

**COMPILING A EUROPEAN-UNION WIDE INVENTORY OF
HEALTH MORBIDITY DATA – DEVELOPMENT OF AN
ELECTRONIC INVENTORY OF DATA SOURCES**

QUESTIONNAIRE

In case of any queries, please contact:

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Many thanks for completing this section:

Date: _____

Name: _____

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Please return the questionnaire to:

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1. The main *organisations that supply morbidity data* in the United Kingdom are the statistical office, like ‘The Office for National Statistics’, and the central health departments, like the ‘Department of Health’.

1a. Could you please state the main organisations in your country that supply morbidity data, including e.g. main academic public health organisations.

2. Does your country have a *unique personal identification number* or patient identifier which allows linkage of information in different data sets?

Yes No

→ If yes, please go to Question 2a → If no, please go to Question 3

2a. Please give details of how this identification number functions and the ways it is used for in regard to linkage in morbidity studies :

3. In the United Kingdom, *registration at death* is compulsory for 100% of the population. The International Classification of Diseases Codes are used to assign the cause of death.

3a. Does your country collect mortality data?

Yes No

→ If yes, please go to Question 3b → If no, please go to Question 4

3b. Is the collection of mortality data compulsory?

Yes No

3c. What proportion of mortality data is reported in your country?

3d. Please add any further explanation concerning the collection of mortality data in your country:

4. In the United Kingdom, *registration at birth* is compulsory for 100% of the population. This includes the registration of live births and stillbirths.

4a. Does your country collect births data?

Yes **No**

→ If yes, please go to Question 4b → If no, please go to Question 5

4b. Is the collection of births data collection compulsory?

Yes **No**

4c. What proportion of births data is reported in your country?

4d. Please add any further information regarding the collection of birth data in your country:

5. Cancer registration in the United Kingdom is conducted by twelve independent registries which collect, on a voluntary basis, data on new cases of cancer in their regions and submit a standard set of these registrations to the Office for National Statistics (ONS). Notification of cancer to cancer registrations is voluntary.

5a. Does your country collect cancer data?

Yes No

→ If yes, please go to Question 5b → If no, please go to Question 6

5b. Is the notification of cancer data compulsory?

Yes No

→ If yes, please go to Question 5c → If no, please go to Question 5c

5c. What proportion of cancer cases are reported in your country?

5d. Is the cancer data collected nationally, or only for one or more regions?

National Regional

→ If yes, please go to Question 5f → If no, please go to Question 5e

5e. If the cancer data is collected in only one or more regions, is it possible to use the regional data to calculate national estimates?

Yes No

→ If yes, please go to Question 5f → If no, please go to Question 5f

5f. How often does your country collect cancer data?

5g. What is the accessibility of the data, i.e. how do people get the data in terms of

- contact points or organisations
- charges / costs
- availability of computerised data
- availability via the Internet
- any restrictions or special criteria for access

5h. Please specify the way cancer data is collected in your country including information on e.g.

- registrations
- surveys
- the number of registries / surveys
- the size of the population under surveillance in respect to the national population
- the period of time of data collection
- which age-groups are included
- which cancers are included
- method of data collection,
- method of data analysis and dissemination

5i. Please list any other important publications regarding cancer data or the collection of cancer data in your country.

6. Registration of *Congenital Anomalies* in the United Kingdom is done by the National Congenital Anomaly Register run by the Office for National Statistics (ONS). Doctors and midwives notify their local authority which in turn notifies ONS of any congenital anomalies. Notification of congenital anomalies is voluntary.

6a. Does your country collect data on congenital anomalies?

Yes

No

→ If yes, please go to Question 6b

→ If no, please go to Question 7

6b. Is the notification of congenital anomaly data compulsory?

Yes

No

→ If yes, please go to Question 6c

→ If no, please go to Question 6c

6c. What proportion of congenital anomaly cases is reported in your country?

6d. Is the congenital anomaly data collected nationally, or only for one or more regions?

National

Regional

→ If yes, please go to Question 6f

→ If no, please go to Question 6e

6e. If the data is collected in only one or more regions, is it possible to use the regional data to calculate national estimates of the number of congenital anomalies?

Yes

No

→ If yes, please go to Question 6f

→ If no, please go to Question 6f

6f. How often does your country collect congenital anomaly data?

6g. What is the accessibility of the data, i.e. how do people get the data in terms of

- contact points or organisations
- charges / costs
- availability of computerised data
- availability via the Internet
- any restrictions or special criteria for access

6h. Please specify the way congenital anomaly data is collected in your country including information on e.g.

- registrations
- surveys
- the number of registries / surveys
- the size of the population under surveillance in respect to the national population
- the period of time of data collection
- which age-groups are included
- method of data collection,
- method of data analysis and dissemination

6i. Please list any other important publications regarding congenital anomaly data or the collection of congenital anomaly data in your country.

7. In the United Kingdom, there are regional *disease registers* for diseases such as diabetes and heart disease, however, there are as yet no national registers. We are initially interested in the following diseases:

- Diabetes
- Coronary Heart Disease
- Hypertension
- Stroke
- Asthma
- Musculo-Skeletal Disorders (Arthritis)
- Mental health (Psychiatric Disorders and Dementia)
- Epilepsy

7a. Do you have in your country specific disease registers?

Yes

No

→ If yes, please go to Question 7b

→ If no, please go to Question 8

7b. For what diseases does your country have disease registers ?

7c. Do the registers collect data nationally?
(Please specify for each disease)

7d. If the data is collected in only one or more regions, is it possible to use the regional data to calculate national estimates of disease prevalence and incidence? *(Please specify for each disease)*

7e. How often do the registries collect data?
(Please specify for each disease)

7f. What is the accessibility of the data, i.e. how do people get the data in terms of

- contact points or organisations
- charges / costs
- availability of computerised data
- availability via the Internet
- any restrictions or special criteria for access

(Please specify for each disease)

7g. Please specify the way the disease registers collect data in your country including information on e.g.

- registrations
- surveys
- the number of registries / surveys
- the size of the population under surveillance in respect to the national population
- the period of time of data collection
- which age-groups are included
- method of data collection,
- method of data analysis and dissemination

(Please specify for each disease)

7h. Please list any other important publications regarding disease registration in your country.

8. Notification of a *termination of a pregnancy* is compulsory in England & Wales. The Department of Health forwards their abortion notification to ONS for statistical processing and analysis of the data.

8a. Does your country collect data on termination of pregnancy?

Yes **No**

→ If yes, please go to Question 8b → If no, please go to Question 9

8b. Is the notification of a termination of pregnancy compulsory?

Yes **No**

→ If yes, please go to Question 8c → If no, please go to Question 8c

8c. What proportion of cases of termination of pregnancy is reported in your country?

8d. Is the data on termination of pregnancy collected nationally, or only for one or more regions?

National **Regional**

→ If yes, please go to Question 8f → If no, please go to Question 8e

8e. If the data is collected in only one or more regions, is it possible to use the regional data to calculate national estimates of the number of terminations of pregnancy?

Yes **No**

→ If yes, please go to Question 8f → If no, please go to Question 8f

8f. How often does your country collect data on termination of pregnancy?

-
- 8g.** What is the accessibility of the data, i.e. how do people get the data in terms of
- contact points or organisations
 - charges / costs
 - availability of computerised data
 - availability via the Internet
 - any restrictions or special criteria for access

-
- 8h.** Please specify the way data on termination of pregnancy is collected in your country including information on e.g.
- registrations
 - surveys
 - the number of registries / surveys
 - the size of the population under surveillance in respect to the national population
 - the period of time of data collection
 - which age-groups are included
 - method of data collection,
 - method of data analysis and dissemination

-
- 8i.** Please list any other important publications regarding data on termination of pregnancy or the collection of data on termination of pregnancy in your country.

9. Information about *General Practice data* in the UK comes from various sources. There is the General Practice Research Database (GPRD), the Weekly Returns Service, and the Morbidity Statistics from General Practice. GPRD is a database of anonymised medical records of over 2 million patients in over 280 GP practices in England and Wales. It represents around 4% of the population and contains information on treatment patterns and prescribing patterns. The Weekly Returns Service contains 85 practices. The main focus is on the numbers of people reporting illness. A mean weekly incidence rate for each disease and in each age group is used

to derive an annual rate. The registered population of the practices is representative of the national population. The Morbidity Statistics are statistics from General Practice from surveys of morbidity in GP practices. GPs in 60 practices who were caring for a population of nearly half a million people throughout England and Wales took part in the study. It contains information on the reasons for which people consult in general practice. Also noted were the diagnosis for each encounter.

9a. Does your country collect General Practice data?

Yes **No**

→ If yes, please go to Question 9b → If no, please go to Question 10

9b. Is the collection of General Practice data compulsory?

Yes **No**

→ If yes, please go to Question 9c → If no, please go to Question 9c

9c. Is the General Practice data collected nationally, or only for one or more regions?

National **Regional**

→ If yes, please go to Question 9e → If no, please go to Question 9d

9d. If the data is collected for only one or more regions, is it possible to use the regional data to calculate national estimates of General Practice data?

Yes **No**

→ If yes, please go to Question 9e → If no, please go to Question 9e

9e. What proportion of General Practices contribute data towards your system (if possible, please give as percentage and absolute number)?

9f. What is the size of the population coverage?

9g. How often does your country collect General Practice data?

9h. What diseases does the General Practice data include. We are initially interested in the following diseases:

- Diabetes
- Coronary Heart Disease
- Hypertension
- Stroke
- Asthma
- Musculo-Skeletal Disorders (Arthritis)
- Mental health (Psychiatric Disorder and Dementia)
- Epilepsy

9i. What is the accessibility of the data, i.e. how do people get the data in terms of

- contact points or organisations
- charges / costs
- availability of computerised data
- availability via the Internet
- any restrictions or special criteria for access

9j. Please specify the way General Practice data is collected in your country including information on e.g.

- registrations
- surveys
- the number of registries / surveys
- the size of the population under surveillance in respect to the national population
- the period of time of data collection
- which age-groups are included
- method of data collection,
- method of data analysis and dissemination

9k. Are there any routine publications in your country based on General Practice data?

Yes

No

→ If yes, please go to Question 9l

→ If no, please go to Question 9m

9l. If yes, which diseases do these publications focus on?

9m. Please list any other important publications regarding General Practice data or the collection of General Practice data in your country.

10. Information is collected about all patients *admitted to NHS hospitals* in England. A standard set is collected on all patients admitted to an NHS hospital and a subset of this data is submitted to the Department of Health. The Department of Health creates the hospital episodes statistics database which contains records on the inpatient care of all patients admitted to NHS hospitals in England. It contains information including length of stay, waiting times, and number of episodes occurring for ranges of diagnoses and operating procedures.

10a. Does your country collect hospital admissions data?

Yes

No

→ If yes, please go to Question 10b

→ If no, please go to Question 11

10b. Is the collection of hospital admissions data compulsory?

Yes

No

→ If yes, please go to Question 10c

→ If no, please go to Question 10c

10c. What proportion of hospital admissions are reported in your country?

10d. Is the hospital admissions data collected nationally or only for one or more regions?

National **Regional**

→ If yes, please go to Question 10f → If no, please go to Question 10e

10e. If the data is collected in only one or more regions, is it possible to use the regional data to calculate national estimates of the number of hospital admissions?

Yes **No**

→ If yes, please go to Question 10f → If no, please go to Question 10f

10f. Is the hospital admissions data collected on all patients or on a sample?
(If the information is collected on a sample, please specify the size of the sample)

10g. Is the information collected on each patient or on an aggregate basis?

10h. How often does your country collect hospital admissions data?

10i. What is the accessibility of the data, i.e. how do people get the data in terms of

- contact points or organisations
- charges / costs
- availability of computerised data
- availability via the Internet
- any restrictions or special criteria for access

10j. Please specify the way hospital admissions data is collected in your country including information on e.g.

- registrations
- surveys
- the number of registries / surveys
- the size of the population under surveillance in respect to the national population
- the period of time of data collection
- which age-groups are included
- method of data collection,
- method of data analysis and dissemination

10k. Are there any routine publications in your country based on hospital admissions data?

Yes **No**

→ If yes, please go to Question 10l → If no, please go to Question 10m

10l. If so, which diseases do these publications focus on? We are initially interested in the following diseases:

- Diabetes
- Coronary Heart Disease
- Hypertension
- Stroke
- Asthma
- Musculo-Skeletal Disorders (Arthritis)
- Mental health (Psychiatric Disorders and Dementia)
- Epilepsy

10m. Please list any other important publications regarding hospital admissions data or the collection of hospital admissions data in your country.

11. In the United Kingdom, there is only limited routine national collection of hospital outpatient data.

11a. Does your country collect hospital outpatient data?

Yes **No**

→ If yes, please go to Question 11b → If no, please go to Question 12

11b. Is the collection of hospital outpatient data compulsory?

Yes **No**

→ If yes, please go to Question 11c → If no, please go to Question 11c

11c. What proportion of hospital outpatient cases are reported in your country?

11d. Is the hospital outpatient data collected nationally, or only for one or more regions?

National **Regional**

→ If yes, please go to Question 11f → If no, please go to Question 11e

11e. If the data is collected in only one or more regions, is it possible to use the regional data to calculate national estimates of hospital outpatient data?

Yes **No**

→ If yes, please go to Question 11f → If no, please go to Question 11f

11f. Is the hospital outpatient data collected on all patients or on a sample?
(If the information is collected on a sample, please specify the size of the sample)

11g. Is the information collected on each patient or on an aggregate basis?

11h. How often does your country collect hospital outpatient data?

11i. What is the accessibility of the data, i.e. how do people get the data in terms of

- contact points or organisations
- charges / costs
- availability of computerised data
- availability via the Internet
- any restrictions or special criteria for access

11j. Please specify the way hospital outpatient data is collected in your country including information on e.g.

- registrations
- surveys
- the number of registries / surveys
- the size of the population under surveillance in respect to the national population
- the period of time of data collection
- which age-groups are included
- method of data collection,
- method of data analysis and dissemination

11k. Are there any routine publications in your country based on hospital outpatient data?

Yes **No**

→ If yes, please go to Question 11l → If no, please go to Question 11m

11l. If so, which diseases do these publications focus on? We are initially interested in the following diseases:

- Diabetes
- Coronary Heart Disease
- Hypertension
- Stroke

- Asthma
- Musculo-Skeletal Disorders (Arthritis)
- Mental health (Psychiatric Disorders and Dementia)
- Epilepsy

11m. Please list any other important publications regarding hospital outpatient data or the collection of hospital outpatient data in your country.

12. *Notification of communicable diseases* in the UK is made via the local government authority in which the disease is identified. Notifications are collected and processed on a weekly basis by the three national Communicable Diseases Surveillance Centres.

12a. Does your country collect data on communicable diseases?

Yes **No**

→ If yes, please go to Question 12b → If no, please go to Question 13

12b. Is the notification of communicable diseases compulsory?

Yes **No**

→ If yes, please go to Question 12c → If no, please go to Question 12c

12c. What proportion of all communicable disease notifications are reported in your country?

12d. Is the communicable diseases data collected nationally, or only for one or more regions ?

National **Regional**

→ If yes, please go to Question 12f → If no, please go to Question 12e

12e. If the data is collected in only one or more regions, is it possible to use the regional data to calculate national estimates of the number of communicable diseases?

Yes

No

→ If yes, please go to Question 12f → If no, please go to Question 12f

12f. How often does your country collect communicable disease data?

12g. What is the accessibility of the data, i.e. how do people get the data in terms of

- contact points or organisations
- charges / costs
- availability of computerised data
- availability via the Internet
- any restrictions or special criteria for access

12h. Please specify the way communicable disease data is collected in your country including information on e.g.

- registrations
- surveys
- the number of registries / surveys
- the size of the population under surveillance in respect to the national population
- the period of time of data collection
- which age-groups are included
- method of data collection,
- method of data analysis and dissemination

12i. Which diseases are included in your country under the notification of communicable diseases?

12j. Please list any other important publications regarding communicable diseases data or the collection of communicable diseases data in your country.

13. There are many surveys in the UK that give information on morbidity data and morbidity data sources. They can be separated into the following sections:

- General Health Surveys that involve a physical examination, as well as an interview, such as the health surveys for England, Wales, Scotland and Northern Ireland;
- Questionnaire based surveys with a health component, such as the General Household Survey or the Labour Force Survey in the UK;
- Disease specific surveys, such as the 'Back Pain' survey, carried out in the UK.

We are initially interested in the following diseases:

- Diabetes
- Coronary Heart Disease
- Hypertension
- Stroke
- Asthma
- Musculo-Skeletal Disorders (Arthritis)
- Mental health (Psychiatric Disorders and Dementia)
- Epilepsy

13a. Please list all relevant surveys containing morbidity data in your country, including information on:

- the number of people selected in the study (is the sample nationally representative)
- the periodicity of the study (how often is the study done)
- the selection process for the sample
- the method for choosing the study population
- the provisions made to deal with bias
- the kind of questions asked, especially regarding health data
- the definition of the health terminology used

General Health Surveys:

Questionnaire based surveys:

Disease specific surveys:

14. In the United Kingdom, there are various *epidemiological studies*, that provide information on morbidity data, e.g. the ‘British Regional Heart Survey’ and the ‘Whitehall Study’, etc.

14a. Please list all relevant epidemiological studies undertaken in your country. We are initially interested in the following diseases:

- Diabetes
- Coronary Heart Disease
- Hypertension
- Stroke
- Asthma
- Musculo-Skeletal Disorders (Arthritis)
- Mental health (Psychiatric Disorders and Dementia)
- Epilepsy

15. In the United Kingdom there are various *publications* that provide information on morbidity data and can therefore be used as morbidity data sources. Those publications are e.g. the annual reports of the Chief Medical Officers, the health statistics for England, Wales, Scotland and Northern Ireland, and periodic journals that give information on health related data.

15a. Please list all relevant health publications in your country, including information on

- the nature of the publication
- the client base
- how often the journal is being published

- the nature of the articles published
- is the information primary or secondary information

If possible, we would be very grateful if you could send us a copy of any relevant publication.

- 16.** Please show details of any other *morbidity* data source that has not been mentioned so far in the questionnaire (e.g. important websites, etc.)

- 17.** Are there any major changes planned in your country regarding the collection of morbidity statistics?

Please append any reports, publications, papers, or any other reports you feel may be of use to us. Please also let us know the names and contact details of any of your colleagues, or people working in other institutions, who may be able to help us with our study.

THANK YOU VERY MUCH FOR YOUR HELP WITH THIS QUESTIONNAIRE!

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