

Report on in-depth analysis of pilot studies in 16 Member States on diagnosis-specific morbidity statistics

Annex 9

Technical descriptions of the call for proposals launched in the years 2004 and 2009

2004

GRANT APPLICATION DOCUMENTATION TECHNICAL ANNEX

PILOT PROJECT ON MORBIDITY STATISTICS

TECHNICAL DESCRIPTION OF ACTION

1. Objectives

Within the Community Statistical Programme 2003-2007, the establishment of EU-wide comparable data on public health and its determinants is the objective of the activities described under work theme 35. Statistics on public health are also closely linked to the Community Action Programme in the field of Public Health 2003-2008.

Within the overall context of the system of health statistics at EU level, the need to develop **statistics on diagnosed related morbidity** emerged in order to have a comprehensive overview or an adequate summary of the occurrence of diseases at population level. For long periods, mortality rates reflected reasonably well the occurrence of major diseases. However, changing morbidity patterns with improved treatment resulting in lower case fatality ratios as well as ageing, together with improved medical knowledge, better diagnostic facilities and public awareness resulted in a new demand of data. Information is requested on incidence and prevalence of diseases in particular on **chronic diseases and non-communicable diseases**. New data demands can be partly covered by information coming from population surveys (e.g. Health Interview Surveys – HIS) but the statistical information as determined by medical professionals is considered to be indispensable.

Under the European Community Statistical Programmes 1993-1997 and 1998-2002, Eurostat already launched and followed a number of activities on morbidity statistics. These activities receive even more attention through the new programme of Community Action in the field of public health (2003-2008). A seminar on morbidity was held in January 2003 (http://www.statistics.gov.uk/events/Eurostat morbidity seminar/). The recommendations of the seminars included:

- to draft a short list of diseases for the collection, analysis and dissemination of diagnosis related morbidity statistics
- to start with pilot projects on the availability and quality of the data coming from some sources analysed at the seminar (General Practitioners/Ambulatory care, insurance or sickness funds).

In order to gain additional experience both on the proposed European short list on disease specific morbidity as well as on potential data sources, the grant action aims at a **pilot project** on morbidity statistics.

The pilot project should include the following elements:

1) Review of the proposed European shortlist for disease specific morbidity in terms of coverage, relevance and applicability and as well agreeability

The current draft list has been developed based on the European Short list for Causes of Death, the draft ECHI list¹, the European list for statistics on occupational diseases and the diagnosis list for hospital data collection. However, in order to collect more information about the relevance of that draft list, as a first step, the pilot project should re-visit the draft list in terms of coverage, relevance and applicability and provide comments and suggestions for the draft short list. This review should keep in mind that such a short list – and thus not necessarily a complete list – for **routine morbidity statistics** needs to be developed and – at a later stage – agreed at European level.

2) Preparation of a matrix on possible data sources (in a selected number of countries) for the collection of morbidity data using the proposed European short list

For the list, a matrix identifying potential data sources should be established for a selected number of countries. The identification of potential sources for data should be innovative and creative and should – by preference – be focussed to data that can be used for arriving at a national estimate. **In particular preference will be given to a project that will test the list on insurance data as a potential data source.** The pilot project should identify these sources in minimum 3 to 5 countries, with different systems for health care and/or with different insurance systems.

In case a potential source turns out to be not feasible, the reasons why should be cautiously documented. For successful data sources, all relevant information such as the population coverage, confidentiality concerns, data quality, sustainability of the source etc. should be documented and evaluated.

¹ European Core Health Indicators, a project of DG Sanco, http://europa.eu.int/comm/health/ph information/indicators/indic data en.htm

Where the evaluation would show that use of the whole list would not be feasible, the reasons should be clearly defined. In that case, the contractor should prepare the matrix for a selection of diseases (minimum 5 (groups of) diseases) from the short list and the selected diseases should be **non-communicable or chronic diseases**. The Eurostat morbidity seminar 2003 stressed the importance of cancer, diabetes, cardio-vascular diseases, mental diseases, dementia and musculo-skeletal diseases. Respiratory diseases are also of special concern.

3) Pilot data collection and evaluation of results

As a third step and on the basis of the results and decisions of the steering committee on phases 1) and 2) a pilot data collection should be carried out - for the selected countries - from the various sources in order to arrive at the best - national - estimate for the diseases of the list or for the selected diseases.

It is important that the pilot data collection considers the numerous ongoing activities in the context of DG SANCO's "Working Party Morbidity and Mortality". In addition, the results and experiences of any former or ongoing European surveillance activities should be taken into account. An overview is provided in the document "Building a European System of Information on Major and Chronic Diseases as a part of a European System of Information on Health", SG SANCO (see below, references).

The ultimate goal of the pilot data collection should be to evaluate whether the identified sources, **in particular insurance data**, would provide comparable data across countries – with different health and/or insurance systems - for specific diseases (either for the whole list or for a selection of diseases) and whether, within a country, a specific data source, **in particular insurance data**, would provide – for the diseases under study - data comparable and/or compatible with other sources.

The results of each of the parts 1-3 of the project should be presented to and discussed and endorsed by a steering committee, to be established under the project.

2. Expected results

With reference to the above described objectives, the pilot project should deliver the following results:

- Comments and suggestions for improving the **draft European short-list** for disease specific morbidity.
- **Identification and evaluation of potential sources**, with special emphasis on new and innovative sources, in particular in the field of insurance data, and this from a number of countries (minimum 3 to 5) with different health and/or insurance systems. The data sources should be identified for the entries of the draft European short-list or, when this would not be feasible, for a selection of diseases (minimum 5) from the list.

² http://europa.eu.int/comm/health/<u>ph_information/implement/wp/morbidity/morbidity_en.htm</u>

- Pilot data collection at the potential sources identified and evaluation of quality and comparability of the data. This includes a clear documentation on why a source failed to provide the requested data as well as an evaluation of the quality of data obtained from a specific source and an evaluation of the cross-country comparability of the data from that source. In case of different possible sources for one disease, the various sources are to be compared in terms of coverage, quality etc. and the feasibility to reconcile the data from various sources to one best national disease statistic is to be tested.

3. Approximate timetable

- 1. Review and comments on the draft European shortlist for disease specific morbidity: **month 1+2**;
- 2. Identification and evaluation of potential new and innovative data sources, preparation of matrix with the identified potential data sources per country and for the list or from a selection of diseases from the list: **month 3-4**;
- 3. Pilot data collection, documentation of results (positive and negative), evaluation of quality and comparability of the data and where needed reconciliation of data from different sources: **month 5-12.**

Reference documents

Eurostat Morbidity Seminar 27-29 January 2003, London, Report available at http://www.statistics.gov.uk/events/Eurostat_morbidity_seminar/

Disease Specific Morbidity, "European Shortlist" (draft, attached)

EUMIP 1 and 2 – Methodologies for Producing EU-wide comparable disease-specific morbidity data; project information available at http://europa.eu.int/comm/health/ph_projects/monitoring_project_full_listing_en.htm

This website contains a full listing of projects funded under the Public Health Programme 1998-2002.

"Methods of collecting morbidity statistics" by Val Mason, Ann Bridgwood. Eurostat Working Papers, Population and Social Conditions 3/1998/E/nº 9

"Building a European System of Information on Major and Chronic Diseases as a part of a European System of Information on Health", SG SANCO, Working Party Morbidity and Mortality, Luxembourg January 2004,

 $\frac{http://europa.eu.int/comm/health/ph_information/implement/wp/morbidity/docs/ev_200}{40120_rd03_en.pdf}$

ONLY FOR PRIVATE COMPANIES
ELIGIBILITY AND EXCLUSION CRITERIA

Grant applications shall **not be accepted** from the following:

- a) Candidates or applicants having been:
 - convicted of an offence concerning their professional conduct by a judgment which has the force of res judicata;
 - the subject of a judgment which has the force of res judicata for fraud, corruption, involvement in a criminal organisation or any other illegal activity detrimental to the Communities' financial interests.
- b) any firm which <u>has been declared bankrupt</u>, is in <u>liquidation</u>, is the subject of a <u>judicial settlement or arrangement with creditors</u>, has ceased activity or is in any similar situation as a result of proceedings of this kind under the provisions of national regulations and laws;
- c) any firm which is the subject of proceedings for the declaration of bankruptcy, liquidation, judicial settlement, arrangement with creditors or any other proceedings of this kind under the provisions of national regulations and laws;
- d) any firm which has not fulfilled its obligations in respect of the payment of social security contributions in accordance with the legal provisions of the country in which it is established;
- e) any firm which has not fulfilled its obligations in respect of the payment of corporate taxes in accordance with the legal provisions of the country in which it is established.

The following (dated no more than 4 months before the final date for receipt of applications) shall be accepted as evidence that the applicant is not in any of the situations described above:

- in the situations mentioned at a) b) and c), production of an extract from the judicial/criminal records or, failing this, an equivalent document issued by a judicial or administrative body in the country of origin or provenance attesting that these requirements are met.
- in the situations mentioned at d) and e), a certificate issued by the appropriate authority in the country of establishment.

Where no such document or certificate is issued by the country concerned, it may be replaced by a declaration under oath by the applicant before a judicial or administrative authority, a notary public or a qualified professional body in the country of origin or provenance.

Grants may not be awarded to applicants who:

- are subject to a conflict of interest;
- are guilty of misrepresentation in supplying the information required or of failing to supply this information;
- have been declared to be in serious breach of contract for failure to comply with their contractual obligations following another procurement procedure or grant award procedure financed by the Community budget.

ONLY FOR NATIONAL STATISTICAL INSTITUTES AND PUBLIC ENTITIES ELIGIBILITY AND EXCLUSION CRITERIA

The National Statistical Institutes should provide a declaration, signed by the General Director of the NSI, stating that the institution is not in any of the following situations:

- a) Being bankrupt or being wound up, having the affairs administrated by the courts, have entered into an arrangement with creditors, have suspended business activities, being the subject of proceedings concerning those matters, or being in any analogous situation arising from a similar procedure provided for in national legislation or regulations;
- b) have been convicted of an offence concerning professional conduct by a judgment which has the force of res judicata (i.e., against which no appeal is possible);
- c) being guilty of grace professional misconduct proven by any means which the contracting authority can justify;
- d) have not fulfilled obligations relating to the payment of social security contributions or the payment of taxes in accordance with the legal provisions of the country in which the NSI is established or with those of the country of the contracting authority or those of the country where the action is to take place;
- e) have been the subject of a judgment which has the force of res judicata for fraud, corruption, involvement in a criminal organisation or any other illegal activity detrimental to the Communities' financial interests;
- f) have been declared to be in serious breach of contract for failure to comply with the contractual obligations in connection with a procurement procedure or other grant award procedure financed by the community budget.

SELECTION CRITERIA

Annual accounts (private companies) / Annual budget (public entities)

Curriculum Vitae of the persons co-ordinating the action to be subsidised as well as of the suggested experts for carrying out the pilot project

AWARD CRITERIA

Quality of the proposed methodology: 60%

Pertinence with the objectives and time schedule for action: 30%

Quality of the organisation and co-ordination of the activities proposed: 10

2007

GRANT APPLICATION DOCUMENTATION

Technical annex

TECHNICAL DESCRIPTION OF ACTION

PILOT PROJECTS ON MORBIDITY STATISTICS

1. Objectives

Background

Within the Community Statistical Programme 2003-2007, the establishment of EU-wide comparable data on public health and on its determinants is the objective of the activities described under work theme 35 – Health and safety; this objective will also be adhered to in the forthcoming Community Statistical Programme 2008 to 2012. The provision of statistics on public health is closely linked to the Community Action Programme in the field of public health 2003-2008 which covers health status (including morbidity), health determinants and health resources. Health statistics are compiled on a 'gentlemen's agreement' basis mainly through decisions taken at the Eurostat Working Group on Public Health Statistics. The Statistical Programme Committee (SPC) and the Meeting of Directors of Social Statistics (DSS) are regularly informed and consulted.

A coherent set of public health statistics comprises causes of death statistics (COD), data from health interview surveys (HIS), health care statistics (CARE, expenditure and non-expenditure data) as well as morbidity statistics (i.e. incidence and prevalence of diagnosed diseases in the overall population). Within the European Statistical System (ESS) statistics on COD, HIS and CARE are already established or well advanced in their development. However, for diagnosis-specific morbidity only limited and scattered data are currently available through the ESS.

Against this background, it is Eurostat's overall aim to contribute to the establishment of an EU-wide system of consistent **diagnosis-specific morbidity statistics** (i.e. data on health as observed by medical professionals). At European level, it is planned to make diagnosis-specific morbidity statistics available by means of a shortlist. The focus is on regular data compilation for a selected set of diseases within the European Statistical System (ESS) in order to provide a general picture of diagnosis-specific morbidity at population level.

Several activities were launched towards this aim, namely the London Morbidity Seminar (2003) and the ad-Task Force Morbidity List (2003). In parallel, a project funded by DG SANCO prepared an inventory on the availability of disease-specific morbidity data sources in all EU countries³. First experiences on the compilation of morbidity statistics were gathered by the "Pilot project on morbidity statistics" (Eurostat 2004 grant action awarded to

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³ EUMIP 1 and EUMIP 2 projects, for details see references documents.

EE-DE-LT; the final report was submitted at the end of 2006). During 2006, the Morbidity Statistics Development Group (MSDG) further developed the methodological guidelines for the compilation of diagnosis-specific morbidity statistics. In line with the Statistical Programme of the Commission for the year 2007, from 2007 onwards work should concentrate on pilot data collection.

Aim of the project: pilot data compilation on diagnosis-specific morbidity statistics

The main objective of the national pilot projects is to test the feasibility of the methodological approach for data compilation as outlined in the document *Principles and guidelines for diagnosis-specific morbidity statistics* (version 6 March 2007) in the various national contexts (i.e. different health care systems, different data sources). It needs to be tested if and how reliable national estimates can be produced for a shortlist of diseases from different available sources (and combinations thereof). Wherever possible, an indication of the expected cross-country comparability should be given. Moreover, the practical testing could provide additional information which can be used to further elaborate and improve the existing set of guidelines.

The work should build on existing work undertaken by Eurostat and within the context of DG SANCO funded projects (see reference documents) and is to be carried out by the national authorities operating within the European Statistical System (ESS). The following activities are to be carried out in order to achieve the objectives (for details see *Principles and guidelines for diagnosis-specific morbidity statistics*, chapter 5).

Inventory of potential national sources for diagnosis-specific morbidity data

A listing and description of all potential national sources for diagnosis-specific morbidity data which could be used to supply data for the diseases listed in the *Diagnosis-specific morbidity - European shortlist (Version 6 March 2007)* and its requested measures (incidence, prevalence). The aim of this part of the methodological approach is to *identify* and to *describe and evaluate* the potential main national sources for diagnosis-specific morbidity statistics.

Elaboration of a methodology for producing best national estimates and pilot data collection

Based on this inventory of potential data sources, a methodology has to be elaborated how the best national estimate can be calculated (from one or several data sources). I.e. for a selected number of entries of the shortlist, available sources (main and additional sources) should be looked at and a decision has to be made on their usefulness in the process to estimate the measures required for the entry (incidence, prevalence). The emphasize is on providing the best national estimate (through a well described and valid procedure), and on its documentation (metadata). The tables for the submission of diagnosis-specific morbidity data are provided in Annex III of the *Principles and guidelines for diagnosis-specific morbidity statistics*. Documentation of the process of estimating the national measure is of utmost importance and has to be reported in the metadata.

Please note: The *inventory of main sources* should preferably cover the <u>whole shortlist</u> (or at least major parts) in order to get a complete as possible picture of available national sources for diagnosis-specific morbidity statistics. The *in-depth elaboration of a methodology for estimating incidence and/or prevalence* and the *provision of pilot data* for specific entries of

the shortlist could focus on a <u>selected number of (groups of) diseases only</u>. The rationale of selecting (groups of) diseases for the estimation process should be explained. If certain disease groups are considered to be already quite well explored in a country, it is highly desirable that the pilot project focuses on other, less explored (groups of) diseases.

It is important that the pilot data collection considers the results of former Eurostat projects as well as the numerous ongoing activities in the context of DG SANCO's "Working Party Morbidity and Mortality". For some disease groups, work on estimating incidence and prevalence is already ongoing, however, often outside the European Statistical System (ESS). In order to benefit from existing knowledge and to avoid any duplication of work, for infections diseases, the results and experiences of any former or ongoing European surveillance activities should be taken into account as well as the activities of the recently established European Centre for Disease Control (ECDC). For cancers, the work carried out by the International Agency for Research on Cancer (IARC) needs to be taken into consideration. Where – in the context of other EU / international projects or programmes such as the above mentioned – national data / estimates are already given, these data / estimates have to be evaluated with respect to their quality.

2. Expected results

It is expected that national projects deliver a set of **pilot data for (selected groups of) diseases of the shortlist** (as specified in the tables for the submission of diagnosis-specific morbidity data, chapter 7 of the document *Principles and guidelines for diagnosis-specific morbidity statistics*), **together with a detailed documentation (metadata) of the estimation process** (according to the approach outlined in chapter 5 of the document *Principles and guidelines for diagnosis-specific morbidity statistics*). As a preparatory step to the pilot data collection, the **national inventory of potential national sources** for diagnosis-specific morbidity data has to be prepared and the findings should be included in the report.

Please note: The overall **project documentation** is of utmost importance. For the inventory, the documentation of the quality of data sources is important for defining the appropriate estimation methods. During the whole estimation process, all relevant elements need to be documented in order to keep the estimation process transparent and enable an overall quality assessment of the results.

Based on the national experiences, the **final report should also contain**:

- an overall assessment of the feasibility of the proposed approach;
- suggestions and recommendations on how to improve the proposed guidelines;
- an assessment of the expected cross-country comparability of the data produced.

3. Approximate timetable

The project should last **a maximum of 18 months** after the signature of the grant agreement. The detailed implementation timetable is to be proposed by the applicant. An approximate timetable could be as follows:

- 1. Review of existing methodological materials and background documents: months 1-2
- 2. Preparation of the inventory of potential national sources for diagnosis-specific morbidity data, documentation: **months 3-4**

- 3. Elaboration of a methodology for producing best national estimates for selected diseases, preliminary estimates, documentation: **months 5-12**
- 4. Interim report: months 10-12
- 5. Final estimations and pilot data compilation, documentation: months 13-16
- 6. Final report, overall documentation and recommendations: months 17-18

(Please note that – except for duly justified cases – the eligible period shall not start at a date prior to the signature date of the grant agreement by the last party. In any case the eligible period may not start before the date of submission of the applicant's proposal).

4. Reference documents

The below listed documents provide methodological and background information. Several documents are publicly available, a link to the website is provided. Other documents are attached to this call; these documents are not yet public and should therefore not be further distributed. A number of background documents is available on request, please e-mail to the address indicated below.

Methodological information

Principles and guidelines for diagnosis-specific morbidity statistics (version 6 March 2007, attached)

Diagnosis-specific morbidity - European shortlist (Version 6 March 2007, attached)

Background material

Val Mason and Ann Bridgwood. Methods of collecting morbidity statistics. Eurostat Working Papers, Population and social conditions 3/1998/E/no.9. Available on request, please e-mail to Sabine.Gagel@ec.europa.eu.

Eurostat Morbidity Seminar (27-29 January 2003, London), information available at http://www.statistics.gov.uk/events/Eurostat_morbidity_seminar/

Ad-Task Force Morbidity List (2003): the recommendations are annexed to the document Tech-HIS/2005/04-1 - Status regarding morbidity task force and morbidity project (see below)

Tech-HIS/2005/04-1 - Status regarding morbidity task force and morbidity project: this document provides an overview on the activities as of June 2005; available in CIRCA (restricted access) http://forum.europa.eu.int/Members/irc/dsis/healthtf/library, there in Technical Group HIS - 22-23/06/2005; also available on request, please e-mail to Sabine.Gagel@ec.europa.eu.

Working Group Public Health Statistics 2006, Item 10 - Statistics on morbidity - Doc. ESTAT/F5/06/HEA/08 Activities and workprogramme; publicly available in CIRCA - http://forum.europa.eu.int/Public/irc/dsis/health/library, there in Working group 2006 - working documents.

Final report of the "Pilot project on morbidity statistics", EE-DE-LT, November 2006. Available on request, please e-mail to Sabine.Gagel@ec.europa.eu.

Morbidity related projects funded by DG SANCO, international data sources

Several projects funded by DG SANCO also deal with morbidity data and related health information. It is recommended to review the activities of DG SANCO and to investigate in how far information from projects could feed into the pilot project. All information can be found in the DG SANCO Health Information website: http://ec.europa.eu/health/ph information/information en.htm. Of particular importance are the activities of the Working Party Morbidity and Mortality and European Community Health Indicators.

For DG SANCO's Working Party on Morbidity and Mortality, additional information can be found here:

http://europa.eu.int/comm/health/ph_information/implement/wp/morbidity/morbidity_en.htm

"Building a European System of Information on Major and Chronic Diseases as a part of a European System of Information on Health", DG SANCO, Working Party Morbidity and Mortality, Luxembourg January 2004,

http://europa.eu.int/comm/health/ph_information/implement/wp/morbidity/docs/ev_2004012 0_rd03_en.pdf

European Union Morbidity Inventory Project (EUMIP 1 and EUMIP 2), information available at http://europa.eu.int/comm/health/ph_projects/monitoring_project_en.htm (projects funded by DG SANCO in 1999 and 2001).

The following are main projects which produce data and which could be considered as additional information sources:

- <u>Cancer</u>: EUNICE (European Union Network for Information on Cancer, coordinated by IARC, see below)
- <u>Alzheimer's disease and other dementias</u>: Alzheimer Europe, EUCODE (European Collaboration on Dementia, http://www.alzheimer-europe.org/)
- <u>Diabetes</u>: Diabetes Atlas if the International Diabetes Federation (IDF, http://www.eatlas.idf.org/), BIRO (Building a shared European Diabetes Information System)
- <u>Asthma and COPD</u>: ECHRS (European Community Health Respiratory Survey), ISAAC (International Study of Asthma and Allergies in childhood), IMCA (Indicators for monitoring Asthma and COPD)
- Mental disorders: The state of mental health in the European Union.

For international data sources the following should be considered for additional information:

- European Centre for Disease Prevention and Control (ECDC): http://www.ecdc.eu.int/
- International Agency for Research on Cancer (IARC): http://www.iarc.fr/

ELIGIBILITY AND EXCLUSION CRITERIA

- 1. The National Statistical Institutes should provide a declaration, signed by the General Director of the NSI, stating that the institution is not in any of the following situations:
 - a) Being bankrupt or being wound up, having the affairs administered by the courts, have entered into an arrangement with creditors, have suspended business activities, being the subject of proceedings concerning those matters, or being in any analogous situation arising from a similar procedure provided for in national legislation or regulations;
 - b) have been convicted of an offence concerning professional conduct by a judgement which has the force of res judicata (i.e., against which no appeal is possible);
 - c) being guilty of grace professional misconduct proven by any means which the contracting authority can justify;
 - d) have not fulfilled obligations relating to the payment of social security contributions or the payment of taxes in accordance with the legal provisions of the country in which the NSI is established or with those of the country of the contracting authority or those of the country where the action is to take place;
 - e) have been the subject of a judgment which has the force of res judicata for fraud, corruption, involvement in a criminal organisation or any other illegal activity detrimental to the Communities' financial interests;
 - f) have been declared to be in serious breach of contract for failure to comply with the contractual obligations in connection with a procurement procedure or other grant award procedure financed by the Community budget.

In case this declaration was already provided to Eurostat in the current year it is not necessary to send it again.

2. The other institutions should provide the same declaration as in point 1 and additionally their statute and a proof that they are the national authority responsible for the provision of the official statistics in the domain covered by the action.

Please note that several countries already receive funding for pilot projects on morbidity statistics through previous grant actions. According to the Commission rules, double financing of an action is not possible.

SELECTION CRITERIA

Applicants' funding sources and their ability to maintain activities for the duration the action as well as their skills and qualifications necessary to carry out the action will be assessed on the basis of the following information and documents:

- Curriculum Vitae of the persons (responsible) who will take part in the action.
- If applicable, letter of intent by each co-financing organisation other than the applicant.
- List of grants awarded for the last three years, limited to the same theme.

AWARD CRITERIA

The quality of the proposals submitted will be assessed on the basis of the following criteria where the percentages indicate a weighting.

- Pertinence to the objectives and time schedule of the action: 30%
- Quality of the proposed methodology: 50%
- Quality of the organisation and co-ordination of the activities proposed: 20%

2009

GRANT APPLICATION DOCUMENTATION Technical annex

TECHNICAL DESCRIPTION OF ACTION

PILOT PROJECTS ON MORBIDITY STATISTICS

1. Background

Within the Community Statistical Programme 2008-2012, the establishment of EU-wide comparable data on public health and on its determinants is the objective of the activities described under work theme 35 – Health and safety. The provision of statistics on public health is also closely linked to the Community Action Programme in the field of public health 2008-2013 which covers health status (including morbidity), health determinants and health resources. Health statistics were compiled on "gentlemen's agreement" basis mainly through decisions taken at the Eurostat Working Group (WG) on Public Health Statistics. Since 16th December 2008, the Regulation (EC) n°1338/2008 of the European Parliament and of the Council establishes a common framework for the production of community statistics on public health statistics and health and safety at work. The Statistical Programme Committee (SPC, become currently European Statistical System Committee – ESS Committee) and the Meeting of Directors of Social Statistics (DSS) are regularly informed and consulted.

A coherent set of public health statistics comprises causes of death statistics (COD), data from health interview surveys (HIS), health care statistics (CARE, expenditure and non-expenditure data) as well as morbidity statistics (i.e. incidence and prevalence of diagnosed diseases in the overall population). Within the European Statistical System (ESS) statistics on COD, HIS and CARE are already established or well advanced in their development. However, for diagnosis-specific morbidity only limited and scattered data are currently available through the ESS.

Against this background, it is Eurostat's overall aim to contribute to the establishment of an EU-wide system of consistent disease-specific morbidity statistics to be regularly reported and to form part of the routine data collection. Indeed, next to causes of death (COD) and health interview surveys (HIS), data on diagnosis-specific morbidity are considered to be

indispensable for providing a comprehensive description of the status of health of European populations by means of statistics. From 2007 onwards, diagnosis-specific morbidity statistics became (in agreement with the Member States) a new strand of European public health statistics. The overall aim is to achieve sustainable data provision on a regular basis for a selected set of diseases within the European Statistical System (ESS) to provide a general picture of diagnosis-specific morbidity at population level.

Several activities were launched towards this aim, namely the London Morbidity Seminar (2003) and the ad-Task Force Morbidity List (2003). In parallel, a project funded by DG SANCO prepared an inventory on the availability of disease-specific morbidity data sources in all EU countries⁴. First experiences on the compilation of morbidity statistics were gathered by the "Pilot project on morbidity statistics" (Eurostat 2004 grant action awarded to EE-DE-LT; the final report was submitted at the end of 2006). During 2006, the Morbidity Statistics Development Group (MSDG) further developed the methodological guidelines for the compilation of diagnosis-specific morbidity statistics.

The work on diagnosis-specific morbidity statistics is still in a development stage, i.e. a methodological approach has been proposed and first pilot data collection exercises to test the feasibility of the approach have started from 2007: 9 pilot studies have been carried out until mid 2008 within the framework of the Multi-Country Transition Facility programme (MCTF 2005) and 2 pilot projects are ongoing until the second half 2009. The analyses of the results of those projects are ongoing. In line with the Statistical Programme of the Commission for the year 2007, from 2007 onwards work concentrates on pilot data collection.

2. Aim of the project: pilot data compilation on diagnosis-specific morbidity statistics

The main objective of the national pilot projects is to test the feasibility of the methodological approach for data compilation as outlined in the document *Principles and guidelines for diagnosis-specific morbidity statistics* (version 23 April 2007) in the various national contexts (i.e. different health care systems, different data sources). It needs to be tested if and how reliable national estimates can be produced for a shortlist of diseases from different available sources (and combinations thereof). Wherever possible, an indication of the expected cross-country comparability should be given. Moreover, the practical testing could provide additional information which can be used to further elaborate and improve the existing set of guidelines.

The work should build on existing work undertaken by Eurostat and within the context of DG SANCO funded projects (see reference documents) and is to be carried out by the national authorities operating within the European Statistical System (ESS). The following activities are to be carried out in order to achieve the objectives (for details see *Principles and guidelines for diagnosis-specific morbidity statistics*, chapter 5).

3. Objectives

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

⁴ EUMIP 1 and EUMIP 2 projects, for details see references documents.

The inventory corresponds to a listing and a description of all potential national sources for diagnosis-specific morbidity data which could be used to supply data for the diseases listed in the *Diagnosis-specific morbidity - European shortlist (Version 6 March 2007)* and its requested measures (incidence, prevalence). The aim of this part of the methodological approach is to *identify* and to *describe and evaluate* the potential main national sources for diagnosis-specific morbidity statistics.

b. Elaboration of a methodology for producing best national estimates

Based on this inventory of potential data sources, a methodology has to be elaborated how the best national estimate can be calculated (from one or several data sources). I.e. for a selected number of entries of the shortlist, available sources (main and additional sources) should be looked at and a decision has to be made on their usefulness in the process to estimate the measures required for the entry (incidence, prevalence). The emphasize is on providing the best national estimate (through a well described and valid procedure), and on its documentation (metadata). The tables for the submission of diagnosis-specific morbidity data are provided in Annex III of the *Principles and guidelines for diagnosis-specific morbidity statistics*. Documentation of the process of estimating the national measure is of utmost importance and has to be reported in the metadata.

c. Pilot data collection

The proposed methodology should be tested by a pilot data collection. It is important that this data collection considers the results of former Eurostat projects. For some disease groups, work on estimating incidence and prevalence is already ongoing, however, often outside the European Statistical System (ESS). In order to benefit from existing knowledge and to avoid any duplication of work, for infections diseases, the results and experiences of any former or ongoing European surveillance activities should be taken into account as well as the activities of the European Centre for Disease Control (ECDC). For cancers, the work carried out by the International Agency for Research on Cancer (IARC) needs to be taken into consideration. Where – in the context of other EU / international projects or programmes such as the above mentioned – national data / estimates are already given, these data / estimates have to be evaluated with respect to their quality.

Please note: While the *inventory of main sources* should preferably cover the <u>whole shortlist</u> (or at least major parts) in order to get a complete as possible picture of available national sources for diagnosis-specific morbidity statistics; the *in-depth elaboration of a methodology for estimating incidence and/or prevalence* and the *provision of pilot data* for specific entries of the shortlist could focus on a <u>selected number of (groups of) diseases only</u>. The rationale of selecting (groups of) diseases for the estimation process should be explained. If certain disease groups are considered to be already quite well explored in a country, it is highly desirable that the pilot project focuses on other, less explored (groups of) diseases.

4. Expected results

It is expected that national projects deliver a set of **pilot data for (selected groups of) diseases of the shortlist** (as specified in the tables for the submission of diagnosis-specific morbidity data, chapter 7 of the document *Principles and guidelines for diagnosis-specific morbidity statistics*). A report with **detailed documentation (metadata) of the estimation process** (according to the approach outlined in chapter 5 of the document *Principles and guidelines for diagnosis-specific morbidity statistics*) will address key results and problems

encountered based on the **national inventory of potential national sources** for diagnosis-specific morbidity data.

Please note: The overall **project documentation** is of utmost importance. For the inventory, the documentation of the quality of data sources is important for defining the appropriate estimation methods. During the whole estimation process, all relevant elements need to be documented in order to keep the estimation process transparent and enable an overall quality assessment of the results.

Based on the national experiences, the **final report should also contain**:

- an overall assessment of the feasibility of the proposed approach;
- suggestions and recommendations on how to improve the proposed guidelines;
- an assessment of the expected cross-country comparability of the data produced.

5. Approximate timetable

The project should last for a maximum of 18 months after the signature of the grant agreement. The detailed implementation timetable is to be proposed by the applicant. An approximate timetable could be as follows:

- 7. Review of existing methodological materials and background documents: months 1-2
- 8. Preparation of the inventory of potential national sources for diagnosis-specific morbidity data, documentation: **months 3-4**
- 9. Elaboration of a methodology for producing best national estimates for selected diseases, preliminary estimates, documentation: **months 5-12**
- 10. Interim report: months 10-12
- 11. Pilot data compilation, final estimations and documentation: months 13-16
- 12. Final report, overall documentation and recommendations: months 17-18

(Please note that – except for duly justified cases – the eligible period shall not start at a date prior to the signature date of the grant agreement by the last party. In any case the eligible period may not start before the date of submission of the applicant's proposal).

6. Reference documents

The below listed documents provide methodological and background information. Several documents are publicly available, a link to the website is provided. A number of background documents is available on request, please e-mail to the address indicated below.

Methodological information

Principles and guidelines for diagnosis-specific morbidity statistics (version 23 April 2007) available in CIRCA: Public health statistics → in library Methodologies and data collections → Diagnosis-specific morbidity statistics

Diagnosis-specific morbidity – European shortlist (version 6 March 2007) available in CIRCA: Public health statistics → in library Methodologies and data collections → Diagnosis-specific morbidity statistics

Diagnosis-specific morbidity statistics – tables for data submission to Eurostat (pilot projects) available in CIRCA: Public health statistics → in library Methodologies and data collections → Diagnosis-specific morbidity statistics

Background material

Val Mason and Ann Bridgwood. Methods of collecting morbidity statistics. Eurostat Working Papers, Population and social conditions 3/1998/E/no.9. Available on request, please e-mail to albane.gourdol@ec.europa.eu

Eurostat Morbidity Seminar (27-29 January 2003, London), information available at http://www.statistics.gov.uk/events/Eurostat_morbidity_seminar/

Ad-Task Force Morbidity List (2003): the recommendations are annexed to the document Tech-HIS/2005/04-1 - Status regarding morbidity task force and morbidity project (see below)

Tech-HIS/2005/04-1 - Status regarding morbidity task force and morbidity project: this document provides an overview on the activities as of June 2005; available in CIRCA (restricted access) http://forum.europa.eu.int/Members/irc/dsis/healthtf/library, there in Technical Group HIS - 22-23/06/2005; also available on request, please e-mail to albane.gourdol@ec.europa.eu

Working Group Public Health Statistics 2006, Item 10 - Statistics on morbidity - Doc. ESTAT/F5/06/HEA/08 Activities and workprogramme; publicly available in CIRCA - http://forum.europa.eu.int/Public/irc/dsis/health/library, there in Working group 2006 - working documents.

Final report of the "Pilot project on morbidity statistics", EE-DE-LT, November 2006. Available on request, please e-mail to albane.gourdol@ec.europa.eu

Final reports of the pilot studies carried out in 2007-2008 in CY, CZ, EE, HU, LT, LV, MT, SI and SK within the Multi-Country Transition Facility programme. Available on request, please e-mail to albane.gourdol@ec.europa.eu

Morbidity related projects funded by DG SANCO, international data sources

Several projects funded by DG SANCO also deal with morbidity data and related health information. It is recommended to review the activities of DG SANCO and to investigate in how far information from projects could feed into the pilot project. All information can be found in the DG SANCO Health Information website: http://ec.europa.eu/health/ph_information/information_en.htm. Of particular importance are the activities of the Working Party Morbidity and Mortality and European Community Health Indicators.

For DG SANCO's Working Party on Morbidity and Mortality, additional information can be found here:

http://europa.eu.int/comm/health/ph_information/implement/wp/morbidity/morbidity_en.htm

"Building a European System of Information on Major and Chronic Diseases as a part of a European System of Information on Health", DG SANCO, Working Party Morbidity and Mortality, Luxembourg January 2004.

European Union Morbidity Inventory Project (EUMIP 1 and EUMIP 2), information available at http://europa.eu.int/comm/health/ph_projects/monitoring_project_en.htm (projects funded by DG SANCO in 1999 and 2001).

The following are main projects which produce data and which could be considered as additional information sources:

- <u>Cancer</u>: EUNICE (European Union Network for Information on Cancer, coordinated by IARC, see below)
- <u>Alzheimer's disease and other dementias</u>: Alzheimer Europe, EUCODE (European Collaboration on Dementia, http://www.alzheimer-europe.org/)
- <u>Diabetes</u>: Diabetes Atlas if the International Diabetes Federation (IDF, http://www.eatlas.idf.org/), BIRO (Building a shared European Diabetes Information System)
- <u>Asthma and COPD</u>: ECHRS (European Community Health Respiratory Survey), ISAAC (International Study of Asthma and Allergies in childhood), IMCA (Indicators for monitoring Asthma and COPD)
- <u>Mental disorders</u>: The state of mental health in the European Union.

For international data sources the following should be considered for additional information:

- European Centre for Disease Prevention and Control (ECDC): http://www.ecdc.europa.eu
- International Agency for Research on Cancer (IARC): http://www.iarc.fr/

ELIGIBILITY AND EXCLUSION CRITERIA

The applicant must be institutions that are identified as National Statistical Institutes or other authorities empowered to produce official statistics and must complete the Solemn Declaration concerning situations which would exclude the applicant from the participation in this grant award procedure provided in the application form.

(Applications submitted by intermediaries will be excluded.)

Only National Statistical Authorities who are also member of the European Statistical System can participate in this call for proposal.

Applicants will not be eligible for a grant if at the time of the award procedure they are in any of the following situations:

- they are in a state of or subject to proceedings for bankruptcy, liquidation, cessation of activity, etc;
- they have been found guilty of an offence affecting professional good standing;
- they are not up to date with social security and tax payments;

- they have been found guilty of fraud, corruption, illegal activities, etc;
- they have been declared to be in serious breach of contract for failure to comply with their contractual obligations;
- they are guilty of misrepresentation, or conflict of interests.

Please note that several countries already receive funding for pilot projects on morbidity statistics through previous grant actions. According to the Commission rules, double financing of an action is not possible. Grants may not be awarded to applicants who are, at the time of a grant award procedure, in one of the situations referred to in Articles 93 (1), 94 and 96(2)(a) of the Financial Regulation.

SELECTION CRITERIA

Applicants' funding sources and their ability to maintain activities for the duration of the action as well as their skills and qualifications necessary to carry out the action will be assessed on the basis of the following information and documents:

- Grant agreements awarded by the Commission in the last three years for actions;
- Grant applications submitted during the current year;
- Curriculum vitae of the person coordinating the action (of the staff involved into the action)
- If applicable, the letter of intent from each co-financing organisation, other than the applicant, indicating the co-financing amount.

AWARD CRITERIA

Detailed award criteria are defined in order to assess the quality of proposals against the set objectives and priorities, so that grants are awarded to the actions which maximise the overall effectiveness. Applications which have successfully passed the selection stage will be assessed on the basis of the following criteria where the percentages indicate a weighting:

- Content of the action and deliverables (description of the planned results in accordance with the aims and objectives), understanding of tasks and quality of proposed approach: 40%
- Presentation of expected results, expected impact and sustainability of the action: 30%
- Time schedule of the action (work plan) and evaluation of progress of the action: 20%
- Overall and detailed budget: applicants must ensure that the budget is relevant, appropriate, balanced and consistent in itself, between partners and with the specific objectives of the project. Budget should be distributed within partners at a minimum reasonable level, avoiding excessive fragmentation: 10%
 - (In the case of a multi-beneficiary agreement the applicants must ensure that the budget is relevant, appropriate, balanced and consistent in itself, between partners and with the specific objectives of the project. Budget should be distributed within partners at a minimum reasonable level, avoiding excessive fragmentation).