

Subject:

A novel standard to support information delivery for the fulfilment of IDF policy in Europe: results of the EU DG SANCO funded BIRO project

Abstract:

Aim. The Report on the Status of Health in the European Union confirms that information on diabetes is heterogeneous, fragmented and still relatively unreliable across the EU. The increasing prevalence of diabetes calls for new forms of collaboration that would ensure timely and broad data collection. Aim of the project is to build a European information system for diabetes through the structured use, the improvement and the permanent connection of regional diabetes registers addressed by the public health project "Best Information through Regional Outcomes" (BIRO) started in December 2005.

Methods. In 40 months, representatives from seven European countries (Austria, Cyprus, Italy, Malta, Norway, Rumania and Scotland) completed the following tasks: clinical review, definition of a diabetes data dictionary, privacy impact assessment, and development of fully operational software featuring the following components: database and statistical engines, communication software, and a dedicated web portal.

Results. Clinical review allowed the definition of N=54 target evidence-based parameters/indicators to be directly estimated from diabetes registers. The required common dataset included N=45 patient items and N=22 clinical site descriptors. An XML data dictionary has been designed to include all definitions and coding. A BIRO export has been defined to load standardized data in a Postgres database. The report template includes as sections: demographic characteristics, clinical characteristics, health system, population, and risk adjusted indicators. Privacy impact assessment has been carried out to identify the best architecture for the BIRO information system. Two-level R statistical routines have been developed to produce a standardized report for each local register, and to deploy a set of de-identified aggregate tables that are sent to a central server. Cumulative data is loaded in a central Postgres database and further processed to deliver the global report through a central engine. Results are uploaded to a EU web portal repository every 6 months. BIRO software is released under the GPL license.

Conclusion. The BIRO project sets new standards for public health information systems through an innovative architecture for data exchange and automated delivery of standardized diabetes indicators. Its sequel "EUBIROD", started in september 2008 and co-funded by DG-SANCO, will apply the system in 20 countries. Complete reports are available at <http://www.biro-project.eu>.

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