# The EUBIROD project: A Shared Evidence-based Diabetes Information System for Europe

Thank you. I am honoured to present the results of the project "European Best Information through Regional Outcomes", co-funded by DG-SANCO, European Commission, in the framework of the Public Health Program, Health Information Strand.

I will describe the rationale of EUBIROD project in the context of the EU resolution on diabetes passed in March this year.

**[SLIDE 2 – Policy Goals]**

The EU Parliament, in point 4, "Calls on the Commission to draw up common, standardised criteria and methods for data collection on diabetes, and, in collaboration with the Member States, to coordinate, collect, register, monitor and manage comprehensive epidemiological data on diabetes, and economic data on the direct and indirect costs of diabetes prevention and management" .

As highlighted yesterday in the plenary, these needs did not just arise overnight, but the European Commission, our Consortium, and other fundamental initiatives have been uninterruptedly conducted for many years. Two projects, EUDIP and EUCID, were funded to define EU Diabetes Indicators in the early 2000s, and a following one, started in 2005 and ended in 2009, Best Information through Regional Outcomes (BIRO), worked out a solution to publish them on a regular basis.

The basic, fundamental principle of this system was that information on diabetes already existed in a fairly standardized format. However, to be fully exploited, such potential required **coordination** at EU level, building on **mutual trust** and **ensuring proper respect** for data ownership and data protection **long term**.

**[SLIDE 3 – Objectives ]**

The EUBIROD Consortium signed its agreement with the European Commission on 19th August 2008 to "aim at establishing a European Diabetes Register through the extension of the BIRO network and the use of related technology" .

At that time, a prototype of the **BIRO** system already existed, representing the basis for the creation of a transnational "Shared Evidence-Based Diabetes Information System".

The EUBIROD project was co-funded by DG-SANCO to operate from September 2009 through to March 2012. Its main output was a fully working tool, implemented on the basis of the existing BIRO model, which shall be used to collect data and deliver indicators from twenty-one countries.

The EUBIROD project has then proceeded through an innovative workplan of what could be broadly defined as "public health intelligence".

**[SLIDE 4 – Our vision]**

Central to the EUBIROD vision was a common understanding that innovative solutions are needed to overcome challenges in the organization, access, continuous update and regular maintenance of complex systems of indicators at an international level. This is well explained at the official project website: www.eubirod.eu.

The approach of the project can be summarized by few fundamental principles.

A shared diabetes information system needs to be fully documented and open to anyone wishing to join. It requires **a community** to contribute with reliable information, including institutions, health professionals, public/private entities, and above all, needs the full support of **citizens and people with diabetes**.

In the IT context, such open philosophy is well represented by what is known as "open source software": programs are not usually realized as business products, but they are as free as language, done to fulfil specific objectives, such as conducting a well defined public health project.

The advantages of this approach under different conditions, such as linking data from developed and developing countries, are entirely evident. By the way, open source software can be available at no cost but require proper training. For this reason, EUBIROD involved dissemination activities coordinated by a targeted **"BIRO Academy"**.

A diabetes information system must be also independent from the industry, as it must ensure proper use of public funding and publication of health information beyond any possible doubt on the credibility of information.

Furthermore, information must be rock solid from the point of view of respect for privacy. EUBIROD implemented the fundamental principle of "**privacy by design**", which is an essential element in the secondary use of health data, as highlighted by the recent activities of the European Commission, and more recently, the OECD.

Finally, few technical aspects are needed to realize the whole model. A

**distributed database, more efficient** because it avoids storing/processing huge amounts of data in one place, and by doing so **preserves the original data ownership**, which in turn guarantees **data quality. In EUBIROD, the same** clinician **involved in the data collection can directly control and correct** the data elements at the basis of diabetes indicators.

**Sound statistical procedures including risk-adjustment** methods, shall be applied in any case, to help tackling selection bias and delivering standardized comparisons. **A common report template** shoult take into account **multiple dimensions**, including structures, processes and outcomes.

How were these principles realized in practice in EUBIROD?

**[SLIDE 5 – Common, standardized criteria]**

In the upper portion of this slides there are **inputs. Common**, standardized criteria were used to collect data directly supplied by the users – in our case, mainly regional diabetes registers. These are not limited to a dataset with a common format – in our case called "merge table", but include fundamental accessory datasets, such as the **"data source profile"** where we collect information on system elements such as the centre workforce, **the activity table**, where we collect data on the status of the subjects included in the register, and the **regional data on the population**.

These elements, all together, help defining a **progressively reliable** set of denominators that can be used to inform public health policy.

In the lower portion of the slides there are **EUBIROD outputs.** The BIRO information system automatically delivers a total of **seventy-nine** indicators, including risk factors, structures, processes, population-based and disease-oriented intermediate and terminal outcomes.

All data standards are continuously evolving and made available on the EUBIROD website.

How is the transition from **inputs to outputs** realized in EUBIROD?

## [SLIDE 6 – Methods for data collection in diabetes]

Here is the technology known as **"the BIRO System"**.

Diabetes registers may be thought as different fruits: some are population-based, others are driven by disease management programs, and so on. A shared diabetes information system can only start from the existing mix of apples and oranges. Through a common data dictionary we discard the heterogeneity and define a common standard that resides on site, the BIRO database. Such database is processed locally by the Statistical Engine that delivers a local report and creates aggregate tables. These tables, which we call "**statistical objects**", are specifically designed to deliver the desired set of diabetes indicators. All data are transmitted to a central server where a new statistical engine **(the central engine**) used to create a global report.

The entire scheme of the report and diabetes indicators is governed by the same rules through a template that ensure consistency of the local and global reports.

## [SLIDE 7 – Privacy by Design]

One of the strongest point in the realization of the BIRO System was privacy enhancement, realized through an architecture identified by a novel method of Privacy Impact Assessment (PIA)[15]. A paper published on the Journal of Medical Ethics shows how such design ensures the full respect of the EU Data Protection Directive by design without hampering the information content of diabetes indicators.

EUBIROD extends this concept through a novel method of "Privacy Performance Assessment" that allows measuring the level of implementation of privacy principles/norms as well as identifying the key areas of concern requiring targeted action at regional, national and European level. The results of this experience will be published in May on the European Journal of Public Health.

**[SLIDE 10 – Comprehensive epidemiological data]**

The latest EUBIROD report included data for 2010 from nineteen participating diabetes registers: Healthgate Styria (Austria), IPH Survey Belgium, the Diabetes Registers of Croatia, Larnaca (Cyprus), Rheinland-Pfalz (Germany), GPMSSP Hungary, Tallaght (Ireland), Umbria/SID (Italy), Latvia, Administrative/Pediatric Data Luxembourg, Mater Dei (Malta), West Friesland (the Netherlands), the Diabetes Register of Norway, Silesia (Poland), Bucharest (Romania), DARTS Tayside (Scotland), the Type 1 Childhood Diabetes Register of Slovenia, IDIBAPS (Spain), Skaraborg (Sweden). The details of participating institutions are available on the EUBIROD website[16].

The total number of patients collected in only 13 days was 199,902. This is only an illustration of what could be realized by a system that now can progressively expand its geographical coverage. The EUBIROD report is currently being checked by partners and will be soon published online and in international journals.

.

## REFERENCES

1. BIRO Consortium. Best information through regional outcomes: a shared European diabetes information system for policy and practice, Università di Perugia, Perugia, Italia, Available at: http://www.biro-project.eu/documents/downloads/D14_4_BIRO_Monograph.pdf (31 January 2012, date last accessed).
2. Di Iorio CT, Carinci F, Azzopardi J *et al.* Privacy impact assessment in the design of transnational public health information systems: the BIRO project. Journal of Medical Ethics 2009; 35(12):753-61.
3. EUBIROD Consortium, EUropean Best Information through Regional Outcomes in Diabetes, Università di Perugia, Perugia, Italia, Available at: **http://www.eubirod.eu/** (31 January 2012, date last accessed)
4. C.T.Di Iorio, F.Carinci, M.Brillante, J.Azzopardi, P.Beck, N.Bratina, S.G.Cunningham, C.De Beaufort, N.Debacker, P.Jarosz-Chobot, M.Jecht, U.Lindblad, T.Moulton, Ž.Metelko, A.Nagy, G.Olympios, S.Pruna, M.Røder, S.Skeie, F.Storms, and M.Massi Benedetti, Cross-border flow of health information: is "privacy by design" enough? Privacy performance assessment in EUBIROD, European Journal of Public Health, In Press, May 2012.