Summary

The main aim of the project was to start to develop an electronic inventory of the main sources of morbidity data in the different Member States. This was achieved by creating a Microsoft Access database to serve as an encyclopaedia of available data sources. Maximum value was obtained by designing a database that could be easily updated in the future to include further countries, diseases, and providers of morbidity data. Hence, the production of an electronic inventory should be seen as the first phase of an ongoing programme of work. To achieve maximum value from the project, the inventory will need to be updated and enhanced regularly.

A steering group was assembled from experienced Public Health researchers in the participating countries. This panel helped to identify one main contact in each of the Member States for the diseases and providers to be included in the first version of the electronic inventory. The project team produced a questionnaire, with the help of the members of the steering group. This was piloted, revised and sent by post or e-mail to specialists in the Member States. The questionnaire asked about the compulsory nature and frequency of data collection for a particular disease or condition. It also enquired about data accessibility and relevant publications. Reminder letters were sent to encourage questionnaire completion. The information received was supplemented through further research carried out using the Internet and publications that provided information on sources of morbidity data. The information obtained through these processes was loaded into the database and a draft version circulated for comments to the members of the steering group and to over 70 interested parties working in the field of public health. Feedback received was either used to modify the design of the database or included in the study report as a recommendation for the future.

We have identified those areas where national and international systems have been devised in an aim to standardise data collection and analysis, for example, registration of births and mortality, congenital anomalies, cerebrovascular events, and cancer. Areas where morbidity data is lacking, or the information obtained by the study is incomplete, for example, respiratory diseases, are also visibly apparent. The study found that many Member States are making efforts to standardise and document procedures within their country for the collection and dissemination of morbidity data. This project could be seen as a way of encouraging Member States to update their own morbidity inventories and keep them up to date.

Key recommendations include using the Internet to make the database easily accessible to policy makers, Public Health officials and researchers within the European Union. Ongoing commitment and resources need to be set aside to ensure that the database is continually updated and thus retains its relevance as a reference tool. Inconsistencies in data entry and the obtaining of missing data need to be addressed. Existing participation at national level in the various international initiatives could be further researched and referenced accordingly.

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