## EU projects set up a Europe-wide diabetes data network

Diabetes prevalence in Europe is expected to increase from approximately 3% of the population today to 5% over the next 15 years. Because of the increased pressure this will place on healthcare systems, it is essential to improve the effectiveness of care. Reliable data on the indicators of the population at risk of diabetes and on the process and outcomes of the care for people who already have diabetes is vital. Being able to compare the results of different countries of Europe will enable healthcare providers to make use of the best ideas and best practices of other healthcare systems and give politicians the opportunity to plan diabetes care resources. However, few European countries have developed comparable systems for measuring and monitoring the care they offer in diagnosing, treating and preventing the complications of diabetes.

Over the last few years, four major EU-sponsored collaborative projects (two complete, one almost complete and one just starting) have prepared the foundations for a comprehensive network giving access to data on risk factors for diabetes, complications and quality of care in up to 20 European countries. With participants from healthcare and academic institutions all over Europe, the projects have been supported under the Health Information strand of the European Commission's Directorate General for Health and Consumer Protection (DG SANCO).

The series of projects began in 2000–2002 with **EUDIP** (the European Diabetes Indicator Project), which established a large number of indicators to show the extent of diabetes, its morbidity and the extent of current monitoring. EUDIP developed a list of core (essential) indicators and secondary indicators. Its final report noted many differences between the types and coverage of the databases recording the indicators (some were only available in a few countries), and the great difficulties it found in obtaining comparable results.

The **EUCID** (European Core Indicators in Diabetes) project set out over 2006–2007 to collect data on the EUDIP indicators, as specifically described in the EUCID codebook, in as many countries as possible. For many indicators there was no national data, so the consortium of project partners defined a regional data set that was large enough to be trusted as representative of the national situation. Some of this data related to primary care, some to secondary care and some to both. This is noted in the report, which highlights the danger of assuming that data on any sample of the population is representative of the whole country.

## Indicators in the EUCID codebook

- Prevalence of diabetes mellitus/1,000 population
- Annual incidence of diabetes in children (0–14 years), type 1 and 2 not separated
- Annual incidence of diabetes in children (0–14 years), type 1 and 2 separated
- % of general population with BMI≥25 and BMI≥30 respectively
- % of general population with impaired fasting glucose
- % with $HbA_{1c}$ tested in last 12 months
- % of those tested with $HbA_{1c}$ >7.0%
- % with total cholesterol tested in last 12 months
- % of those tested with total cholesterol > 5 mmol/l
- % with LDL cholesterol tested in last 12 months
- % of those tested with LDL cholesterol > 2.6 mmol/l
- % with HDL cholesterol tested in last 12 months
- % of those tested with HDL cholesterol < 1.0 mmol/l for men and < 1.25 mmol/l for women
- % with triglycerides tested in last 12 months
- % of those tested with triglycerides > 2.3 mmol/l
- % with microalbuminuria (and % with proteinuria if persistent proteinuria exists) tested in the last 12 months
- % of those tested with abnormal albuminuria or proteinuria in the last 12 months
- % with blood pressure measured in last 12 months
- % of those tested with blood pressure > 140/90 mmHg in last 12 months
- % with BMI measured
- % of those measured with BMI ≥ 25 kg/m2
- % of those measured with BMI ≥ 30 kg/m2
- % current smokers in diabetic population
- % with fundus inspection in last 12 months
- % of those tested with proliferate retinopathy in last 12 months
- % of those inspected and diagnosed with proliferative retinopathy who received laser treatment < 3 months after diagnosis of proliferative retinopathy
- % of blindness caused by diabetes (core indicator)
- % with serum creatinin tested in last 12 months
- % of those tested with creatinin who has End Stage Renal Failure (ESRF) in last 12 months
- Annual incidence of dialysis and/or transplantation (renal replacement therapy) per 100,000 diabetic population (core indicator)
- Prevalence (stock) of dialysis/transplantation per 100,000 diabetic population (core indicator)
- Annual incidence of stroke per 100,000 diabetic population
- Annual incidence of any myocardial infarction (MI) per 100,000 diabetic population
- Annual incidence of major amputations (major = above ankle – not inside!) per 100,000 diabetic population
- Annual death rate in patients who have as primary or any cause of death diabetes mellitus/100,000 general population, adjusted for European Standard Population (core indicator) OR annual death rate in the general population from all causes/100,000 general population, by age bands

(See appendix 3 of the EUCID report for further information.)

The project partners, which are public health institutes, hospitals, university medical schools and diabetes units from the 20 participating countries, coordinated by the Dutch Institute of Health Care Improvement, collected and provided data to the EUCID database. EUCID now has access to data on 35 indicators from these countries; some of which indicate processes used (eg frequency of blood pressure measurement) and some indicate outcomes (eg incidence of blindness). Because of the varying age structure of the population in different countries, data was collected in age bands wherever possible to enable comparison between countries.

***European countries included in the EUCID project***

Picture courtesy of EUCID

*Countries contributing data were: Austria, Belgium, Cyprus, Denmark, England (considered as a country for the purposes of analysis due to separate systems within the UK), Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Poland, Portugal, Romania, Scotland (considered as a country for the purposes of analysis due to separate systems within the UK), Spain, Sweden, the Netherlands, Turkey*

Striking differences appear in the number of countries able to provide data even on the eight core indicators. While 15 countries (out of 20) had data on the prevalence of diabetes, and 13–14 could provide data on the proportion of the general population who are overweight or obese, only four countries could report the incidence of blindness related to diabetes. The prevalence of diabetes ranged from 2.6% in Finland to 7.6% in Cyprus. Among the process indicators, $HbA_{1c}$ was measured once a year for 99% of people with diabetes in France, Belgium and the Netherlands, but for only 51% in Ireland.

Complication rates vary very significantly too – eg the incidence of diabetes-related amputation was 78 per 100,000 in Scotland compared with 574 in Spain. All these differences are evidence of the essential need for this sort of measuring, recording and sharing – which is the aim of the Changing Diabetes Barometer.

The **BIRO** Project (Best Information through Regional Outcomes; 2005–2008) is a feasibility study to build a European online system for exchange of standardised regional data on diabetes care. Led by the University of Perugia (Italy), BIRO has five partner organisations contributing data from regional databases, and three of its partners are universities or ministries from recently-joined EU member states (Romania, Malta and Cyprus). The software system developed by the project enables regional databases to be questioned and to provide standard reports. Users – who may be healthcare professionals, policy-makers or patient organisations – can obtain information on diabetes care in the participating regions, but no individual data leaves its own regional database.

***Next steps***

The work of the EUCID and BIRO projects is now coming together into a new project with very exciting prospects for diabetes care monitoring in Europe. **EUBIROD** (European Best Indicators for Regional Outcomes of Diabetes, 2008–2010) will extend the number of regions to 20. It aims to set up a sustainable European Diabetes Register through the coordination of existing national or regional frameworks. The BIRO software, now validated, will link the best database for each country, and the organisations supporting them are also being asked to invite other regional centres to participate. It is expected that perhaps 80 regional databases will be linked by the end of the project. EUBIROD will include all the indicators gathered by EUCID. Again, only summary tables will be collected by the central software engine, and all data stays in its own regional database, but the central engine can question the data in any of the databases.

Starting with the definition of what indicators should be recorded in order to build up a picture of diabetes care and how well it is performing, the project series has evaluated the presently available information and developed the software to enable databases throughout 20 countries to be questioned. Not only will this enable extensive epidemiological research on diabetes, but it will also create one of the largest data networks in the world in which healthcare professionals and policy-makers can question reasons for differences in outcomes and learn from the achievements and best practices of other countries.

The final report of EUCID can be downloaded at
http://www.eucid.eu/eucid/home.do