to 2008.

The DYNAMO-HIA project has produced age- and gender-specific data on prevalence, as well as incidence, case fatality and mortality of lung, breast (only females), colorectal, oesophageal and oral cancer for 22 of the EU27 countries (42). They used the DISMOD model with the following input:

- age-specific cancer-site incidence rates from the Cancer Incidence in V Continents – Vol IX (43);
- age-specific cancer-site mortality rates from WHO Mortality Database.

Gatta and colleagues in the RARECARE (Surveillance of Rare Cancers in Europe) Working Group (2010) provided European estimates for the 15-year prevalence of several rare cancers. Rare cancers are cancer with an incidence of less than 6 per 100,000 per year (44).

## Current initiatives to improve the data situation

Currently register-based data collected in the Eurostat morbidity statistics pilot are not available yet. However, the final aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. Furthermore, all EU Member States will probably conduct EHIS in the second wave, which is planned for 2014. Both initiatives will significantly improve the availability of data for the prevalence of cancer and provide possibilities to monitor trends.

The European Network of Cancer Registries (ENCR <sup>12</sup>), established within the framework of the Europe Against Cancer Programme of the European Commission, has been in operation since 1990. The Network has the following objectives (see [www.enrcr.com.fr](http://www.enrcr.com.fr)):

- to improve the quality, comparability and availability of cancer incidence data;
- to create a basis for monitoring cancer incidence and mortality in the European Union;
- to provide regular information on the burden of cancer in Europe;
- to promote the use of cancer registries in cancer control, health-care planning and research.

The CaMon <sup>13</sup> project (Comprehensive Cancer Monitoring in Europe) extends the role of the ENCR beyond its broad aim of promoting cancer registration. CaMon aims to develop a cancer surveillance system for cancer occurrence and outcome (incidence, mortality,

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<sup>12</sup> [www.enrcr.com.fr/](http://www.enrcr.com.fr/)

<sup>13</sup> [www-dep.iarc.fr/hmp/camon.htm](http://www-dep.iarc.fr/hmp/camon.htm)

prevalence and survival), permitting situation analysis and monitoring of cancer burden in the Member States of the European Union and applicant states.

Another relevant network is RARECAREnet<sup>14</sup> (Information network on rare cancers). RARECARE assessed the quality and comparability of data (including prevalence) on rare cancers across European countries. Its successor RARECAREnet aims at building an information network to provide comprehensive information on rare cancers.

The EUNICE (EU Network for Indicators on Cancer) aims to establish a common cancer database, which will be used to plan programmes of cancer control in the EU (benchmarking and scenario development) and to monitor their results.

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<sup>14</sup> [www.rarecare.eu](http://www.rarecare.eu)

**Table 2: Overview of available data on the prevalence of cancer.**

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
<b>Database (see annex 4 for indicator definitions)</b>						
EHIS	European Health Interview Survey	database (data not available yet)	BE, BG, CZ, DE, EE, EL, ES, FR, CY, LV, HU, MT, AT, PL, RO, SI, SK, CH and TR conducted a first wave of EHIS between 2006 and 2010.	by sex and 8 age groups (15-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+)	first wave between 2006 and 2010. Second wave planned for 2014.	(20)
Eurostat diagnosis-specific morbidity data activities	administrative sources (clinical records, insurance data), disease registers, etc.	database (data not available yet)	16 countries carried out the pilot (CZ, CY, EE, HU, LT, LV, MT, SI, SK, AT, DE, BE, DE, FI, NL, PL and RO)	by sex and by 18 age groups (0-4, 5-9, etc., 85+)	pilot study in 2007-2009	see info on Circa <sup>15</sup>
GLOBOCAN	estimates based on incidence and survival	database	all EU, EFTA, Accession, Candidate and Potential Candidate countries (BE, BG, CZ, DK, DE, EE, IE, EL, ES, FR, IT, CY, LV, LT, LU, HU, MT, NL, AT, PL, PT, RO, SI, SK, FI, SE, UK, IS, NO, CH, ME, HR, MK, RS, TR, AL, BA)	by sex for population 15+, not by age groups	prevalence estimates pertain to the number of cancer cases diagnosed between 2004 and 2008 who were still alive at the end of 2008.	(37)
SHARE	interview	database	17 EU countries: 2004 (AT, BE, CH, DE, DK, ES, EL, FR, IT, NL and SE), 2006/7 (plus CZ and PL), 2008/9, 2010 (plus EE, HU, PT, SI, data for 2010 not released yet).	by sex, people aged 50 and over	4 waves: 2004, 2006/7, 2008/9, 2010 (data for 2010 not released yet)	(21, 25, 33)

<sup>15</sup> <http://circa.europa.eu/Public/irc/dsis/health/library?!=/methodologiessandsdatasc/diagnosis-specific&vm=detailed&sb=Title>

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
WHO-HfA	registers	database	recent (since 2005) data available for BG, CZ, DK, FI, IT, LV, LT, AT, PT, RO, SI, SK, IS, NO, HR	only by sex	data are updated annually	(39)
<b>Reports and articles</b>						
DYNAMO-HIA <sup>a</sup>	based on incidence and mortality rates from registers	project	for 22 of the EU27 countries:	age- and gender-specific data	input data: 1998-2002 for incidence and 2000-2002 for mortality	(42)
EUROPREVAL project <sup>b</sup>	registers	project	16 European countries with varying coverage: DE, DK, EE, ES, FR, IT, NL, AT, PL, SI, SK, FI, SE, UK, IS, CH	age-adjusted	1992 estimates based on cancer patients diagnosed from 1970 to 1992	(40, 41)
Bray et al., 2012 <sup>c</sup>	estimates based on incidence and survival	article	averages for Northern, Western, Southern and Central and Eastern Europe	by sex for population 15+, not by age groups	prevalence estimates pertain to the number of cancer cases diagnosed between 2004 and 2008 who were still alive at the end of 2008.	(38)

<sup>a</sup> prevalence for lung, breast (only females), colorectal, oesophageal and oral cancer

<sup>b</sup> observed total, 2-, 5-, 10 and 15-year cancer prevalence at 31/12/1992 for the following cancers: stomach, colon, rectum, lung, breast, cervix uteri, corpus uteri and prostate cancer, as well as of melanoma of skin, Hodgkin's disease, leukaemia and all malignant neoplasms combined.

<sup>c</sup> 1-, 2-3- and 4-5-year prevalence for 26 cancers + all cancers combined

## 4.4 Diabetes

Diabetes is a metabolic disorder causing chronically increased levels of glucose in the blood. It can lead to complications such as blindness, heart and blood vessel disease, stroke, kidney failure, amputations, and nerve damage. Obesity is a risk factor for diabetes and the current strong increases in obesity in Europe predict a strong increase in diabetes prevalence in Europe in the near future.

### Key messages:

- The prevalence of diabetes is an ECHI shortlist indicator.
- At present, routinely updated sources of Europe-wide data on the prevalence of diabetes are scarce. The IDF Diabetes Atlas is an important data source, but the underlying data come from a variety of sources and for several countries data are estimated because national data are not available.
- Information on diabetes prevalence is available from the first wave of EHIS and the ECHIM data collection pilot for many EU countries. Data on diabetes prevalence have also been collected in the Eurostat morbidity statistics pilot for many EU countries, but Eurostat will not publish the data as comparable statistics.
- For several European countries information on diabetes prevalence is available from epidemiological studies, but comparability is limited due to differences in study design.
- The aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. Furthermore, all EU Member States will probably conduct EHIS in the second wave, which is planned for 2014. In addition, the EHES pilot contains measurements to estimate the number of undiagnosed cases. Finally, the EUBIROD project aims to implement a sustainable European Diabetes Register. These initiatives will significantly improve the data availability for the prevalence of diabetes and provide possibilities to monitor trends.

## Indicator development

The aim of the EU funded European Diabetes Indicator Project (EUDIP 2000-2002) was the “establishment of indicators monitoring diabetes and its morbidity” on a national level. The project resulted in a set of indicators that are feasible to collect on a national basis. The availability of the data was dependent on the existing monitoring systems in the collaborating countries. Because the types of databases and data collection methods differed between countries the comparability of the national indicators was quite complicated (45). The EUDIP core indicators represent a fundamental framework for the future collection of diabetes data (46). The activities of the EUDIP project have contributed to the development of indicators in the ECHI project (3). Diabetes prevalence is included in the ECHI shortlist.

The aim of EUDIP’s successor, the EUCID project (European Core Indicators for Diabetes Mellitus) was to set up a stable organisation to collect and analyse data on health status and care delivery for diabetes mellitus in the EU countries and the future Member States. This in order to promote the planning for a good diabetes health status assessment and healthcare organisation in the different countries.

The project's objectives were:

- to show the feasibility of the data collection;
- to create a stable platform for the data collection;
- to create a reporting platform for the indicators.

## **Data situation and main gaps**

Table 3 gives an overview of available data sources for diabetes. It shows that there are many different sources of information on the prevalence of diabetes, but routinely updated sources of Europe-wide data on the prevalence of diabetes are scarce. The different data sources may provide very different figures on diabetes prevalence and therefore a good comparable analysis of diabetes data at the EU level is rather difficult (46).

### **Databases**

Data on 12-months prevalence (self-reported) of diabetes are available from EHIS and national HIS data as, for instance, collected within the ECHIM data collection pilot (15, 16). Not all EU countries have participated in the first wave of EHIS. It is expected that all EU Member States will conduct EHIS in the second wave, which is planned for 2014.

Self-reported data will only provide a rough and incomplete estimate of the prevalence of diabetes. Therefore, the Joint Action for ECHIM has also collected register-based data on the prevalence of diabetes. Together both sources give a more complete picture. However, the attempt to collect administrative/register-based data was less successful than the collection of national HIS-based data. Only a limited number of EU countries were able to deliver register-based data according to the breakdowns requested by ECHIM (16).

The Eurostat morbidity statistics pilot, has also collected data on the prevalence of diabetes. Eurostat will not publish the morbidity pilot data because they were collected to assess the feasibility of the proposed method. Countries may decide by themselves whether they want to publish the data or not.

The International Diabetes Federation (IDF) Diabetes Atlas provides 'best estimates' for all European countries (47). The underlying data come from a variety of sources, including peer-reviewed literature, national and regional health surveys, personal communications provided by investigators in the IDF network and official reports by multinational organisations (48). For countries that do not have information on diabetes, data are estimated based on information from other countries that are matched on ethnicity, income level, and geography. IDF published its estimates also in the report 'Diabetes - The Policy Puzzle: Is Europe Making Progress?'. In this report, the estimates from the Diabetes Atlas are accompanied with prevalence figures from a variety of national sources. Similarly, data in the WHO-HfA database come from a large variety of sources (national diabetes register, routine reporting system, hospital discharges, surveys) and are considered not very well comparable (39).

### **Reports and articles**

The EUCID project has concluded that data on diabetes prevalence were available for almost all countries. However, data could not be age-standardised for Spain, Romania, Ireland, Portugal because no age-band data were available. Furthermore, the sources for the data were still different, so that the comparability of the indicators is not optimal (45).

The DYNAMO-HIA project has gathered age- and gender-specific data on prevalence and/or incidence and mortality of diabetes from as many of the EU27 countries as possible, using

existing data sources, with the aim to create an EU-wide dataset. The project concluded that the UK GP research database <sup>16</sup> and the Netherlands GP registry data were the most complete and reliable source of data for diabetes. Fleming et al. (2008) also demonstrated the capacity of GP networks to deliver data on the prevalence of known diabetes (49). A disadvantage of registers is that they do not provide information on undiagnosed patients and the general population.

For countries for which prevalence data were missing, the DYNAMO-HIA project used DISMOD II software to estimate diabetes prevalence. These estimates were based on country-specific mortality data and relative risks from the UK GP research database (26, 28). Details of the sources of data obtained for each country are described in the annex of the DYNAMO-HIA report (26).

More recently, Kanavos and colleagues (2012) gathered prevalence estimates for 5 EU countries using a survey, developed to collect country-level data via interviews with key diabetes stakeholders. They also used national or regional data from a variety of sources, such as diabetes databases and the peer reviewed literature (50).

The main advantage of surveys using health examination, such as in the DECODE study, is that they provide information on both undiagnosed and diagnosed diabetes. The data in the DECODE study are somewhat outdated. Furthermore, there were differences in study design, participation rate, and classification of known diabetes because the individual surveys have been carried out independently (51).

## **Current initiatives to improve the data situation**

Currently register-based data collected in the Eurostat morbidity statistics pilot are not available yet. However, the final aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. Furthermore, all EU Member States will probably conduct EHIS in the second wave, which is planned for 2014. In addition, the EHES pilot includes measurement of fasting glucose or HbA1c. These measurements will provide information on the number of undiagnosed cases. The three initiatives will significantly improve the data availability for the prevalence of diabetes and provide possibilities to monitor trends.

The EU-co-funded project EUBIROD (EUropean Best Information through Regional Outcomes in Diabetes) aims to implement a sustainable European Diabetes Register through the coordination of existing national and/or regional frameworks and the systematic use of the technology developed by its predecessor BIRO ([www.eubirod.eu](http://www.eubirod.eu)) (52). Since 2008, a total of 26 partners from 21 countries joined the Consortium. Finally, a pilot European Diabetes Report will be automatically produced using the BIRO technology to collect/analyse data for 2010. These data are based on clinical records collected across nineteen European countries, using the same European standardised data definitions, statistical routines and transmission formats.

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<sup>16</sup> [www.gprd.com](http://www.gprd.com)



**Table 3: Overview of available data on the prevalence of diabetes.**

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
<b>Database (see annex 4 for indicator definitions)</b>						
Eurostat	European Health Interview Survey	database	17 EU countries: BE, BG, CZ, DE, EE, EL, ES, FR, CY, LV, HU, MT, AT, PL, RO, SI, SK + CH and TR. For CH data are not computed.	by sex and 8 age groups (15-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+)	first wave between 2006 and 2010. Second wave planned for 2014.	(15)
Eurostat diagnosis-specific morbidity data activities	administrative sources (clinical records, insurance data), disease registers, etc.	database (data not available yet)	16 countries carried out the pilot (CZ, CY, EE, HU, LT, LV, MT, SI, SK, AT, DE, BE, DE, FI, NL, PL and RO)	by sex and by 18 age groups (0-4, 5-9, etc., 85+)	pilot study in 2007-2009	see info on Circa <sup>17</sup>
IDF Diabetes Atlas	variety of sources, including peer-reviewed literature, national and regional health surveys, personal communication and official reports by multinational organisations	database	data available from AT, BE, BG, FI, DK, DE, EL, ES, FR, IT, LU, NL PL, PT, SI, SK, HU, SE, UK, HR, IS, NO, CH, AL, TR. Estimates available for the other EU and Candidate countries.	age-standardised data for population aged 20-79 years	data for 2011 and projections for 2030 based on studies from different years since 1995 (except Sweden), depending on country. Previous editions published in 2000, 2003, 2006 and 2009.	(47, 48, 53)
JA for ECHIM data collection pilot	national health interview surveys	database	BE, DK, DE, EE, IE, FR, IT, NL, AT, CH	by sex and for age groups 15+, 15-64 and 65+	between 2005 and 2008 depending on country	(16)

<sup>17</sup> <http://circa.europa.eu/Public/irc/dsis/health/library?!=/methodologiessandsdatasc/diagnosis-specific&vm=detailed&sb=Title>

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
JA for ECHIM data collection pilot	administratively deduced and register-based data	database	CZ, FI, HU, LV, LT, NL and UK (the latter providing totals only).	by sex and for age groups 15-64 and 65+	pilot collection in 2010-2011	(16)
SHARE	interview	database	17 EU countries: 2004 (AT, BE, CH, DE, DK, ES, EL, FR, IT, NL and SE), 2006/7 (plus CZ and PL), 2008/9, 2010 (plus EE, HU, PT, SI, data for 2010 not released yet).	by sex, people aged 50 and over	4 waves: 2004, 2006/7, 2008/9, 2010 (data for 2010 not released yet)	(21, 25, 33)
WHO-HfA	variety of sources (National diabetes register, Routine reporting system, Hospital discharges, Surveys)	database	recent (since 2005) data available for AT, BE, CZ, DK, EE, EL, ES, FI, IT, LV, LT, MT, PT, RO, SK, UK, AL, BA and MK	only overall prevalence	data are updated annually but not all countries provide annual data.	(39)
<b>Reports and articles</b>						
Danaei et al., 2011	health examination surveys, epidemiological studies, multicentre studies	review article	regional estimates for West, Central and Eastern Europe	data are sex-specific and age-standardised	trend between 1980 and 2008, based on different studies	(54)
DECODE study group, 2003	population-based studies including physical exams	research article	13 studies from nine European countries (ES, FI, IT, MT, NL, PL, SE and UK)	by sex and by age groups (30–39, 40–49, 50–59, 60–69, 70–79, 80–89) depending on study	studies performed between 1981 and 1997	(51)

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
DYNAMO-HIA	variety of sources (surveys, registries)	project report	data available for few EU27 countries, therefore prevalence is estimated with DISMOD	age- and sex-specific data	preferably data collected since 2000	(26)
EUCID	interview survey, registry, administrative sources	project report	AT, BE, CY, DK, ES, FI, FR, IE, LU, NL, PT, RO, SE, England and Scotland	by age groups (0-14, 15-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+)	2004, 2005 or 2006.	(45)
Fleming et al., 2004	the Sentinel Practice Surveillance Network (SPSN).	research article	BE, ES, FR, HR, NL, PT, SI and England	by sex and by age groups (0-24, 25-44, 45-64, 65-74, ≥75)	1999/2000	(49)
Kanavos et al., 2012	variety of sources (surveys, registries)	report	data for DE, ES, FR, IT, UK	preferably population 18+. Not by sex	different years depending on country	(50)

## **4.5 Respiratory diseases and allergies**

Respiratory diseases and allergies include COPD (chronic obstructive pulmonary disease) asthma, and allergic rhinitis. COPD is characterised by chronic airway obstruction resulting in airflow limitation that is not fully reversible. COPD is accompanied by coughing, sputum production and/or difficulty breathing. Asthma is a chronic inflammation of the airways often caused by allergens and leading to coughing, wheezing, and difficulty breathing. Allergic rhinitis is a collection of symptoms, mostly in the nose and eyes, which occur after breathing allergic substances such as dust or pollen. The occurrence of COPD is strongly influenced by smoking history. Because of the dynamics of the smoking epidemic in Europe the occurrence of COPD may fluctuate strongly over time and by age and sex.

### **Key messages:**

- The prevalence of asthma and COPD are ECHI shortlist indicators.
- At present, routinely updated sources of Europe-wide data on the prevalence of asthma and COPD are very scarce.
- Information on the prevalence of asthma and COPD is available from the first wave of EHIS and the ECHIM data collection pilot for many EU countries. Data on asthma and COPD prevalence have also been collected in the Eurostat morbidity statistics pilot for many EU countries, but Eurostat will not publish the data as comparable statistics.
- For several European countries information on COPD prevalence is available from epidemiological studies, but comparability is limited due to differences in study design. For asthma information on prevalence is available from two large international epidemiological studies (ECRHS and ISAAC).
- The aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. Furthermore, all EU Member States will probably conduct EHIS in the second wave, which is planned for 2014. Both initiatives will significantly improve the data availability for the prevalence of diabetes and provide possibilities to monitor trends. Repetition of ECRHS and ISAAC also provides information on trends.

### **Indicator development**

The overall aim of the EU funded IMCA project (Indicators for monitoring COPD and asthma in the EU) was to get a consensus on a proposal for a set of indicators to monitor COPD and asthma in all EU Member States. The project has defined a large number of indicators useful to monitor COPD and asthma, but only a small proportion of them are routinely available. A very large number of indicators are not available from routine health examination surveys but they could be obtained from large international epidemiological studies using standardised methods such as the European Community Respiratory Health Survey (ECRHS) and the International Study of Asthma and Allergies in Childhood (ISAAC) (55).

The first aim of the successor of the earlier mentioned IMCA project, IMCA II, has been to extend the work on indicators already carried out by the IMCA I project. It intends to do this by collecting or using already available data from completed European-wide research projects (ECRHS, ISAAC and Asthma Insights & Reality in Europe (AIRE)) and producing reports/papers on all groups of indicators recommended (mortality, prevalence, risk factors, clinical management/health services and outcomes) (56). The second aim was to develop a module of COPD and asthma to be incorporated into health examination surveys and testing its feasibility and pilot performance in five selected small geographical areas of Spain, Italy (two areas), Sweden and Germany (56). Currently a lung function test is an optional measurement in the EHES pilot.

The activities of the IMCA project have contributed to the development of indicators in the ECHI project (3). Both COPD prevalence as well as asthma prevalence is included in the ECHI shortlist.

## **Data situation and main gaps**

Table 4 and 5 give an overview of available data sources on COPD, asthma and allergic rhinitis. It shows that routinely updated sources of Europe-wide data on the prevalence of asthma and COPD are very scarce. Information is available from epidemiological studies, but they are difficult to compare due to a lack of consensus on the methods and definitions. This is especially the case for COPD. For asthma prevalence, information is available from large multicenter epidemiological studies using standardised methodology.

### **Databases**

Data on 12-months prevalence (self-reported) of asthma and COPD are available from EHIS and national HIS data that have been collected within the ECHIM data collection pilot (15, 16). Not all countries participated in the first wave of EHIS. Self-reported COPD and asthma prevalence is also available from the SHARE survey. Self-reported data will only provide an estimate of prevalence of asthma and COPD prevalence.

The Eurostat morbidity statistics pilot also collected data on the prevalence of asthma and COPD. Eurostat will not publish the Eurostat morbidity pilot data because they were collected to assess the feasibility of the proposed method. Countries may decide themselves whether they want to publish the data.

ECHIM has also collected register-based data on the prevalence of COPD and asthma. However, this attempt to collect administrative/register-based data was less successful than the collection of national HIS based data. Only few countries were able to deliver register-based data according to the breakdowns requested by ECHIM (16). The WHO-HfA database also provides register-based data on COPD prevalence, but the data come from a great variety of sources and therefore their comparability is limited (39).

### **Reports and articles**

According to the IMCA project the information provided by epidemiological studies is often difficult to compare due to a lack of consensus on the methods and definitions, especially with regard to COPD (55). However, several recent international guidelines or research initiatives, such as the Burden of Obstructive Lung Disease study (BOLD), have boosted a substantial standardisation of methodology in data collection and have resulted in the availability of more comparable epidemiological estimates across countries (57).

In a review, Atsou et al. (2011) identified 32 studies on COPD prevalence from 13 European countries and the cross-national ECRHS. In the majority of studies COPD was assessed with spirometry (20 studies) (57). In 3 studies COPD was assessed on the basis of symptoms, in 6 on physician reports and in 3 on models. Earlier, Halbert et al. (2003) also identified 32 sources of COPD prevalence rates, representing 17 countries and also including the ECRHS. Prevalence estimates were based on spirometry (11 studies), respiratory symptoms (14 studies), patient-reported disease (10 studies), or expert opinion (58). In 2006, Halbert et al. also performed a meta-analysis. A total of 62 studies reported 101 overall prevalence estimates from 28 different countries, 17 of which were European (59).

The DYNAMO-HIA project gathered age- and gender-specific data on prevalence and/or incidence and mortality of COPD in as many of the EU27 countries as possible, using existing data sources. Different institutions and projects make use of slightly differing definitions and these different definitions can lead to different estimates of the occurrence of COPD within a population. In the DYNAMO-HIA project it was pragmatically decided to include COPD defined according to all different criteria. Nevertheless, the search showed that COPD data is scarce (60). The UK GP research database<sup>18</sup> and the Netherlands GP registry data were the most complete and reliable source of data for COPD. COPD prevalence data were available for few countries. For the other EU countries (except Austria, Bulgaria, Cyprus, Luxembourg, Malta, Romania and Slovenia) prevalence was estimated with DISMOD II software based on relative risks from the UK GP research database and 'proxy-incidence' based on smoking (28, 60). A detailed overview of COPD data availability and quality in the 27 EU countries is given in the annex of the DYNAMO-HIA report (60).

In the DYNAMO-HIA project the reliability of the SHARE data (and other self-reported surveys) was questioned a-priori as it is based on self-report and in different countries there might be differing diagnostic approaches and ways to communicate COPD. According to the DYNAMO-HIA project COPD prevalence patterns in the second wave of the SHARE study (collected 2006/07) are not plausible because e.g. in contrast with existing evidence, COPD prevalence from SHARE for several countries is similar for both sexes, or even higher for women in some countries (60). The BOLD study, based on questionnaires and spirometry, also gave unexpectedly high prevalence figures for three EU countries included in DYNAMO-HIA (61, 62). The 'Confronting COPD International Survey' collects self-reported data as well. It focuses on costs, symptoms and hospitalisations and therefore, it does not provide detailed data on incidence and prevalence (60, 63-67). Because COPD is a chronic disease with sometimes few symptoms, self-reporting data can be of lesser quality than for more 'permanent' chronic diseases (60).

According to a review by Ozdoganoglu and Songu (2012) there are insufficient epidemiologic data on asthma and allergic rhinitis. They also conclude that differences in study selection criteria, survey methods and diagnostic criteria contribute to the wide range of reported prevalence rates of allergic rhinitis in Europe (68). However, in the early 1990s, two large studies were set up which have standardised methods for data collection on asthma and allergies. The first one was ISAAC focusing on children (69). The study was repeated in ISAAC phase III to provide information on trends (70). The second was the ECRHS focusing on young to middle aged adults (71). The AIRE study has used telephone interviews for data collection and included patients from all age groups with current asthma (72).

From the year 2000 onwards few data on asthma have been published. A review by von Hertzen and Haahtela (2005) and another one by Anandan et al. (2010) have analysed the most recent literature on time trends in asthma prevalence among children and adults (73, 74).

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<sup>18</sup> [www.gprd.com](http://www.gprd.com)

## **Current initiatives to improve the data situation**

Currently register-based data collected in the Eurostat morbidity statistics pilot are not available yet. However, the final aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. Furthermore, all EU Member States will probably conduct EHIS in the second wave, which is planned for 2014. Both initiatives will significantly improve the data availability for the prevalence of COPD and asthma and provide possibilities to monitor trends.

In phase III of the ECRHS participants are currently followed up for a second time. One of the aims of the ECRHS III is to describe changes in the prevalence of respiratory symptom in adults as they age (75). Furthermore, the members of the Global Allergy and Asthma European Network (GA<sup>2</sup>LEN) carry out the GA<sup>2</sup>LEN epidemiological survey. This is a new study to assess the prevalence and trends in prevalence of allergic and airway diseases, such as asthma. The study is extending the method of the ECRHS to study a wider age range and to include other conditions such as chronic rhino-sinusitis (76).

**Table 4: Overview of available data on the prevalence of COPD.**

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
<b>Database (see annex 4 for indicator definitions)</b>						
Eurostat	European Health Interview Survey	database	17 EU countries: BE, BG, CZ, DE, EE, EL, ES, FR, CY, LV, HU, MT, AT, PL, RO, SI, SK + CH and TR. For DE and CH data are not computed.	by sex and 8 age groups (15-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+)	first wave between 2006 and 2010. Second wave planned for 2014.	(15)
Eurostat diagnosis-specific morbidity data activities	administrative sources (clinical records, insurance data), disease registers, etc.	database (data not available yet)	16 countries carried out the pilot (CZ, CY, EE, HU, LT, LV, MT, SI, SK, AT, DE, BE, DE, FI, NL, PL and RO)	by sex and by 18 age groups (0-4, 5-9, etc., 85+)	pilot study in 2007-2009	see info on Circa <sup>19</sup>
JA for ECHIM data collection pilot	national health interview surveys	database	BE, DK, DE, EE, FR, IT, AT, FI	by sex and for age groups 15+, 15-64 and 65+	between 2005 and 2008 depending on country	(16)
JA for ECHIM data collection pilot	administratively deduced and/or register-based data	database	CZ, HU, LT, NL, FI, and UK, whereas the latter delivered only data on totals	by sex and for age groups 15-64 and 65+	pilot collection in 2010-2011	(16)
SHARE	interview	database	17 EU countries: 2004 (AT, BE, CH, DE, DK, ES, EL, FR, IT, NL and SE), 2006/7 (plus CZ and PL), 2008/9, 2010 (plus EE, HU, PT, SI, data for 2010 not released yet).	by sex, people aged 50 and over	4 waves: 2004, 2006/7, 2008/9, 2010 (data for 2010 not released yet)	(21, 25, 33)

<sup>19</sup> <http://circa.europa.eu/Public/irc/dsis/health/library?l=/methodologiessandsdatasc/diagnosis-specific&vm=detailed&sb=Title>



Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
WHO-HfA	register	database	recent (since 2005) data available for AL, BA, BE, CZ, CH, DE, EL, FI, HR, HU, IE, LT, MK, MT, NL, NO, RO, SK, UK	only overall prevalence	data are updated annually but not all countries provide annual data.	(39)
<b>Reports and articles</b>						
Atsou et al., 2011	studies using different criteria to identify COPD based on symptoms, physician reports, spirometry and models.	review article	AT, DE, DK, EL, ES, FI, FR, IT, NL, NO, PL, SE, UK + ECRHS countries	different age groups depending on study	studies published between 1991 and 2009	Atsou et al., 2011
BOLD study	spirometry testing plus questionnaires about respiratory symptoms	research article	AT, DE, IS, PL, NO, TR	by sex and age groups (40–49, 50–59, 60–69, 70+)	2006	(61, 62)
DYNAMO-HIA	variety of sources (surveys, registries)	project report	data available for few EU27 countries, therefore prevalence is estimated with DISMOD	sex- and age-specific data for age > 40 years	not specified	(60)
ECRHS	questionnaire	research article	10 EU countries (BE, DE, DK, ES, IE, FR, IT, NL, SE, UK) + IS, NO, CH	by sex, adults aged 20 to 44 years	phase 1: beginning of the 1990s. phase 2: 1998-2002, phase 3: currently	(77)

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
Halbert et al., 2003	estimates were based on spirometry (11 studies), respiratory symptoms (14 studies), patient-reported disease (10 studies), or expert opinion	review article	DK, EE, ES, FI, IS, IT, NO, SE, England + ECRHS countries	by sex and different age groups depending on study	studies published between 1962 - 2001	(58)
Halbert et al., 2006	different diagnostic criteria (chronic productive cough, spirometry, patient-reported diagnosis, physician diagnosis or physical/radiographic findings)	review article	CZ, DK, EE, ES, FI, FR, IT, LT, NO, PL, RO, SE, CH, TR, UK and Scotland	pooled estimates by sex and for age groups <40 yrs, ≥40 yrs, 40–64 yrs and ≥65 yrs	studies published between 1990–2004	(59)

**Table 5: Overview of available data on the prevalence of asthma and allergic rhinitis.**

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
<b>Database (see annex 4 for indicator definitions)</b>						
Eurostat	European Health Interview Survey <sup>a</sup>	database	17 EU countries: BE, BG, CZ, DE, EE, EL, ES, FR, CY, LV, HU, MT, AT, PL, RO, SI, SK + CH and TR. For CH data are not computed.	by sex and 8 age groups (15-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+)	first wave between 2006 and 2010. Second wave planned for 2014.	(15)
Eurostat diagnosis-specific morbidity data activities	administrative sources (clinical records, insurance data), disease registers, etc.	database (data not available yet)	16 countries carried out the pilot (CZ, CY, EE, HU, LT, LV, MT, SI, SK, AT, DE, BE, DE, FI, NL, PL and RO)	by sex and by 18 age groups (0-4, 5-9, etc., 85+)	pilot study in 2007-2009	see info on Circa <sup>20</sup>
JA for ECHIM data collection pilot	national health interview surveys	database	BE, DK, DE, EE, FR, IT, AT, FI (for the latter reported, not diagnosed)	by sex and for age groups 15+	between 2005 and 2008 depending on country	(16)
JA for ECHIM data collection pilot	administratively deduced and/or register-based data	database	CZ, HU, LT, NL, FI, and UK, although the latter delivered estimates on totals	by sex and for age groups 0-14 and 15+	pilot collection in 2010-2011	(16)
SHARE	interview	database	17 EU countries: 2004 (AT, BE, CH, DE, DK, ES, EL, FR, IT, NL and SE), 2006/7 (plus CZ and PL), 2008/9, 2010 (plus EE, HU, PT, SI, data for 2010 not released yet).	by sex, people aged 50 and over	4 waves: 2004, 2006/7, 2008/9, 2010 (data for 2010 not released yet)	(21, 25, 33)

<sup>20</sup> <http://circa.europa.eu/Public/irc/dsis/health/library?l=/methodologiessandsdatasc/diagnosis-specific&vm=detailed&sb=Title>

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
<b>Reports and articles</b>						
AIRE	telephone interviews	research article	ES, UK, FR, DE, NL, SE and IT	children with asthma (age < 16 years)		(72)
ECRHS	questionnaire for asthma, skin prick tests for allergic rhinitis	research articles	15 EU countries (AT, BE, DE, DK, EE, EL, ES, FR, IE, IT, NL, PL, PT, SE, UK) plus CH, IS and NO	age- and sex-standardised for adults aged 20 to 44 years	phase 1: beginning of the 1990s. phase 2: 1998-2002, phase 3: currently	(78-80)
ISAAC	questionnaire	research articles	phase 3: 19 EU countries (AT, BE, BG, DE, EE, EL, ES, IE, FI, HU, IT, LV, LT, NL, PL, PT, RO, SE UK) plus HR, AL, RS and ME	children aged 13–14 and 6–7 years	phase 1: 1993-1995; phase 2: 1998; phase 3: 2001-2003	(69, 70, 81)

<sup>a</sup> a question on 12-months prevalence of allergy, such as rhinitis, eye inflammation, dermatitis, food allergy or other (allergic asthma excluded) is also included in EHIS, but data are not available on the Eurostat website yet.

## **4.6 Mental disorders (depression)**

Mental disorders include affective mood disorders (such as depression), anxiety disorders, schizophrenia and, for instance, eating disorders. In this paragraph the overview of available data will be mainly limited to depression because of all mental disorders, depression is responsible for the highest disease burden in DALYs in the WHO European region (22). Early detection and treatment are important to lessen this disease burden and opportunities for prevention have not been fully implemented yet.

### **Key messages:**

- The prevalence of depression is an ECHI shortlist indicator.
- At present, routinely updated sources of Europe-wide data on the prevalence of depression are scarce.
- Information on depression prevalence is available from the first wave of EHIS and the ECHIM data collection pilot for many EU countries. Data on depression prevalence have also been collected in the Eurostat morbidity statistics pilot for many EU countries, but Eurostat will not publish the data as comparable statistics.
- For several European countries information on depression prevalence is available from epidemiological studies, but comparability is limited due to differences in study design. An exception is ESEMeD. ESEMeD is a multi site survey that uses standardised mental health instruments.
- The aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. Furthermore, all EU Member States will probably conduct EHIS in the second wave, which is planned for 2014. Both initiatives will significantly improve the data availability for depression prevalence and provide possibilities to monitor trends.

## **Indicator development**

The overall aim of the MINDFUL project was to improve the status of mental health information within the European Union. It built upon previous work to establish indicators for mental health monitoring in Europe (82). The MINDFUL project recommended a final set of 35 mental health indicators, including the prevalence of major depression assessed by a health interview (CIDI-SF) (83). The activities of the MINDFUL project have contributed to the development of indicators in the ECHI project (3). Depression prevalence is included in the ECHI indicator shortlist.

## **Data situation and main gaps**

Table 6 gives an overview of available data sources for depression. It shows that at present, routinely updated source of Europe-wide data on the prevalence of depression are scarce. However, for several European countries information on depression prevalence is available from epidemiological studies.

## **Databases**

Data on 12-months prevalence (self-reported) of depression is available from EHIS and national HIS data collected within the ECHIM data collection pilot (15, 16). In answering the EHIS question respondents have to indicate whether they were diagnosed by a doctor. EHIS also includes anxiety and other mental health problems. Not all countries participated in the first wave of EHIS.

The SHARE study has also attempted to take into account mental health by including questions on psychological symptoms. Although SHARE is a multi-centre study using a common harmonised methodology, SHARE does not provide morbidity data derived from validated mental health scales. Interpretation of the data in terms of psychiatric diagnoses is therefore difficult (46). The SHARE schedules include the EURO-D scale which has been validated in an earlier cross-European study of depression prevalence, EURODEP (84, 85).

The Eurostat morbidity statistics pilot has collected registry-based data on the prevalence of depression as well as data on schizophrenia, anxiety, eating disorders and mental and behavioural disorders due to use of psychoactive substances. Eurostat will not publish the morbidity pilot data because they were collected to assess the feasibility of the proposed method. Countries can decide themselves whether they want to publish the data.

The Joint Action for ECHIM has also collected register-based data on the prevalence of depression. However, this attempt to collect administrative/register-based data was less successful than the collection of national HIS based data. Only few countries were able to deliver register-based data according to the breakdowns requested by ECHIM (16).

The MINDFUL project has resulted in an online MINDFUL database with metadata and numerical data on mental health indicators. This database contains morbidity data for any anxiety disorder, major depression, hazardous and harmful drinking and suicide attempts for all 27 EU Member States (except Romania and Bulgaria) (86). The data availability varies significantly, however, between indicators and countries. Data on depression prevalence are available for five countries only (83). The WHO-HfA database also contains some data on the prevalence of mental disorders, but not on the prevalence of depression alone. Furthermore, the data come from a great variety of sources and therefore comparability is limited (39).

Both EHIS and registry-based data might result in underestimation of depression prevalence, because many people with depressive symptoms do not seek professional help and therefore they will not be diagnosed with depression. Moreover, physicians who are not specialised in mental disorders (e.g. GPs) will not always fully recognise depressive symptoms. Therefore, epidemiological surveys using more comprehensive measurement instruments tend to find higher prevalence estimates than estimates based on registered and diagnosed cases (18).

## **Reports and articles**

The World Mental Health surveys are a series of community-based studies using comprehensive measurement instruments, namely the CIDI (87, 88). This initiative is promoted by WHO. The objective of the EU funded project European Contribution to the WMH Surveys Initiative (EU-WMH) in 2009-2011 has been to produce and disseminate new and valid information on the mental health situation in Europe in a way that is useful for monitoring health policy reforms in Europe. The project has included the 6 countries participating in the European Study of Epidemiology on Mental Disorders (ESEMED) (Belgium, France, Germany, Italy, the Netherlands and Spain) plus Bulgaria, Northern Ireland, Portugal and Romania (89).

Because most surveys are not designed as replications with standardised methods, differences in study design might influence comparability between the studies included in the WMH Survey Initiative. Furthermore, cultural differences in the acceptance and meaning of question items might influence comparability and therefore translation protocols are important. The ESEMeD study, however, is one of the few multi site surveys using standardised mental health instruments that are currently available. The data for the European countries included in the WMH survey comes from ESEMeD (87, 90). The PREDICT study among general practice attendees is another multi site study using standardised instruments (91).

Data from ESEMeD are also included in a systematic review of Wittchen and Jacobi (92). This review included data from national surveys as well as data from cross-national comparisons (ESEMeD, DEPRES and ODIN). The review was a result of a Task Force commissioned by the European College of Neuropsychopharmacology (ECNP) and the European Brain Council (EBC). The ECNP and EBC represent professional and health care institutions for mental and neurological disorders. The aim of this Task Force was to conduct a systematic analysis of all available epidemiological studies in the EU. This was prompted by the lack of EU-specific, comprehensive data on the size, burden and cost of mental and neurological disorders.

Wittchen and Jacobi published an update of their 2005 review in 2011 (92, 93). The authors mentioned several limitations of the studies they have identified. It was, for instance, not always possible to account for the different methodologies used in the different studies. Therefore, total European prevalence estimates should be regarded with some caution. For many countries no epidemiological data were available on the majority of diagnoses. For calculating total European prevalence estimates, it has been assumed that the prevalence estimates from some EU countries can be generalised to other EU countries, but this assumption needs future investigation. Studies typically cover only one diagnosis, or a restricted set of diagnoses. The authors concluded that there is a strong need for greater coordination and even standardisation of methods to improve the quality and comparability of epidemiological data in the EU (92, 93). In addition, Paykel et al., (2005) concluded that there is a gap in information for countries in central and Eastern Europe (94).

Several Eurobarometers also contain questions on mental health (psychological distress and negative feelings, but not depression). The Eurobarometers use validated instruments used in the same way in all countries. However, comparability might be hampered by difficulties in the translation of terms relating to psychological symptoms and the relatively low sample sizes. Furthermore, the acceptance of mental health problems and self-reporting them varies between countries and this may influence the frequency of positive answers (46, 95, 96)

Recently, a multi-country study based on the European Social Survey has been published. In this study the eight-item version of the Center for Epidemiological Studies Depression Scale (CES-D) was used. However, the CES-D was constructed to identify populations at risk for developing depressive disorders. It should not be used as a clinical diagnostic tool by itself (97).

## **Current initiatives to improve the data situation**

Currently register-based data collected in the Eurostat morbidity statistics pilot are not available yet. However, the final aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. Furthermore, all EU Member States will probably conduct EHIS in the second wave, which is planned for 2014. Both initiatives will significantly improve the data availability for depression prevalence and provide possibilities to monitor trends.

**Table 6: Overview of available data on the prevalence of depression.**

Source			Availability			References
name	type of data collection (interview <sup>a</sup> , examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
<b>Database (see annex 4 for indicator definitions)</b>						
Eurostat	European Health Interview Survey	database	17 EU countries: BE, BG, CZ, DE, EE, EL, ES, FR, CY, LV, HU, MT, AT, PL, RO, SI, SK + CH and TR. For AT, EE, DE and CH data are not computed.	by sex and 8 age groups (15-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+)	first wave between 2006 and 2010. Second wave planned for 2014.	(15)
Eurostat diagnosis-specific morbidity data activities	administrative sources (clinical records, insurance data), disease registers, etc.	database (data not available yet)	16 countries carried out the pilot (CZ, CY, EE, HU, LT, LV, MT, SI, SK, AT, DE, BE, DE, FI, NL, PL and RO)	by sex and by 18 age groups (0-4, 5-9, etc., 85+)	pilot study in 2007-2009	see info on Circa <sup>21</sup>
JA for ECHIM data collection pilot	national health interview surveys	database	BE, DK, DE, EE, IE, FR, IT, NL, AT, CH	by sex and age groups 15+, 15-64 and 65+	between 2005 and 2008 depending on country	(16)
JA for ECHIM data collection pilot	administratively deduced and/or register-based data	database	CZ, EE, FI, HU, LV, LT, NL and UK (the latter providing totals only).	by sex and for age groups 15-64 and 65+	pilot collection in 2010-2011	(16)
MINDFUL	interview (CIDI-SF)	project database	DE, EL, FI, FR, NL	age- and sex-adjusted, age groups depending on national surveys	DE, FR, EL 2001; NL 1996, FI 1996, 2001	(83)

<sup>21</sup> <http://circa.europa.eu/Public/irc/dsis/health/library?!=/methodologiessandsdatasc/diagnosis-specific&vm=detailed&sb=Title>



Source			Availability			References
name	type of data collection (interview <sup>a</sup> , examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
SHARE	interview (EURO-D scale)	database	17 EU countries: 2004 (AT, BE, CH, DE, DK, ES, EL, FR, IT, NL and SE), 2006/7 (plus CZ and PL), 2008/9, 2010 (plus EE, HU, PT, SI, data for 2010 not released yet).	by sex, people aged 50 and over	4 waves: 2004, 2006/7, 2008/9, 2010 (data for 2010 not released yet)	(21, 25, 33, 98)
WHO-HfA <sup>b</sup>	registers	database	recent (since 2005) data available for BA, BG, CZ, DK, EE, FI, HU, LV, LT, PL, RO, SK	only overall prevalence	data are updated annually	(39)
<b>Reports and articles</b>						
DEPRES	interview (MINI)	research article	BE, DE, ES, FR, NL, and UK	by sex and age groups (<34, 35-44, 45,54, 55-64, 65>)	data collected in 1994 and 1995	(99)
ESEMeD	diagnostic interview (CIDI)	research article	BE, DE, ES, FR, IT, NL	by sex and age groups (18-24, 25-34, 35-49, 50-64, 65+)	data collected between 2001-3	(90, 100)
EURODEP	interview (EURO-D scale)	research article	AL, BE, DE, ES, IE, IT, IS, FI, FR, NL, PT, SE, UK	by sex and 5 years age groups for population aged 65+	studies performed between 1983-1996	(84, 85, 101)
PREDICT study	CIDI (among general practice attendees)	research article	EE, ES, NL, PT, SI, UK	by sex and age (people aged 18-76)	study conducted between 2003-2004	(91)
Paykel et al., 2005	diagnostic interview (CIDI, CIS-R/SCAN)	literature review	DE, FI, FR, IT, NL, UK + ESEMeD	by sex and different age groups depending on study	studies performed between 1993-2002	(94)

Source			Availability			References
name	type of data collection (interview <sup>a</sup> , examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
WHO WMH Survey Initiative	diagnostic interview (CIDI)	research article	BE, DE, ES, FR, IT, NL (data from ESEMeD)	by sex and age groups (18-34, 35-49, 50-64, 65+)	studies performed between 2001-2007	(87, 88, 102)
Wittchen and Jacobi, 2011	studies using established diagnostic instruments, reanalyses of existing data sets, national surveys and expert consultations	literature review	BE, CH, CZ, DE, DK, FI, FR, HU, IS, IT, NL, NO, SE, UK	age- and sex-specific average EU estimates	studies published between 1990-2010	(92, 93)

<sup>a</sup> CIS-R = clinical interview schedule-revised, SCAN = Schedules for Clinical Assessment in Neuropsychiatry, CIDI = Composite International Diagnostic Interview

<sup>b</sup> Mental disorders prevalence

## **4.7 Neurodegenerative disorders**

Neurodegenerative diseases are characterised by progressive nervous system dysfunction. These disorders are often associated with atrophy of the affected central or peripheral structures of the nervous system. They include many different disorders. This paragraph, however, is limited to dementia (Alzheimer's Disease), Parkinson's disease and multiple sclerosis, because these are the neurodegenerative disorders which are responsible for the highest disease burden in DALYs in the WHO European region (22).

### **4.7.1 Dementia**

#### **Key messages:**

- The prevalence of dementia is an ECHI shortlist indicator.
- At present, there is no routinely updated source of Europe-wide data on the prevalence of dementia.
- The Eurostat morbidity statistics pilot has collected data on the prevalence of dementia, but Eurostat will not publish the data as comparable statistics.
- The EuroCode project provided country-specific estimates based on estimated European average prevalence rates.
- The aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. This will significantly improve the availability of data on dementia prevalence and provide possibilities to monitor trends. The Joint Action ALCOVE also aims to improve knowledge on the prevalence of dementia.

### **Indicator development**

The developmental work of Alzheimer Europe has resulted in the inclusion of dementia prevalence in the ECHI shortlist. Alzheimer Europe is a non-profit organisation which aims to improve the care and treatment of Alzheimer patients through intensified collaboration between its member associations.

### **Data situation and main gaps**

Table 7 gives an overview of available data sources for dementia. It shows that currently there is no routinely updated source of Europe-wide data on the prevalence of dementia. Prevalence in the EU Member States can only be roughly estimated. Disease registers do not exist and population-based surveys are usually not feasible due to methodological reasons.

## Databases

The Eurostat morbidity statistic pilot has also collected data on the prevalence of dementia. Eurostat will not publish the morbidity pilot data because they were collected to assess the feasibility of the proposed method. Countries can decide themselves whether they want to publish the data.

Dementia is also included in a question in the SHARE study, which asks the respondents whether they have a specific chronic disease listed on a show card (21). However, a health interview survey-based estimate is not recommended for dementia as people with dementia are often not reached and if they are reached, they may not answer that they have dementia.

## Reports and articles

The most recent estimates are available from the EuroCoDe project (European Collaboration on Dementia) that has been lead by Alzheimer Europe. EuroCoDe's country-specific estimates are based on age distribution statistics for European countries provided by Eurostat and on estimated European average prevalence rates from the EURODEM group and from a study by Ferri et al. (2005) (103). In addition, EuroCoDe has pooled data from 31 studies from 12 (mostly Western European) countries to provide prevalence rates for 8 different age groups ( 60-64, 65-69, 70-74, 75-79, 80-84, 85-89, 90-94 and 95+) (104, 105). Recently Kiejna et al. (as part of the EUROCoDe project) concluded that there are very few epidemiological studies from Eastern and Middle Europe (106).

An estimation of the total number of people with dementia in each of the EU27 countries, Iceland, Norway and Switzerland is also provided by Gustavsson (2011). This study was based on a review of published articles and was commissioned by the European Brain Council (EBC). For countries for which data was either not available or for which the data did not provide sufficient detail, the available evidence for countries *with* data has been extrapolated to countries *without* adequate data (107).

## Current initiatives to improve the data situation

Currently register-based data collected in the Eurostat morbidity statistics pilot are not available yet. However, the final aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. This will significantly improve the data availability for dementia prevalence and provide possibilities to monitor trends.

One of the aims of the Joint Action ALCOVE, which started in 2010, is to improve knowledge on prevalence of dementia and the exposure of people with dementia to psychotropic drugs. The operational objectives of work package 4 of ALCOVE, which focuses on dementia prevalence, are (108):

1. Assessment of available epidemiological studies on prevalence of dementia in relation with the previous EuroCoDe results and recommendations by other European organisations (European Alzheimer's Disease Consortium);
2. Investigation of the possibility to collect data on early cognitive deficiencies (SHARE, EHES, etc.);
3. Assessment of national information systems other than epidemiological registries or studies;
4. Assessment of the exposure of patients with dementia to psychotropic drugs.

**Table 7: overview of available data on the prevalence of dementia.**

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
<b>Database (see annex 4 for indicator definitions)</b>						
Eurostat diagnosis-specific morbidity data activities	administrative sources (clinical records, insurance data), disease registers, etc.	database (data not available yet)	16 countries carried out the pilot (CZ, CY, EE, HU, LT, LV, MT, SI, SK, AT, DE, BE, DE, FI, NL, PL and RO)	by sex and 18 age groups (0-4, 5-9, etc., 85+)	pilot study in 2007-2009	see info on Circa <sup>22</sup>
SHARE	interview	database	17 EU countries: 2004 (AT, BE, CH, DE, DK, ES, EL, FR, IT, NL and SE), 2006/7 (plus CZ and PL), 2008/9, 2010 (plus EE, HU, PT, SI, data for 2010 not released yet).	by sex, people aged 50 and over	4 waves: 2004, 2006/7, 2008/9, 2010 (data for 2010 not released yet)	(25, 33)
<b>Reports and articles</b>						
EUROCoDe Project lead by Alzheimer Europe	Systematic literature review and meta-analysis of high quality studies	report	31 studies from 12 countries identified (BE, DE, DK, ES, FR, IT, NL, PL, SE, UK and CH). High quality studies selected from DE, DK, ES, FR, IT, NL, PL, SE and CH	pooled prevalence rates by sex and for 8 different age groups (60-64, 65-69, 70-74, 75-79, 80-84, 85-89, 90-94 and 95+).	studies performed between 1990 and 2005	(109)

<sup>22</sup> <http://circa.europa.eu/Public/irc/dsis/health/library?!=/methodologiessandsdatasc/diagnosis-specific&vm=detailed&sb=Title>

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
EUROCoDe Project lead by Alzheimer Europe	country-specific estimates based on population statistics provided by Eurostat and on European average prevalence rates from the EURODEM-group and from a study by Ferri et al. (2005).	report	EU and EFTA (except Liechtenstein) countries plus TR	by sex and by age groups (30-59, 60-64, 65-69, 70-74, 75-79, 80-84, 85-89, 90-94 and 95-99).	see Ferri et al., 2005 and EURODEM	(103)
EURODEM <sup>a</sup>	studies which used an individual examination (e.g. diagnostic interview)	research article	DE, ES, FI, IT, NL, NO, SE, UK	by sex and nine different age groups (30-59, 60-64, 65-69, 70-74, 75-79, 80-84, 85-89, 90-94 and 95-99).	studies performed between 1971 and 1990	(110)
Ferri et al., 2005 <sup>b</sup>	Ferri et al. developed their prevalence rates through a DELPHI approach i.e. based on a consensus statement by experts in the field of dementia and not directly from epidemiological studies.	research article	3 WHO European regions (Euro-A, Euro-B and Euro-C)	five year age groups from 60 to 84 years and for people over 85	2001, projections for 2020 and 2040	(111)

<sup>a</sup> European average prevalence rate of diagnosed cases of dementia (DSM-III or equivalent) or Alzheimer.

<sup>b</sup> consensual prevalence estimates.

## 4.7.2 Parkinson's disease

### Key messages:

- The prevalence of Parkinson's disease is not an ECHI shortlist indicator.
- At present, routinely updated sources of Europe-wide data on the prevalence of Parkinson's disease are very scarce.
- The Eurostat morbidity statistics pilot has collected data on the prevalence of Parkinson's disease, but Eurostat will not publish the data as comparable statistics. Data on the prevalence of Parkinson's disease are available from epidemiological studies, but their comparability is limited due to methodological differences and difference in age distribution.
- The aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. This will significantly improve the availability of data on Parkinson's Disease prevalence and provide possibilities to monitor trends.

### Indicator development

The prevalence of Parkinson's disease is not included in the ECHI shortlist.

### Data situation and main gaps

Table 8 gives an overview of available data sources on Parkinson's disease. The overview shows that at present, there is no routinely updated source of Europe-wide data on the prevalence of Parkinson's disease.

### Databases

The Eurostat morbidity statistics pilot has collected data on the prevalence of Parkinson's disease. Eurostat will not publish the morbidity pilot data because they were collected to assess the feasibility of the proposed method. Countries may decide themselves whether they want to publish the data.

Parkinson's disease is also included in the questionnaire from the SHARE study, in which respondents are asked whether they have a specific chronic disease as listed on a show card (21).

One of the aims of the EuroPa (the European Cooperative Network for Research, Diagnosis and Therapy of Parkinson's Disease) project (2001-2004) was to establish a European registry of clinically well-defined Parkinson's disease patients ([www.europarkinson.net](http://www.europarkinson.net)). EuroPa brings together clinical centres from 10 EU countries and Israel. EuroPa intends to become an independent, non-profit organisation including additional members from various European countries.

## **Reports and articles**

In a worldwide review Muangpaisan et al. (2011) concluded that comparing the incidence and prevalence of Parkinson's disease is difficult. The variation in prevalence between countries may partly be due to differences in case ascertainment, diagnostic criteria, actual data collection, and most importantly to different population age structures (112). Furthermore, studies concerning neurological disorders largely refer to clinical and treatment samples and provide no comparable 12-month estimates (93). Studies that rely on existing medical records exclude from the prevalence estimate those patients who failed to seek medical attention for their symptoms and those who were incorrectly diagnosed (113).

An estimation of the total number of people with Parkinson's disease in each of the EU27 countries, Iceland, Norway and Switzerland has been given by Gustavsson (2011). The study was based on a review of published articles and was commissioned by the European Brain Council (EBC). For countries for which data was either not available or for which the data did not provide sufficient detail, the available evidence for countries *with* data was extrapolated to countries *without* adequate data (107).

The EUGLOREH report presents data on the prevalence of Parkinson's disease that were derived from a systematic literature review including ten European countries (114). The review identified data on Parkinson's disease prevalence for eight of the ten countries included in the review. The authors conclude that the observed variations in prevalence and incidence of Parkinson's disease may result from environmental or genetic factors, but might also be a consequence of differences in methodologies for case ascertainment, diagnostic criteria, or age distributions of the study populations. The comparability of existing studies is limited (114).

Earlier, in the EUROPARKINSON study (European Community Concerted Action on the Epidemiology of Parkinson's disease) the authors concluded that the prevalence of Parkinson's disease is rather similar across European countries (113). EUROPARKINSON was a collaborative effort to study the prevalence, incidence, and determinants of Parkinson's disease in Europe. It comprised of five studies, one each from France, Italy and the Netherlands, and two from Spain. All five studies are community surveys of both independently living and institutionalised elderly subjects 55 years of age or older which were screened in person for parkinsonism. To allow comparisons across countries, an effort was made to increase the homogeneity of case finding strategies and diagnostic criteria in the five European surveys.

## **Current initiatives to improve the data situation**

Currently register-based data collected in the Eurostat morbidity statistics pilot are not available yet. However, the final aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. This will significantly improve the data availability for Parkinson's Disease prevalence and provide possibilities to monitor trends.



**Table 8: Overview of available data on the prevalence of Parkinson's disease.**

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
<b>Database (see annex 4 for indicator definitions)</b>						
Eurostat diagnosis-specific morbidity data activities	administrative sources (clinical records, insurance data), disease registers, etc.	database (data not available yet)	16 countries carried out the pilot (CZ, CY, EE, HU, LT, LV, MT, SI, SK, AT, DE, BE, DE, FI, NL, PL and RO)	by sex and by 18 age groups (0-4, 5-9, etc., 85+)	pilot study in 2007-2009	see info on Circa <sup>23</sup>
SHARE	interview	database	17 EU countries: 2004 (AT, BE, CH, DE, DK, ES, EL, FR, IT, NL and SE), 2006/7 (plus CZ and PL), 2008/9, 2010 (plus EE, HU, PT, SI, data for 2010 not released yet).	by sex, people aged 50 and over	4 waves: 2004, 2006/7, 2008/9, 2010 (data for 2010 not released yet)	(21, 25, 33)
<b>Reports and articles</b>						
Von Campenhausen et al., 2005	most studies combined questionnaires or patient/prescription records with neurological examinations	literature review	AT, CZ, DE, ES, IT, FR, NL, PT, SE and UK. No publications could be identified for AT or CZ	most studies included age-specific prevalences, different age groups depending on study	studies published between 1966 and 2004	(114)
EUROPARKINSON study	questionnaire and physical examination	research article	five studies, one each from FR, IT, and NL, and two from ES	by sex and by the following age groups 65-69, 70-74, 75-79, 80-84, 85-89, 90-94 and 95-99	surveys performed between 1988 and 1991	(113)

<sup>23</sup> <http://circa.europa.eu/Public/irc/dsis/health/library?!=/methodologiessandsdatasc/diagnosis-specific&vm=detailed&sb=Title>

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
Muangpaisan et al., 2011	case-finding varied from door-to-door surveys to hospital records and self- report	literature review	ES, IT, NL, UK (+ Scotland) and EUROPARKINSON	different age groups depending on study	studies published between 1965 and January 2010	(112)
Wirdefeldt et al., 2011	door-to-door surveys and clinical examination	literature review	ES, FR, IT, NL, SE	different age groups depending on study	studies published between 1992 and 2008	(115)

### 4.7.3 Multiple sclerosis

#### Key messages:

- The prevalence of multiple sclerosis is not an ECHI shortlist indicator.
- At present, there is no routinely updated source of Europe-wide data on the prevalence of multiple sclerosis.
- The Eurostat morbidity statistics pilot has collected data on the prevalence of multiple sclerosis, but Eurostat will not publish the data as comparable statistics.
- Data on the prevalence of multiple sclerosis are available from epidemiological studies, but their comparability is limited due to methodological differences and difference in age-distribution.
- The aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. This will significantly improve the availability of data on multiple sclerosis prevalence and provide possibilities to monitor trends. Also the EUREMS project will improve the data situation by creating a European multiple sclerosis register.

#### Indicator development

The prevalence of multiple sclerosis is not included in the ECHI shortlist.

#### Data situation and main gaps

Table 9 gives an overview of available data sources on multiple sclerosis (MS). It shows that at present, there is no routinely updated source of Europe-wide data on the prevalence of multiple sclerosis.

#### Databases

The Eurostat morbidity statistics pilot has collected data on the prevalence of multiple sclerosis (MS). Eurostat will not publish the morbidity pilot data because they were collected to assess the feasibility of the proposed method. Countries may decide themselves whether they want to publish the data.

#### Reports and articles

Both the EUGLOREH report and the Major and Chronic Diseases (MCD) report present data from a review of studies that were published between 1970 and 2001 by Pugliatti et al. (2006) (7, 46). Recently, Koutsouraki et al. (2010) published a review of newer studies, i.e. published between 2000 and 2001 (116). Also recently, two meta-analysis investigated the association between MS prevalence and latitude (117, 118).

In the MCD report it was concluded that despite the wealth of data from systematic epidemiological studies on MS, reliable information on age-specific prevalence rates is lacking for nearly two thirds of all European countries (7). Koutsouraki et al. also highlight

the need for age- and sex-adjusted prevalence rates for reliable comparisons between countries (116).

International comparisons are also difficult because of the following arguments (7):

1. the variability of the surveyed populations with respect to size, age structure, ethnic origin;
2. differences in the capability to detect benign and/or early cases;
3. the different degree of case ascertainment coverage;
4. differences in diagnostic criteria used.

To address these problems a collaborative multicentric European project for the assessment of the current burden of MS in Europe is needed (119).

Gustavsson et al. (2011) gives an estimation of the total number of people with multiple sclerosis in each of the EU27 countries, as well as Iceland, Norway and Switzerland. The study was based on a review of published articles and was commissioned by the European Brain Council (EBC). For countries for which data was either not available or for which the data did not provide sufficient detail, the available evidence for countries *with* data was extrapolated to countries *without* adequate data (107).

## **Current initiatives to improve the data situation**

Currently register-based data collected in the Eurostat morbidity statistics pilot are not available yet. However, the final aim of the Eurostat morbidity statistics activities is to set up a regular data collection on morbidity within the European Statistical System. This will significantly improve the data availability for multiple sclerosis prevalence and provide possibilities to monitor trends.

One of the objectives of the EU funded project called Multiple Sclerosis - the Information Dividend (MS-ID) (2007-2009) was the use of high quality comparable data at EU and transnational levels to positively impact on EU and national policy and programmes towards MS (120). The MS-ID project has demonstrated the feasibility of a European Register for Multiple Sclerosis for trans-national data analysis and comparison. Such a registry should be based on the identification and evaluation of existing data collection methodologies, MS databases and MS registries across Europe, and results of a literature search. The project is continued in the EUREMS project (European Register for Multiple Sclerosis) which has started in 2011 (121). The European Multiple Sclerosis Platform coordinates both projects.

**Table 9: Overview of available data on the prevalence of multiple sclerosis.**

Source			Availability			References
name	type of data collection (interview, examination, register)	source type (database, report, article)	countries	by sex and age groups	year of data collection and periodicity	
<b>Database (see annex 4 for indicator definitions)</b>						
Eurostat diagnosis-specific morbidity data activities	administrative sources (clinical records, insurance data), disease registers, etc.	database (data not available yet)	16 countries carried out the pilot (CZ, CY, EE, HU, LT, LV, MT, SI, SK, AT, DE, BE, DE, FI, NL, PL and RO)	by sex and by 18 age groups (0-4, 5-9, etc., 85+)	pilot study in 2007-2009	see info on Circa <sup>24</sup>
<b>Reports and articles</b>						
Koutsouraki et al., 2010	population-based studies	literature review	BA, EL, DE, EL, ES, FI, FR, HU, IT, MT, NO, RS, SE and UK	by sex	studies published between 2000 and 2009	(116)
Pugliatti et al., 2006	population-based studies (registry-based and nationwide surveys were preferably considered)	literature review	EU countries (except LT, SK and LU, EFTA (except Liechtenstein), AL, HR, RS and MK	by sex and by age groups (<17, 18-34, 35-49, 50-64, 65-74, 75>) but depending on study	studies between the 1980s and 2001	(119)

<sup>24</sup> <http://circa.europa.eu/Public/irc/dsis/health/library?!=/methodologiessandsdatasc/diagnosis-specific&vm=detailed&sb=Title>

## 5 Conclusions and recommendations

### **Availability of timely and comparable chronic disease prevalence data is far from ideal in Europe**

Based on the overviews in chapter 4 we conclude that the availability of timely and comparable chronic disease prevalence data is far from ideal in the European Union. The paucity of the data for these chronic diseases contrasts with their large burden of disease. The availability of timely data is especially problematic for cardiovascular diseases, whereas data on cancer is much more widely available than for other chronic diseases. For some diseases (e.g. multiple sclerosis, Parkinson's disease, diabetes) a wealth of data exists but because these data are originating from a great variety of national studies, they are still far from comparable. Furthermore, the available information on the prevalence of chronic diseases is scattered among several reports, (project) websites, research articles and international databases, with generally only the latter being a source with some form of sustainability. Availability of the data is also not equally distributed among countries and this leads to large 'health information inequalities' within the EU27. Data availability is generally better in the 'old' EU15 countries and worse in the countries that became EU member in 2004 or later. Furthermore, trend data are not always available and several studies/projects highlight the need for more age and sex-specific data collection to be able to age- and sex-standardise which is needed to allow for international comparisons. In conclusion, a balanced, timely and adequate picture of chronic disease prevalence is lacking. This impedes health policy development and evaluation throughout Europe.

### **Health interview surveys, registries and population-based studies are important data sources**

The most important sources of data on the prevalence of chronic disease in terms of coverage and timely availability are:

1. general health interview surveys (EHIS and national HIS);
2. registries (e.g. hospital discharge registers, GP registers, disease registers; data collected by the Eurostat morbidity statistics pilot);
3. epidemiological (population-based) studies using (diagnostic) interviews, physical exams or both (including HES).

In addition, health examination surveys (HES) provide information on the determinants of major chronic diseases (e.g. blood pressure, BMI, and cholesterol) and undiagnosed diabetes.

### **Despite recommendations by indicator projects, use of different methods still hampers comparability**

The data quality and comparability of these sources mainly depends on the methods used in each specific survey or register. Due to a lack of consensus, these methods often differ. Many EU funded projects on health indicators, such as EUROCISS, EUDIP/EUCID, IMCA, MINDFUL, EuroCoDe, MS-ID have been working, often on a limited time base, on indicator development and incidental data collections for specific chronic disease groups. Various EU funded indicator projects have also made recommendations on the best possible or available methods for data collection and harmonisation, but full implementation thereof throughout the EU is lacking because of discontinuities in project funding or national impediments to investing in larger studies.

### **Together HIS, HES and registries form a good basis for national and international health monitoring systems**

Because both (E)HIS and registry-based data have advantages as well as disadvantages the Joint Action for ECHIM has proposed both approaches to collect data for several of their proposed set of health indicators. Population-based studies that include some form of screening or physical examination and general health examination surveys (HES) are complementary to HIS and medical registers because they can provide information on undiagnosed cases, which is not available from other data sources. Together HIS, HES and registries form a good basis for national and international health monitoring systems.

### **EU-wide data collections important to boost the data situation**

From the overviews in chapter 4 it is clear that EU-wide data collections such as EHIS and the Eurostat morbidity statistics activities are important future or potential sources of data on the prevalence of chronic diseases in the EU27. For this reason and because they are complementary to each other, these pilot initiatives together with EHES-related initiatives may boost the data situation in the future and therefore need to be sufficiently supported. The full implementation of EHIS will provide important comparable data on chronic diseases and their risk factors in the European Union. Implementation of a harmonised European Health Examination Survey (EHES) in all EU Member States would provide a major source of comparable data on chronic diseases and their determinants (including the biological risk factors). The implementation of an EHES could build on preliminary work that has already been done in previous EU-projects like the EHES pilot project and the Feasibility of a European Health Examination Survey (FEHES). Although determinant data are not falling within the scope of this report, data on determinants are also very important for monitoring of chronic diseases, for example for modelling and projecting future disease trends.

### **Sustainable investments needed for monitoring disease trends**

European-wide data collection activities, such as EHIS, EHES and the Eurostat morbidity data activities are important sources for several ECHI indicators on the prevalence of chronic diseases. In addition to benchmarking and supporting health policies, the purpose of ECHI indicators is to monitor trends. Monitoring trends within countries is also possible when data are not completely harmonised between countries, however. In order for EHIS, EHES and the Eurostat morbidity statistics activities to fully reach their potential for health monitoring, sustainable investments are necessary to make sure that the current pilots become a sustainable data source and provide possibilities to monitor trends. Furthermore, these studies can be the basis of relevant disease mechanistic and epidemiological research including underlying genetics. Therefore, when these pilots are finished it is essential that the EU and its Member States keep investing in improving data availability, comparability and quality in a coordinated fashion and according to a clearly defined health information strategy.

### **Stimulate the use of existing routinely collected data**

Because disease registers, HIS and HES activities are expensive, it is worthwhile to further stimulate the use of existing routinely collected data as done by the Eurostat morbidity pilot and develop protocols to arrive at optimal comparability for such data sets. Part of this process of improving data is creating more possibilities for record linkage among the different sources of information. This is especially useful for data on the attack rate of AMI and stroke. Due to data protection legislation, this linkage is not possible in several countries. Another aspect of data processing, which is influenced by data protection legislation, is secondary use of (health) data that have been collected for another purpose, e.g. administrative reasons. The EU legislative data protection framework is currently being revised. It is important that under the revised legislation it will be possible to make optimal use of health data for public health purposes in ways that provide adequate safeguards for the data subject (122).

### **Regularly updating multicenter studies also important for monitoring disease trends**

For international comparisons multicenter research or health examination studies using the same methodology in different countries (such as ECRHS, ISAAC, MONICA) are probably the most reliable sources. However, they are often carried out on an ad hoc basis, because they are expensive. Therefore, they are most often not a sustainable source of information for analysing disease trends. Strong time trends in disease incidence and prevalence for certain chronic diseases (e.g. diabetes and COPD) point at the importance to regularly repeat such studies, but on a longer time base.

### **Stimulate joint data collection between Eurostat, the OECD, the WHO and EU Member States**

EU funded projects and work by organisation such as Eurostat, the OECD, the WHO and EU Member States have resulted in considerable progress in improving data availability, comparability and quality. DG SANCO should stimulate joint data collection between these organisations by bringing them together on morbidity data and other health information topics as part of a common health information strategy. The organisations should join forces and use each others' expertise and networks to improve the availability, quality and comparability of health data in general and for chronic diseases in particular. For Member States this would be attractive as it would result in a lower burden of data deliveries. An example is the EU funded EU-WMH project that contributes to the WHO World Mental Health Surveys Initiative. These efforts ideally should not be limited to data collection for chronic disease prevalence, however, but also to data on their risk factors (lifestyle factors and biological risk factors) as well as for the assessment of quality of healthcare and prevention.

### **A web-based chronic disease monitoring system to increase visibility of available information**

A way to improve the scattered data situation could be envisaged by integrating available information on a web-based chronic diseases monitoring system, or a broader public health monitoring system, for example the HEIDI-Wiki and the pilot system which was developed in the EUPHIX project (123). Such a web-based system may improve data access and visibility and its usability for public health professionals and policy makers and could thereby also provide an opportunity to increase Member States' commitment.

### **Need for central coordination and Member State commitment**

Sustainable investments in improving data availability, comparability and quality cannot be achieved without the commitment of the Member States and some central form of coordination and should be part of a common European health information strategy. Eurostat is already the coordination point responsible for EU data collection, but other organisations (e.g. OECD, WHO) collect data as well. However, these organisations do not have a common plan on health data collection and harmonisation. The scattered data situation in Europe therefore, shows a strong need for central coordination, priority setting and support. Still, a solid form of sustainable general coordination and harmonisation that could lead to a better balanced, more timely and adequate picture of chronic disease prevalence is lacking. In the past decade the ECHI projects and the JA for ECHIM have fulfilled an important part of this coordinating and harmonisation function. Now that the JA for ECHIM will end by July 2012 this role has to be taken up by another body or organisation. Such a body should stimulate ongoing and future developments towards better availability and comparability of health data, such as the Eurostat morbidity statistics pilot and the ECHIM data collection pilot. For chronic disease policy development in Europe, we will also need more data, however, than prevalence data alone. In addition to data on mortality, which are generally available for most



disease groups, we also need adequate data for risk factors for chronic diseases, for the economic costs of these illnesses as well as data on the use, costs and quality of healthcare and prevention that need to combat these diseases.

In summary, to improve the rather weak health data situation in the European Union we need a central coordinating effort which will implement a common health information strategy not just for information on chronic disease prevalence, but for the full area of public health and healthcare. Such a strategy can build upon the experience gained in numerous previous EU sponsored projects on chronic diseases, most of which have contributed to this review of prevalence data availability for chronic diseases. Sustainable support for that type of work is needed to make sure that the current pilots become a sustainable data source and provide possibilities to monitor trends and to ascertain that previously build up know-how, experience and networks will not be lost.

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## **Disclaimer**

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## Annex 1: List of abbreviations

ADI	Alzheimer's Disease International
AIRE	Asthma Insights & Reality in Europe
ALCOVE	ALzheimer's COoperative Valuation in Europe
AMI	acute myocardial infarction
BIRO	Best Information through Regional Outcomes
BMI	Body Mass Index
BOLD	Burden of Obstructive Lung Disease study
CaMon project	Comprehensive Cancer Monitoring in Europe
CES-D scale	Center for Epidemiological Studies Depression Scale
CHD	coronary heart disease
CIDI	Composite International Diagnostic Interview
CIDI-SF	Composite International Diagnostic Interview - Short Form
COPD	Chronic Obstructive Pulmonary Disease
CVD	cardiovascular disease
DALY	Disability Adjusted Life Years
DEPRES	Depression Research in the European Society
DG SANCO	Directorate-General Health and Consumers
DSM-III	Diagnostic and Statistical Manual of Mental Disorders, 3rd edition
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4th edition
DYNAMO-HIA	DYNAmic MOdel for Health Impact Assesment
EADC	European Alzheimer's Disease Consortium
EBC	European Brain Council
ECHIM	European Community Health Indicators Monitoring
ECNP	European College of Neuropsychopharmacology
ECRHS	European Community Respiratory Health Survey
EEA	European Economic Area
EFTA	European Free Trade Association (EFTA) (EFTA has four Member States: Iceland, Liechtenstein, Norway and Switzerland)
EHIS	European Health Interview Survey
EHN	European Heart Network
EMSP	European Multiple Sclerosis Platform
ENCR	European Network of Cancer Registries
ERS	European Respiratory Society
ESEMeD	European Study of the Epidemiology of Mental Disorders
ESS	European Social Survey
EU	European Union
EU15	The 15 countries making up the European Union before 1 May 2004: Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Portugal, Spain, Sweden and the United Kingdom
EU27	The 27 Member States of the European Union since 1 January 2007: these are the EU15 countries plus Bulgaria, Cyprus, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Romania, Slovakia and Slovenia
EUBIROD	EUropean Best Information through Regional Outcomes in Diabetes
EUCID	European Core Indicators in Diabetes
EUDIP	European Diabetes Indicators Project

EUGLOREH	Global Report on the Health Status in the European Union
EUNICE	EU Network for Indicators on Cancer
EUPHIX	EU Public Health Information & Knowledge System
EUREMS	European Register for Multiple Sclerosis
EUROCHIP	European Cancer Health Indicator Project
EUROCISS project	EUROpean Cardiovascular Indicators Surveillance Set
EuroCoDe	European Collaboration on Dementia
EURODEM	The European Community Concerted Action on the Epidemiology and Prevention of Dementia
EURODEP	European Depression study
EuroHeart	European Heart Health strategy
EuroPa	European Cooperative Network for Research, Diagnosis and Therapy of Parkinson's Disease
Eurostat	Statistical Database of the European Union
EU-SILC	European Union Statistics on Income and Living Conditions
FEHES	Feasibility of a European Health Examination Survey
GA <sup>2</sup> LEN	Global Allergy and Asthma European Network
GBD	Global Burden of Disease
GP	General Practitioner
GPRD	general practice research database
HES	Health Examination Survey
HIS	Health Interview Survey
HMP	Health Monitoring Programme
IARC	International Agency on Research on Cancer
ICD	International Classification of Diseases
IDF	International Diabetes Federation
IHD	ischemic heart disease
IMCA	Indicators for monitoring COPD and asthma in the EU
ISAAC	International Study of Asthma and Allergies in Childhood
MCD	Major and chronic diseases
MEHM	Minimum European Health Module
MINI	Mini International Neuropsychiatric Interview
MONICA	MONItoring trends and determinants in CARDiovascular disease
MS	multiple sclerosis
MS-ID	Multiple Sclerosis - the Information Dividend
NOMESCO	Nordic Medico-Statistical Committee
ODIN	Outcomes of Depression International Network
OECD	Organisation of Economic Cooperation and Development
RARECARE	Surveillance of Rare Cancers in Europe
RARECAREnet	Information network on rare cancers
SHARE	Survey of Health, Ageing and Retirement in Europe
UN	United Nations
WHO	World Health Organization
WHO-Europe	World Health Organization Regional Office for Europe
WHO-Hfa	Health for All database
WMH survey	World Mental Health Survey

## Annex 2: List of country name abbreviations

EU27	European Union (27 countries)
EU15	European Union (15 countries)
BE	Belgium
BG	Bulgaria
CZ	Czech Republic
DK	Denmark
DE	Germany
EE	Estonia
IE	Ireland
EL	Greece
ES	Spain
FR	France
IT	Italy
CY	Cyprus
LV	Latvia
LT	Lithuania
LU	Luxembourg
HU	Hungary
MT	Malta
NL	Netherlands
AT	Austria
PL	Poland
PT	Portugal
RO	Romania
SI	Slovenia
SK	Slovakia
FI	Finland
SE	Sweden
UK	United Kingdom
IS	Iceland (EFTA and Candidate country)
NO	Norway (EFTA)
CH	Switzerland (EFTA)
ME	Montenegro (Candidate country)
HR	Croatia (Acceding country)
MK	Former Yugoslav Republic of Macedonia, the (Candidate country)
RS	Serbia (Candidate country)
TR	Turkey (Candidate country)
AL	Albania (Potential Candidate)
BA	Bosnia and Herzegovina (Potential Candidate)
XK	Kosovo (Potential Candidate)

## Annex 3: Search strategy

In April 2012 (July for cancer) we conducted a literature search in MEDLINE, EMBASE, SciSearch and PsycINFO for reviews, meta-analyses and comparative studies performed after 2008. In step 1 and 2 different terms for the chronic disease groups included in this report were defined. Next, for each chronic disease these terms are combined with step 3-22.

### Cardiovascular disease

- 1 \*cardiovascular diseases/ or \*cerebrovascular disorders/ or \*vascular diseases/ or exp \*heart diseases/ or exp \*myocardial ischemia/ or \*stroke/ or \*aneurysm/ or \*blood pressure/
- 2 (cardiovascular or vascular or blood vessels or coronary or cerebrovascular or stroke or ischemic or ischaemic or heart or infarction or myocardial or cardiac or atherosclerosis or blood pressure).ti.

### Cancer

- 1 (cancer\* or neoplasm\* or neoplastic\* or tumor\* or melanoma\*).ti.
- 2 exp \*neoplasms/

### Diabetes

- 1 \*diabetes mellitus/ or \*diabetes mellitus, type1/ or \*diabetes mellitus, type 2/ or (diabetes or niddm or iddm).ti.

### Respiratory diseases

- 1 exp \*asthma/ or \*rhinitis, allergic, perennial/ or \*rhinitis, allergic, seasonal/ or \*respiratory hypersensitivity/ or exp \*chronic obstructive pulmonary disease/ or \*lung disease obstructive/ or \*chronic bronchitis/
- 2 (asthma\* or copd or chronic obstructive pulmonary or chronic obstructive lung or chronic obstructive airway\* or chronic airflow obstruct\* or respiration disorders or chronic bronchitis or allergic rhinitis or atopic rhinitis or hay fever or hayfever).ti.

### Depression

- 1 (depression or depressions or depressive or depressed or mental disorder\* or mood disorder\* or mental disease\*).ti.
- 2 \*depression/ or exp \*depressive disorder/ or \*mental disorders/ or \*mood disorders/

### Dementia and Parkinson's disease

- 1 \*dementia/ or \*cognition disorders/ or \*mental retardation/ or \*alzheimer disease/ or \*parkinson disease/ or \*parkinsonian disorders/
- 2 (dementia or cognitive impairment or alzheimer\* or parkinson\*).ti.

### Multiple sclerosis

- 1 multiple sclerosis.ti. or (ms.ti. and sclerosis.ab.)
- 2 exp \*multiple sclerosis/

### Step 3-22

- 3 (prevalence\* or burden or epidemiology).ti. or prevalence/
- 4 (1 or 2) and 3
- 5 exp europe/ or exp european union/
- 6 (european populations or european communit\* or europ\* or iceland or norway or sweden or finland or denmark or great britain or united kingdom or england or scotland or wales or (ireland not ireland ltd) or netherlands or belgium or france or luxemburg or spain or portugal or italy or switzerland or austria or germany).tw.

- 7 (poland or hungary or czech or croatia or slovakia or slovenia or romania or bulgaria or lithuania or latvia or estonia or estland or greece or turkey or albania or serbia or macedonia or bosnia or herzegovina or cyprus or malta).tw.
- 8 (european populations or europ\* or iceland or norway or sweden or finland or denmark or great britain or united kingdom or uk or england or scotland or wales or ireland or netherlands or belgium or france or luxemburg or spain or portugal or italy or switzerland or austria or germany).in.
- 9 (poland or hungary or czech or croatia or slovakia or slovenia or romania or bulgaria or lithuania or latvia or estonia or estland or greece or turkey or albania or serbia or macedonia or bosnia or herzegovina or cyprus or malta).in.
- 10 (8 or 9) not (exp africa/ or exp asia/ or exp australasia/ or exp americas/)
- 11 (5 or 6 or 7 or 10) not (new south wales or turkey meat).tw.
- 12 (worldwide or global or international variation or geographical distribution).ti.
- 13 4 and (11 or 12)
- 14 (cross-national or cross national or cross-cultural or cross-european or across europe\* or european cohort\* or european countries or european regions or eu-countries or world region\* or worldwide trends or worldwide burden or global burden or international variation or geographical distribution).tw.
- 15 ((comparative stud\* or (comparative and study) or comparison\* or compare or compared or comparing or comparative) and (countries or states or european population\* or populations or governments or multi-countr\* or multicountr\* or international)).tw.
- 16 13 and (14 or 15)
- 17 (review or meta-analysis or multicenter study or comparative study).pt. or (review or meta-analysis or multi-center study or comparative study).ti.
- 18 13 and 17
- 19 16 or 18
- 20 19 and english.lg.
- 21 limit 20 to yr=2008-2012
- 22 remove duplicates from 21

## Annex 4: Indicator definitions according to different databases

Disease	Indicator definition
<b>Eurostat/EHIS</b>	
cardiovascular disease	<p>self-reported prevalence: proportion of individuals reporting to have been diagnosed with the disease which occurred during the past 12 months. Self-reported prevalence has been computed for diabetes, chronic depression, asthma, chronic obstructive pulmonary disease (COPD). Even though ICD10 codes were not explicitly asked in the survey, following scale is used for the dissemination:</p> <ul style="list-style-type: none"> <li>- (any types of) diabetes E10-E14 (diabetes mellitus)</li> <li>- chronic depression F32_F33 (depressive disorders)</li> <li>- asthma J45 (asthma)</li> <li>- J41 - J44 (Chronic bronchitis, emphysema, other chronic obstructive pulmonary diseases).</li> </ul> <p>The EHIS question also includes myocardial infarction, coronary heart disease (angina pectoris), stroke (cerebral haemorrhage, cerebral thrombosis) and cancer (malignant tumour, also including leukaemia and lymphoma), but prevalence has not been computed by Eurostat.</p>
cancer	
diabetes	
COPD	
asthma	
depression	
<b>Eurostat morbidity pilot</b>	
cardiovascular disease	period prevalence of ischemic heart diseases (including AMI) (I20-I25), heart failure (I50) and cerebrovascular disease (I60-I69)
cancer	period prevalence of all malignant neoplasms (cancer) (C00-C97) and 13 cancer types
diabetes	period and point prevalence of diabetes mellitus (E10-E14)
COPD	period prevalence of chronic lower respiratory diseases other than asthma (incl. COPD) (J40-J44, J47)
asthma	period prevalence of asthma (J45, J46)
depression	period prevalence of depression and other affective disorders (F30-F39)
dementia	period prevalence of dementia (incl. Alzheimer's disease) (F00-F03, G30)
Parkinson's disease	period prevalence of Parkinson's disease (G20)
multiple sclerosis	period prevalence of multiple sclerosis (G35)
<b>GLOBOCAN</b>	
cancer	estimated 1-, 3- and 5-year cancer prevalence (numbers and proportions per 100.000) for 26 cancers + all cancers combined
<b>IDF</b>	
diabetes	the national prevalence is a percentage of the number of adults (20 - 79 years) who have diabetes in the given year (either 2011 or 2030) in a country or region. It is calculated by taking the number of cases in adults and dividing by the total population in adults. The comparative prevalence is age-adjusted and should be used to compare the relative burden of diseases in different countries.

<b>Disease</b>	<b>Indicator definition</b>
<b>JA for ECHIM</b>	
diabetes	self-reported prevalence: proportion of individuals reporting to have ever been diagnosed with diabetes and to have been affected by this condition during the past 12 months.
	register-based prevalence: number of individuals that have ever been diagnosed with diabetes and that have been affected by this condition during the past 12 months. Expressed per 100,000 and as percentage of total population.
COPD	self-reported prevalence: proportion of individuals reporting to have ever been diagnosed with chronic obstructive pulmonary disease (COPD) and to have been affected by this condition during the past 12 months.
	register-based prevalence: number of individuals that have ever been diagnosed with chronic obstructive pulmonary disease and that have been affected by this condition during the past 12 months. Expressed per 100,000 and as percentage of total population.
asthma	self-reported prevalence: proportion of individuals reporting to have ever been diagnosed with asthma and to have been affected by this condition during the past 12 months.
	register-based prevalence: number of individuals that have ever been diagnosed with asthma and that have been affected by this condition during the past 12 months. Expressed per 100,000 and as percentage of total population.
depression	self-reported prevalence: proportion of individuals reporting to have ever been diagnosed with chronic depression and to have been affected by this condition during the past 12 months.
	register-based prevalence: number of individuals that have ever been diagnosed with depression and that have been affected by this condition during the past 12 months. Expressed per 100,000 and as percentage of total population.
dementia	register-based prevalence: number of individuals aged 65+ that have been diagnosed with dementia. Expressed per 100,000 and as percentage of total population.
<b>MINDFUL</b>	
depression	Age and sex-adjusted prevalence of cases fulfilling the criteria of major depression for an episode of depression for at least two weeks during past 12 months; instrument: CIDI-SF.



<b>Disease</b>	<b>Indicator definition</b>
<b>SHARE</b>	
cardiovascular disease	<p>self-reported prevalence based on the following question: Has a doctor ever told you that you had / Do you currently have any of the conditions on this card? With this we mean that a doctor has told you that you have this condition, and that you are either currently being treated for or bothered by this condition.</p> <p>The card with answer categories includes the following diseases of interest in the current report:</p> <ul style="list-style-type: none"> <li>- A heart attack including myocardial infarction or coronary thrombosis or any other heart problem including congestive heart failure</li> <li>- A stroke or cerebral vascular disease</li> <li>- Diabetes or high blood sugar</li> <li>- Chronic lung disease such as chronic bronchitis or emphysema</li> <li>- Asthma</li> <li>- Cancer or malignant tumour, including leukaemia or lymphoma, but excluding minor skin cancers</li> <li>- Parkinson disease</li> <li>- Alzheimer's disease, dementia, organic brain syndrome, senility or any other serious memory impairment</li> </ul>
cancer	
diabetes	
COPD	
asthma	
depression	
dementia	
Parkinson's disease	
<b>WHO-HfA</b>	
cancer	cancer prevalence in % and number of all cases of cancer: cumulative number of cancer patients (old and new cases). Data from the cancer register whenever available or from the existing routine reporting system of health establishments.
diabetes	diabetes prevalence in % and number of all cases of diabetes mellitus at year's end: cumulative number of patients with diabetes (ICD-9: 250; ICD-10: E10-E14) at the end of the calendar year. Data from the national diabetes register, whenever available, or from the routine reporting system.
COPD	COPD prevalence in % and number of chronic obstructive pulmonary diseases: cumulative number of patients with chronic obstructive pulmonary diseases (ICD-9: 490-496; ICD-10: J40-J47) at the end of the calendar year.
mental disorders	mental disorders prevalence in % and number of all cases of mental disorders at year's end: cumulative number of registered mental patients at the end of the calendar year (chapter V of ICD-9/10).