



High Level Conference  
"EU Health Programmes:  
results and future perspectives"  
Brussels, 3 May 2012

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

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**Technical Coordinator**

**European Best Information through  
Regional Outcomes in Diabetes (EUBIROD)  
(Project Leader: Prof.M.Massi Benedetti, Un.Perugia, ITALY)**



# Policy Goals

## ***EU Parliament Resolution on Diabetes (14 March 2012):***

*“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**”*



# Objectives

<http://www.eubiroad.eu>

“EUBIROD aims at establishing a European Diabetes Register through the extension of the BIRO network and the use of related technology”

*EC Grant Agreement 2007115 EUBIROD, Brussels, 19/8/2008*

**DG-SANCO Health Information**  
**EC Contribution (60%): 1,114,117.71€**  
**Duration: 42 months**  
**Total N.Participants: 26**  
**N.Countries: 21**



# Our Vision

<http://www.eubirod.eu>

“Complex systems of health indicators require access to different sources, continuous update and regular maintenance. Our vision is to create sustainable solutions for public information in ways never done before, in Europe and beyond”  
([www.eubirod.eu](http://www.eubirod.eu), February 2009)

**Shared = Owned by a Community: Anyone can Join**  
**Open Source = Free to Modify and Use, Widely distributable**  
**Industry Independent = Public**  
**Privacy by Design = Legally Viable**  
**Distributed = Efficient and Sustainable**  
**Standardized = Evidence-based**  
**Risk Adjusted = Statistically Robust**  
**Multidimensional = Policy Relevant**

# “..common, standardized criteria...”

<http://www.eubirod.eu/biroDataStandards.htm>

## User supplied Datasets

Source Profile (Structure, Items, Privacy)  
Merge Table (Multiple Episodes)  
Activity Table (Master Index)  
Population Table (Region)  
Diabetic Population Table (Region)

## BIRO Indicators (N=79)

Clinical Characteristics: Risk Factors (N=19)  
Health System: Structures, Processes (N=20)  
Population: Vital Statistics (N=3)  
Risk Adjusted: Outcomes (N=31)  
Pediatric Section (N=6)

## BIRO Data Standards

**EUBIROD** European Best Information through Regional Outcomes in Diabetes

Home | News | BIRO Data Standards | Project | The BIRO Academy | The BIRO Web Portal | Publications | Restricted Area | Links | Contacts

Download BIRO Definitions as a pdf Document (S Cunningham) September 2011

1. The BIRO Common Dataset

Ref.	BIRO Name	Description	Data Type	Enumerated Values/ Measurement Units
BP0001	PAT_ID	Patient ID	String(12)	
BP0002	DS_ID	Data Source ID	String(10)	
BP0003	TYPE_DM	Type Of Diabetes	Enumerated	1=Type 1 2=Type 2 3=Other
BP0004	SEX	Sex	Enumerated	1=Male 2=Female
BP0005	DOB	Date of Birth	Date/Time	
BP0006	DT_DIAG	Date of Diagnosis	Date/Time	
BP0007	EPI_DATE	Episode Date	Date/Time	
BP0008	SMOK_STAT	Smoking Status	Enumerated	1=Current Smoker 2=Non-Smoker 3=Ex-smoker
BP0009	CIGS_DAY	Cigarettes per day	Integer	
BP0010	ALCOHOL	Alcohol Intake	Integer	g/week g/day
BP0011	WEIGHT	Weight	Real	kg
BP0012	HEIGHT	Height	Real	m cm
BP0013	BMI	Body Mass Index	Real	
BP0014	SBP	Systolic Blood Pressure	Integer	mmHg
BP0015	DBP	Diastolic Blood Pressure	Integer	mmHg

Final EUBIROD Meeting to be held in Larnaca, Cyprus 24-25 February 2012

Third EUBIROD Annual Meeting [See here](#)

Commissioner J.Dalli addresses the audience at the EUBIROD 2011 Meeting, 22-25th January 2011 [read more](#)

EUBIROD methods presented at EUPHA, Amsterdam, 10-13th November 2010 [read more](#)

BIRO and EUBIROD podium presentation at the Academy Health Annual Research Meeting, Boston, USA, 29th June 2010 [read more](#)

Special BIRO Academy Meeting held in Rome 4-5 June 2010 [read more](#)

## QUESTION 1

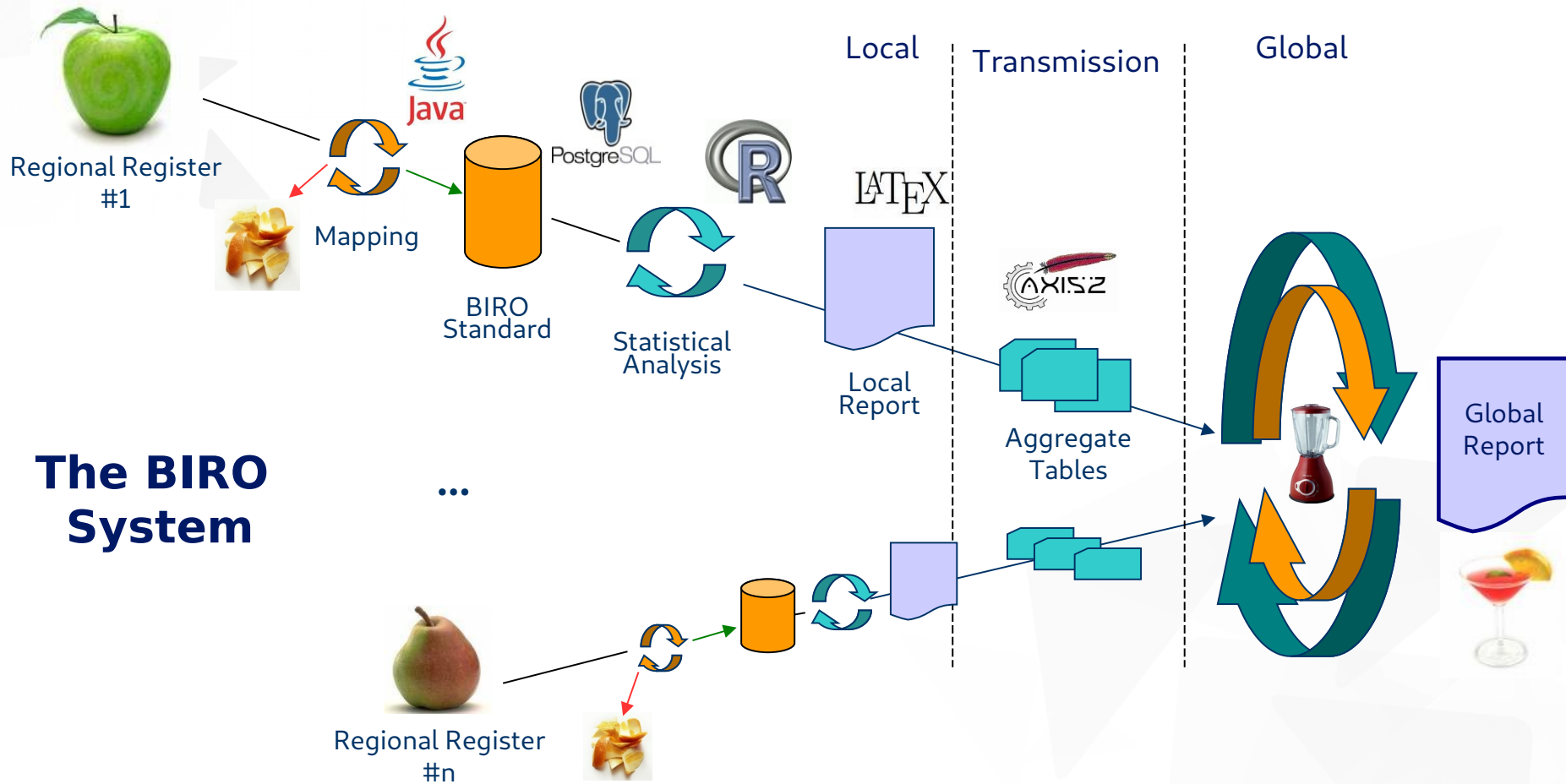
### How does your project contribute to the measurable health effects in the population?

- ◆ Diabetes is a top health priority on a global scale
- ◆ Despite of a massive amount of scientific literature, only three studies out of a total of over 1,500 compared quality across countries (IDF Atlas, 4<sup>th</sup> Edition)
- ◆ Although the OECD identified N=9 diabetes indicators, only N=2 were actually computed (Annual Eye Examination, Amputation Rates)
- ◆ EUBIROD has been specifically designed to solve this problem through the automatic computation of N=79 indicators across the European Union



# “..methods for data collection on diabetes..”

[http://www.eubirod.eu/images/eubirod\\_homepage\\_mainfigure\\_explained.png](http://www.eubirod.eu/images/eubirod_homepage_mainfigure_explained.png)



# Privacy by Design (EU Data Directive)

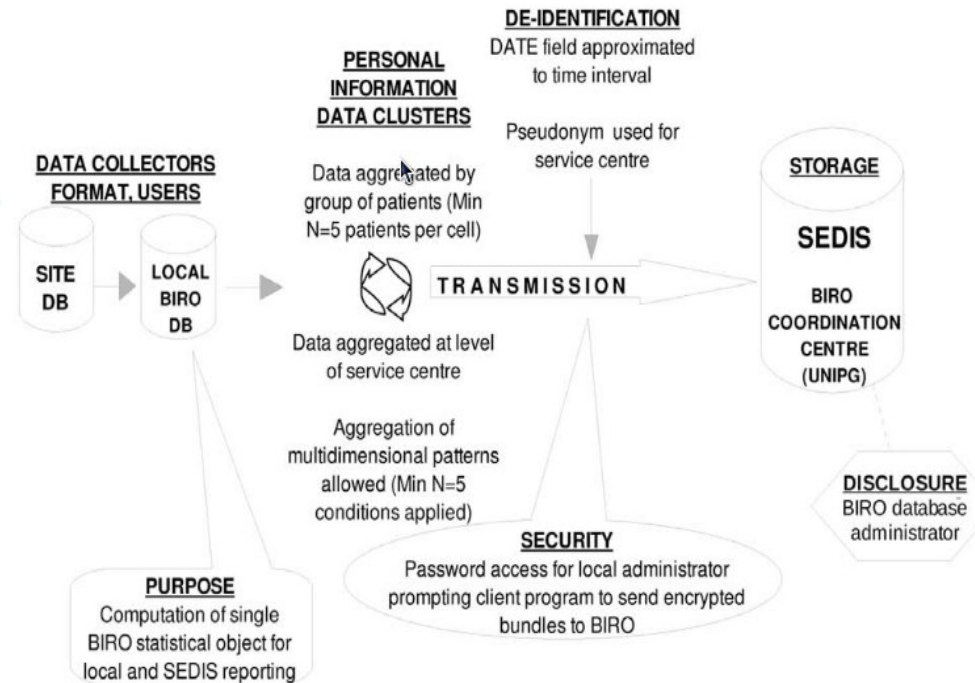
DI IORIO CT et al, J Med Ethics. 2009 Dec;35(12):753-61

Law, ethics and medicine

## Privacy impact assessment in the design of transnational public health information systems: the BIRO project

C T Di Iorio,<sup>1</sup> F Carinci,<sup>1</sup> J Azzopardi,<sup>2</sup> V Baglioni,<sup>3</sup> P Beck,<sup>4</sup> S Cunningham,<sup>5</sup> A Evripidou,<sup>6</sup> G Leese,<sup>7</sup> K F Loevaas,<sup>8</sup> G Olympios,<sup>6</sup> M Orsini Federici,<sup>3</sup> S Pruna,<sup>9</sup> P Palladino,<sup>10</sup> S Skeie,<sup>8</sup> P Taverner,<sup>8</sup> V Traynor,<sup>6</sup> M Massi Benedetti<sup>3</sup>

## Result of the BIRO Delphi panel: best alternative identified to balance privacy protection and information content





## QUESTION 2

# How does your project contribute to growth and jobs in Europe? (1)

- ◆ BIRO is a **multidisciplinary collaboration** and a **spinoff of practical action** involving researchers (epidemiologists, statisticians, informaticians), health professionals (nurses, clinicians), policy makers and citizens.
- ◆ Through the project, the **Cyprus Ministry of Health** launched the diabetes data collection by **opening the first diabetes clinic** in Larnaca, now using BIRO for **clinical audit in the region**. Two highly productive BIRO/EUBIROD meetings were held in Larnaca, with the generous support of the Cyprus Diabetes Association.
- ◆ In a time of financial crisis, the choice of **investing in health systems** (see **WHO Europe Tallinn Charter**) can invert the trend of linear budget cuts. EUBIROD offers a practical experience of how new approaches to using information for policy, by involving the whole community - from health professionals to health information specialists - can create new jobs and optimize the delivery of health services to European citizens.

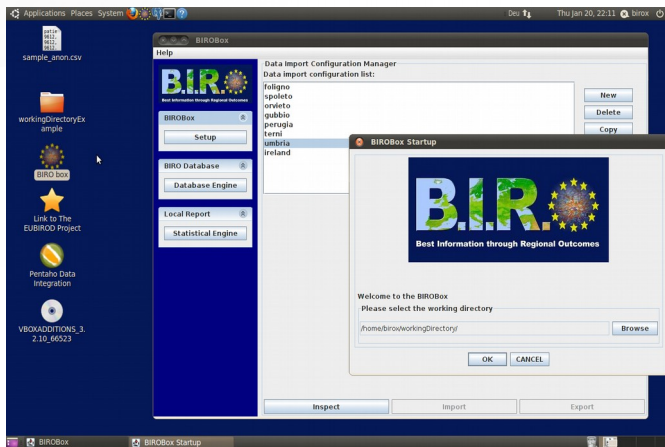
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**“..collect, register, monitor, manage..”**

<http://www.eubirod.eu/academy/software/software.html>

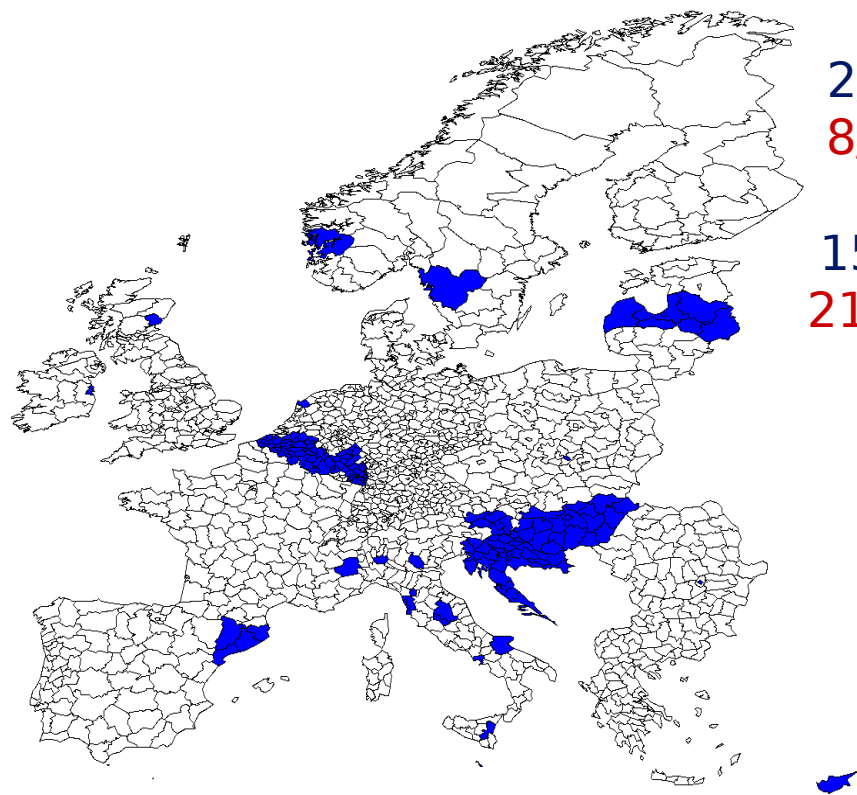


The **BIRO System** is an open source suite of integrated software tools distributed as a complete Linux operating system running on Virtual Machine: **BIROX**. Runs on any platform (Windows, Linux, MacOS) = *no need to change the setup of the local environment!*

**BIROBox** is the Graphical User Interface. **Database Engine** transforms local definitions into the European BIRO format and loads data in the local BIRO Database; **Statistical Engine** processes the local BIRO Database and computes European BIRO Indicators; **Communication Software** sends data to the European server; **Central Engine** compiles results from multiple sources

# ***“..comprehensive epidemiological data..”***

EUBIROD Diabetes Report, YEAR 2010 – N=199,902

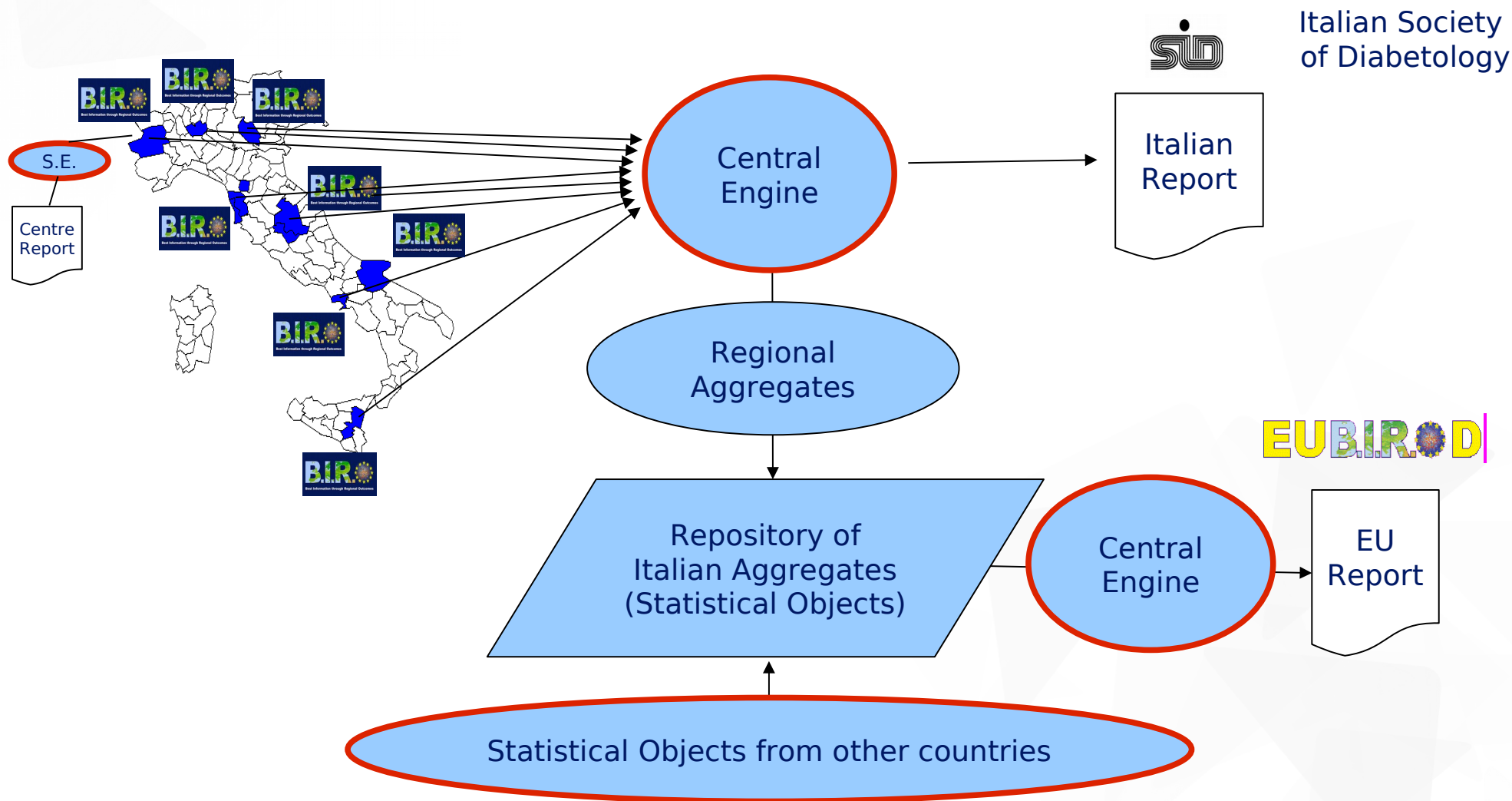


23/12/2011: Start Evaluation Report 2009  
10<sup>th</sup> January 2012: Evaluation closed  
2/2/2012: New BIRO Release 2.1.11 – Major fixes  
**8/2/2012: New BIRO Release 2.1.12 – Minor fixes**  
9/2/2012: NEW USER! Latvia downloads BIROX  
15/2/2012: Collection of statistical objects closed  
**21/2/2012: EU Report available (N=79 indicators)**

**13** Days from Software Release  
to Online Publication of the results !  
[Previously: 52 days (8/2011), 60 days (1/11)]

# How EUBIROD works: country example

ITALY: BIRO installed in N=8 centres  
DATABASES OF INDIVIDUAL RECORDS STAY WITH  
THE ORIGINAL DATA CUSTODIAN





# Multivariate Risk Adjustment

(AHRQ Health Care Quality Indicators)

Risk adjustment model (in each region)

$$Y(\%) = \beta_0 + \beta_1(\text{females}) + \beta_2(\text{age\_class1}) + \dots + \beta_k(\text{age\_class4})$$

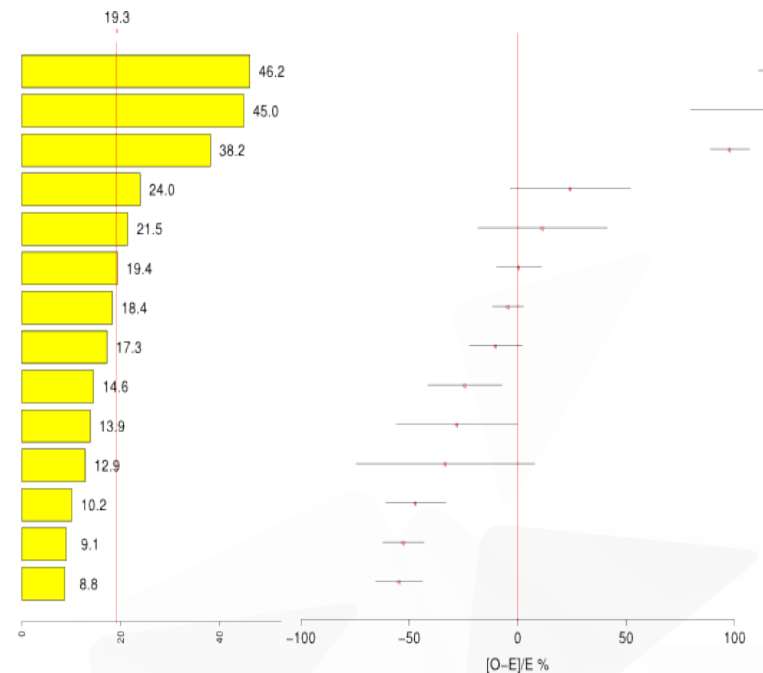


Source unit

$$Y_i \text{ exp} = \beta_0 + \beta_1(\text{females}) + \beta_2(\text{age\_class1}) + \dots + \beta_k(\text{age\_class4})$$

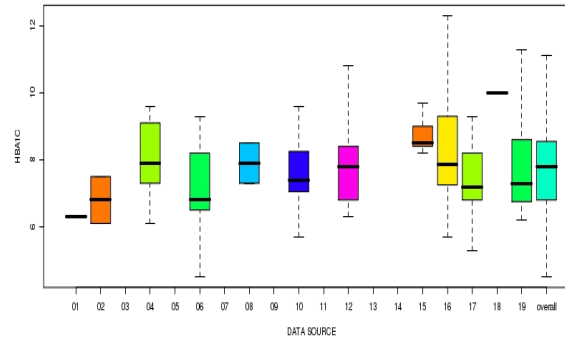
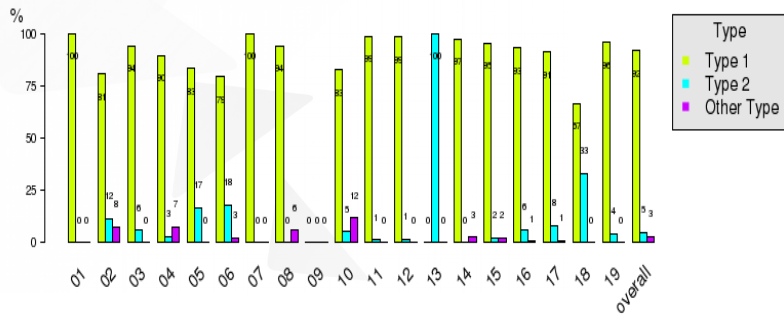
$$\Sigma \text{Pred}_i \times 100 = \text{Expected Rate}$$

$$\text{Standardized Rate} = (\text{observed rate} / \text{expected rate}) * \text{pop.rate}$$

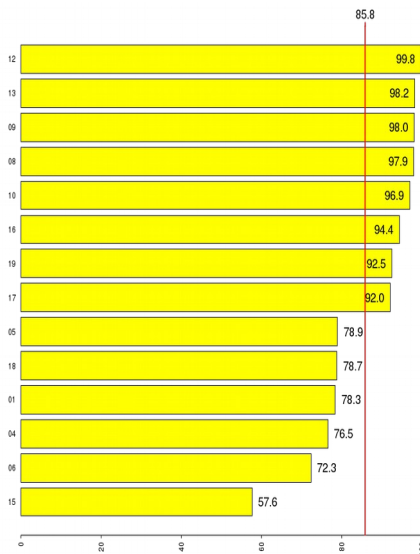




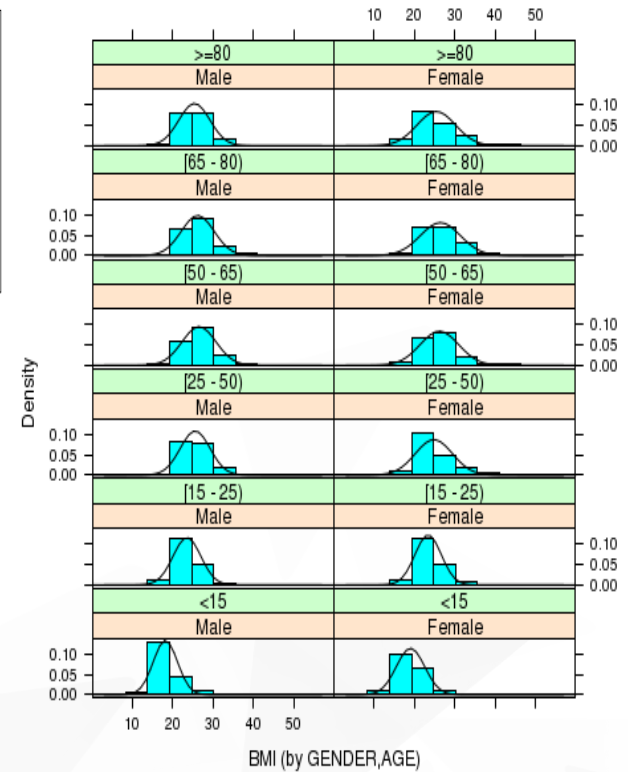
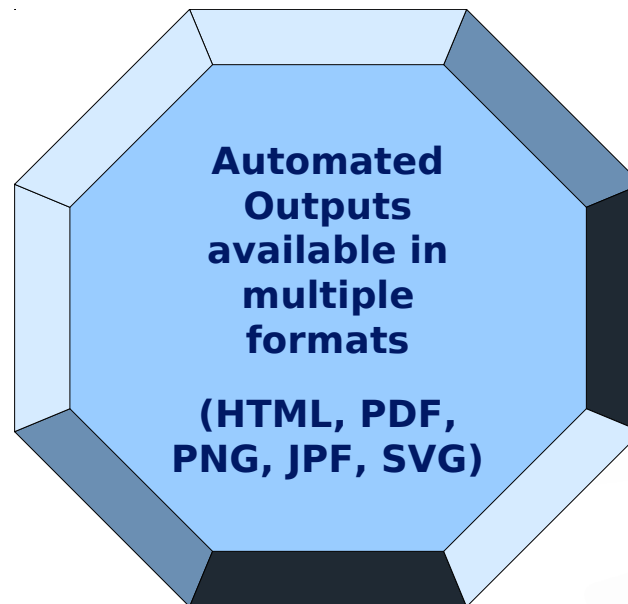
# Flexible Reporting



## Assessing Data Quality / Variability across Sources



## Benchmarking EU-Adjusted Standardized Indicators



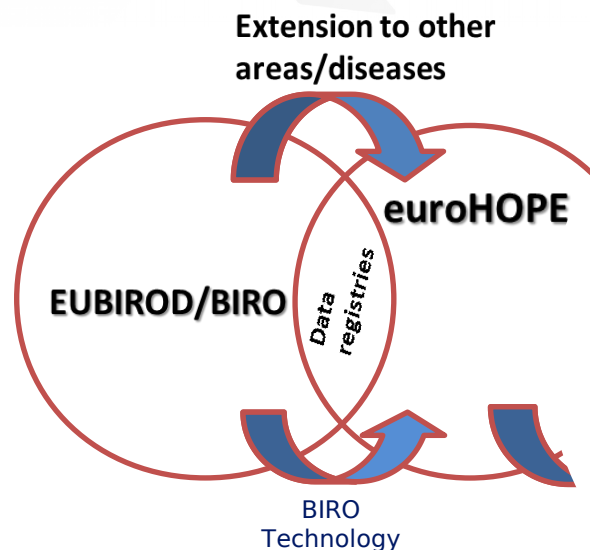
## Distribution of Risk Factors

# Independent Evaluation

Euroreach WP2: Coordination with EU/International Health Data Initiatives  
<http://www.euroreach.net/activities/workpackages/w2>

“Based on the success factors and key facts of Best Practice examples....**Recommendation: use of BIRO technology**”

“Establishment of nationwide databases with multiple administrative registry linkages at individual level...”



**Recommendation: BIRO can be extended to further diseases and has even been specifically conceived and realized for that, since the entire platform may be parameterized to allow the computation of health indicators for a wide range of diseases”**

# An avenue for the future: the BIRO Academy

<http://www.eubirod.eu/academy/index.html>

**BIRO Academy** Meta Registry of Diabetes Data Sources **EUBIROD**

Welcome Guest User. You have a role of: Guest, and you are displaying data for: Bourgogne

User: Guest User  
Country: France  
Delivers report to: Guest User (France)

Dear Guest User,  
As a registered BIRO user, you are now entitled to edit the contents of the diabetic data sources that you manage in France to produce the local and global EUBIROD Diabetes Reports.

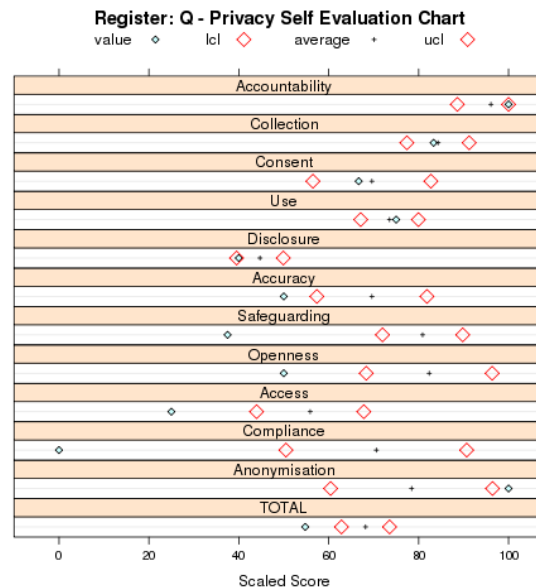
The details for a specific data source, more fully completed, will be used to create a validated counterpart that can be included in the integrated BIRO software.

To successfully complete the process, please consider the following:

- the final aim of EUBIROD is to produce population-based health system indicators. As a first, we request you to identify the "prevalent" catchment area for each data source, and include the relevant information in the "site profile"
- This may involve a specific search for figures published by the national/regional statistical office.
- size of the integrated BIRO software requires a validated **BIRO Unique Data Source Identifier**. To provide you with maximum flexibility, we request a "prepaid code" for each catchment area identified. The temporary ID will be validated by the BIRO Central Administrator and safely stored in the system in your configuration.
- clinical data items** are essential to evaluate the quality and completeness of the data across the network. We rely on your local knowledge and subjective judgment. Careful consideration of these items will help us improving and updating the BIRO standardized definitions taking your local situation into account.
- The **privacy questionnaire** will serve you as a self-evaluation tool, through which each the "privacy performance" of each data source can be independently benchmarked against the average of the network and the optimal values. Your results will never be disclosed to third parties. Overall figures will be used anonymously format to analyse variations in practices and to identify pathways for quality improvement.

Further details are included in the specific sections of each data source configuration.

2011 Eubirod Developed by: Marianne Billardie (University of Montreal)



**BIRO Academy** **EUBIROD**

You are not logged in. (Logout)

**Navigation**  
Home  
Site news  
Courses

**Site news**  
Welcome to the Eubirod E-learning platform  
This portal contains self-administered tests and questionnaires to evaluate the effectiveness of the training activity.  
If you wish to have a look at the available courses, please simply click on any of the courses listed below or in the "Courses" navigation link on your left.  
Guests are able to access the Course content automatically, but not to attempt Course quizzes or assessments.

**Online users**  
(last 5 minutes)  
None

**Courses**  
Eubirod Core  
Common Dataset  
Customised Toolbox  
EU Diabetes Report  
International Diabetes Report  
Privacy, Data Protection and Health Information Systems

**1. Integrated Network of Diabetes Data Sources (Meta-Registry)**

**2. "...economic data on the direct and indirect costs of diabetes prevention and management.."**

**3. Promotion of Best practices in Privacy Protection (validating objective metrics for "Privacy Performance Assessment (EJPH 2012)")**

**4. Dissemination of the BIRO approach (e.learning platform)**

## QUESTION 3

# Why the project is so valuable that you could find other possibilities for a sustainable future outside EU funding?

- ◆ EUBIROD embeds a multilevel approach through which targeted teams of health professionals, policy makers and citizens may be formed anywhere to coordinate the fight against diabetes
- ◆ The approach offers an ideal response to the EU Parliament Resolution on Diabetes, through the organization of a European Diabetes Register that was originally presented as the general objective of the project
- ◆ The BIRO technology has been recommended by an independent FP7 project as a general approach, worth to be extended to other non communicable diseases. EUBIROD showed it can be applied on a global scale
- ◆ To ensure that the BIRO approach remains widely and publicly available, the European Commission should call Member States and international organizations e.g. WHO, OECD, United Nations and the IDF, to cooperate in support of the regular activity of the BIRO Academy



# Conclusions

- ✓ EUBIROD has practically realized a European Diabetes Register through a coalition of multiple registers and different data sources
- ✓ The BIRO technology is open, sustainable, generally valid and, most importantly, **it has proved to work**. The results can be automatically linked to official EU platforms e.g. HEIDI.
- ✓ Our experience paves the way for a new generation of translational evidence-based information systems whose objective will be...

**...to bring health information  
“Bedside to Brussels” (b2B)**