Health Information Strand BIRO: 2005 - 2008 EUBIROD: 2008 - 2010



EUropean Best Information through Regional Outcomes in Diabetes

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European Public Health Projects

DG Health and Consumer Protection

The BIRO project

"Best Information through Regional Outcomes" (B.I.R.O.) is a three year Public Health project started on 1st December 2005 with funds provided by DG-SANCO, Health Information Strand, European Commission.

The Consortium includes seven partners from academic and governmental institutions sharing extensive experience in diabetes research, policy and management and a genuine enthusiasm for European health policy.

The project aims at providing the infrastructure for an *ad hoc*, evidence and population-based information system to be used on a routine basis.

Objectives

The main objective is to build a European model for standardized data exchange to regularly monitor, update and disseminate evidence on the application of best practice guidelines in diabetes care.

To accomplish this task, we propose the following:

- ◆A systems approach to make best use of routine collection of health outcomes
- ◆A way to explore regional information systems and disease registers
- ◆A methodology to compile European reports directly from regional participation.

Introducing EUBIROD

Building upon the collaboration between the projects BIRO and EUCID, a new Consortium has been formed to establish a permanent and sustainable European Diabetes register: EUBIROD.

Through the coordination of existing national/regional initiatives and the systematic use of the BIRO technology, the system will be able to respond to the Conclusions of the EU Council for the systematic monitoring of diabetes complications and outcomes across Europe.

EUBIROD proposes an action to implement, extend, and customize the application of the BIRO technology in at least 20 European Member States. Participants will be connected through a system that will safely collect aggregated data and produce systematic EU reports of diabetes indicators.

Activities

EUBIROD is planning to actively involve national/regional networks in the collection of diabetes data through the following activities:

- Data collection across 20 countries based on the BIRO technology to ensure full respect of privacy and security
- Epidemiological analysis allowing the routine delivery of standardized indicators
- Technological transfer of a toolbox that will facilitate the adoption of standards and connection between centers
- Dissemination and training "on field" through the activity of a newly created "BIRO academy"
- Evaluation of the system through the participation of the international indipendent evaluators.

Watch this space!

The B.I.R.O. website is easy to reach for most recent updates, newsletter and links to all major activities in the field of diabetes, including the forthcoming startup of the EUBIROD project. Anyone interested in our activities is invited to join, subscribing the B.I.R.O. Forum to share our challenge for innovative solutions in public health.

Results 2006 - 2007

Target Indicators

<u>CLINICAL REVIEW</u>: a systematic review of the scientific literature has identified all basic data components for the development of the BIRO. The report provides an up-to-date definition of all data items and a shortlist of target indicators split by categories: Epidemiology, Structural Quality, Process Quality, Intermediate and Terminal Outcomes.

<u>REPORTS TEMPLATE</u>: a common structure for diabetes reports that can be automatically generated by BIRO, defined on the basis of the actual feasibility of computation. The report, providing full specification of tabular and graphical outputs, represents the main reference for the application of statistical procedures.

Data Model

<u>COMMON DATASET</u>: a common dataset that can be rapidly extracted by all members of the Consortium to feed the statistical engine, resulting from the review of database systems in place in participating regions. Precise specifications are provided for each data item including clinical measurements, intermediate and terminal outcomes at the individual level, and characteristics of the health system.

<u>DATA DICTIONARY</u>: basic and derived data components have been compiled into a common data dictionary that serves as a reference for the entire BIRO data model. The structure of the Data Dictionary, based on international standards, adds flexibility to the dataset, allowing continuous updating until the end of the project, and beyond.

<u>XML SCHEMA</u>: automation of the use of both the common dataset and entire data dictionary is guaranteed through the specification of an *ad hoc* XML Schema. The "BIRO data exchange format" will be used by each participating partner to export and submit validated data to the statistical engine.

PRIVACY IMPACT ASSESSMENT: a review of the literature on privacy protection in relation to the adoption of BIRO has determined the following legal implications: 1) use within a single region complies with both national and European directives; 2) data exchange at the international level may be hampered by inappropriate definition of the overall architecture. A modified Delphi panel has identified the following best architecture among three candidate ones previously outlined: a) records aggregated by group of patients; b) stratification by service centre and/or multidimensional patterns allowed; c) date fields approximated to months; d) measurements averaged over time; e) pseudonym used for service centres; f) data transmission prompted by authorized administrators of local registers; g) central database of aggregated data and web portal maintained by the Coordinating Centre.

Coordination

1st PROGRESS REPORT: the Coordinating Centre has successfully delivered the 1st Executive and Technical Implementation Reports to the European Commission at the end of 2006. DG-SANCO has positively evaluated the Consortium achievements.

 $\underline{\mathsf{1}}^{\operatorname{st}}$ EVALUATION REPORT: international clinical experts have been involved as independent evaluators to provide valuable advise on the following aspects: completeness of the clinical review, ability to monitor diabetes in all its components, effectiveness of the dissemination strategy.

Expected Deliverables 2008

Database, Statistical and Communication Software, Automation of the Web Portal,1st BIRO Diabetes Report, Final Meeting

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EUBIROD Consortium

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Supporting Institutions:

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Norwegian Centre for Quality Improvement in primary Health Care (NOKLUS)

Norvegian Diabetes Registry for Adults

B.I.R.O. Coordination Centre

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