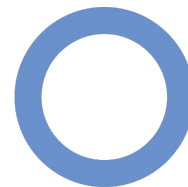


The EUBIROD project: A Shared Evidence-based Diabetes Information System for Europe



TODAY, WE CAN CHANGE TOMORROW
EUROPEAN DIABETES LEADERSHIP FORUM
COPENHAGEN 2012

Fabrizio Carinci, Technical Coordinator

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

UNDER THE AUSPICES OF:



HOSTS:



SUPPORTED BY:



PARTNERS:



ENDORSERS:



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.eubirod.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

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, 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

BIRO Data Standards

Download BIRO Definitions as a pdf Document (5 Curringham) September 2011

1. The BIRO Common Dataset

Ref.	BIRO Name	Description	Data Type	Enumerated Values/ Measurement Units
BIPO001	PAT_ID	Patient ID	String(12)	
BIPO002	DS_ID	Data Source ID	String(10)	
BIPO003	TYPE_DM	Type Of Diabetes	Enumerated	1-Type 1 2-Type 2 3-Other
BIPO004	SEX	Sex	Enumerated	1-Male 2-Female
BIPO005	DOB	Date of Birth	Date/Time	
BIPO006	DT_DIAG	Date of Diagnosis	Date/Time	
BIPO007	EPI_DATE	Episode Date	Date/Time	
BIPO008	SMOK_STAT	Smoking Status	Enumerated	1-Current Smoker 2-Non-Smoker 3-Ex-smoker
BIPO009	CIGS_DAY	Cigarettes per day	Integer	
BIPO010	ALCOHOL	Alcohol Intake	Integer	g/week g/day
BIPO011	WEIGHT	Weight	Real	Kg
BIPO012	HEIGHT	Height	Real	m cm
BIPO013	BMI	Body Mass Index	Real	
BIPO014	SBP	Systolic Blood Pressure	Integer	mmHg
BIPO015	DBP	Diastolic Blood Pressure	Integer	mmHg

News

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](#)

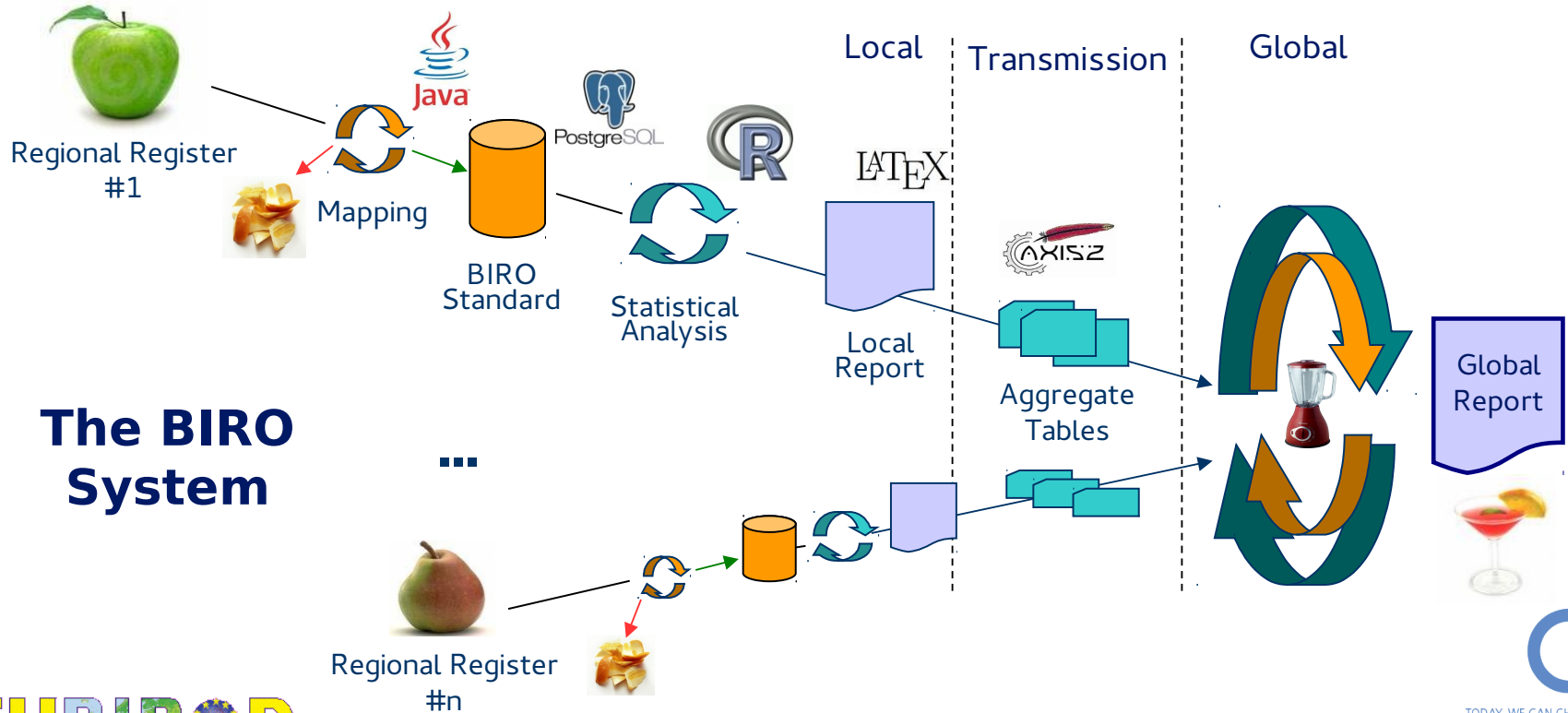
EUBIROD methods presented at EUPHA, Amsterdam, 10-13th November 2010 [Read more](#)

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 4-6 June 2010 [Read more](#)

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

http://www.eubiroad.eu/images/eubiroad_homepage_mainfigure_explained.png



The BIRO System

Privacy by Design (EU Data Directive)

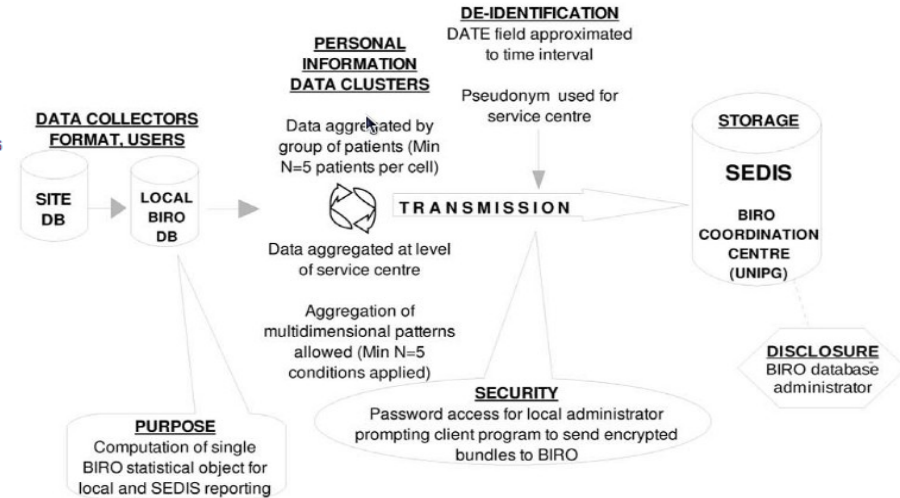
DI IORIO CT et al, J Med Ethics. 2009 Dec;35(12):753-61

Law, ethics and medicine

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

C T Di Iorio,¹ F Carinci,¹ J Azzopardi,² V Baglioni,³ P Beck,⁴ S Cunningham,⁵ A Evripidou,⁶ G Leese,⁷ K F Loevaas,⁸ G Olympios,⁶ M Orsini Federici,³ S Pruna,⁹ P Palladino,¹⁰ S Skeie,⁸ P Taverner,⁸ V Traynor,⁶ M Massi Benedetti³

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



“..in collaboration with the Member States..”

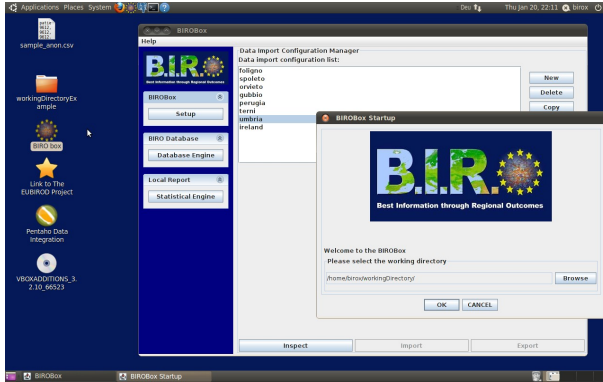
- ◆ BIRO is a **multidisciplinary collaboration** and a **spinoff of practical action** involving researchers (epidemiologists, statisticians, informaticians), health professionals (nurses, clinicians), policy makers and citizens.
- ◆ Through the project, the **Cyprus Ministry of Health** launched the 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.
- ◆ At the 1st BIRO Residential Course, held at the **Dasman Institute, Kuwait City** (5/2009), a first analysis of diabetes data from Al Amiri hospital was performed with the collaboration of representatives of the local community.
- ◆ At the 2nd BIRO Residential Course, organized by IDF in Brussels (1/2011), policy makers from **Tanzania, Lebanon, China, Barbados** and **Cuba** planned a National diabetes register. The meeting was closed by the EU Health Commissioner, **J.Dalli**.

“..collect, register, monitor and 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

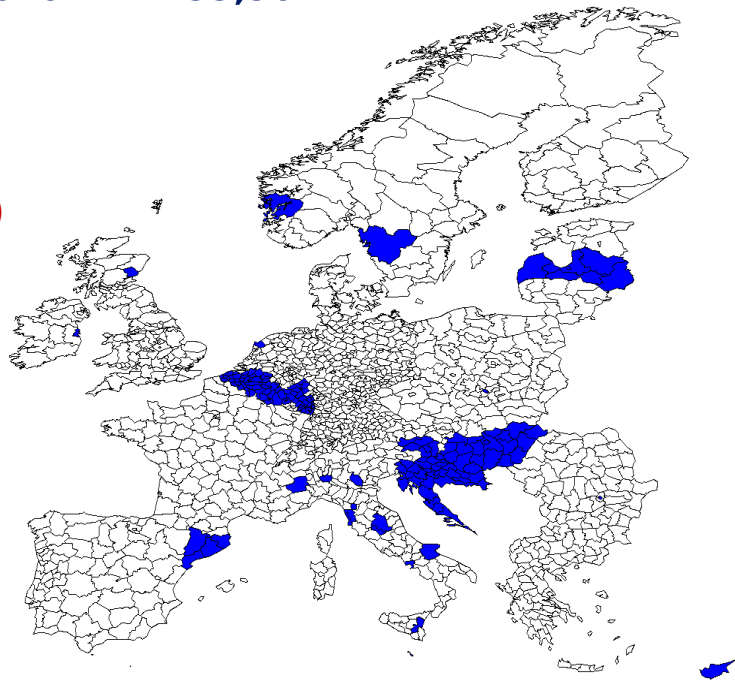
8/2/2012: New BIRO Release 2.1.12

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 !

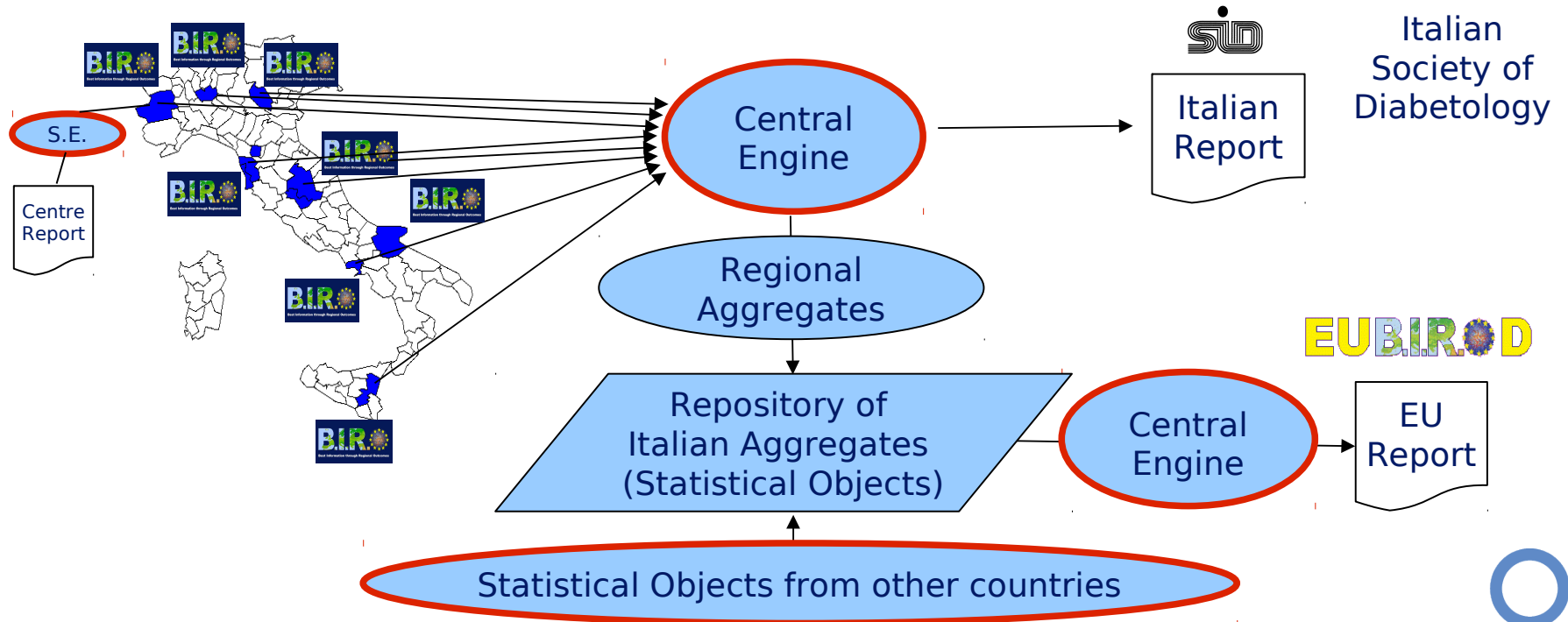
[Previously: 52 days (8/2011), 60 days (1/11)]



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)

$$Y(\%) = \beta_0 + \beta_1(\text{females}) + \beta_2(\text{age_class1}) + \dots + \beta_k(\text{age_class4})$$

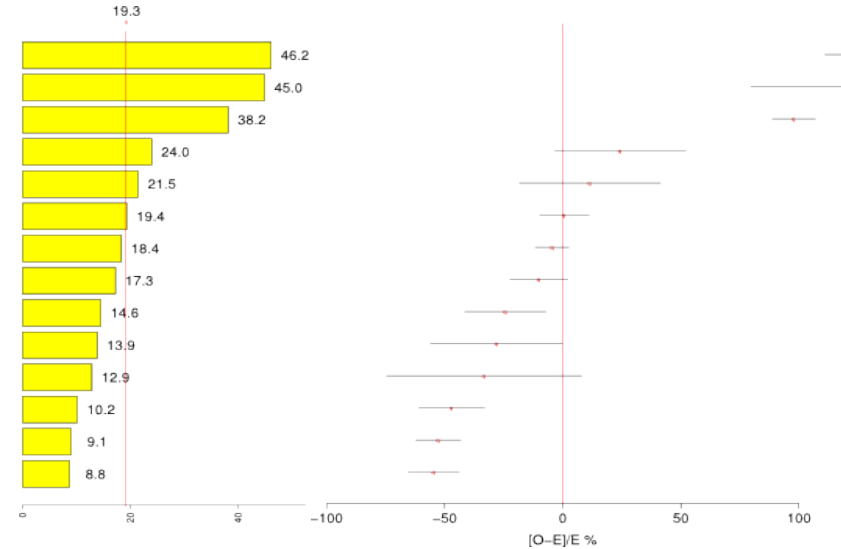


Source unit

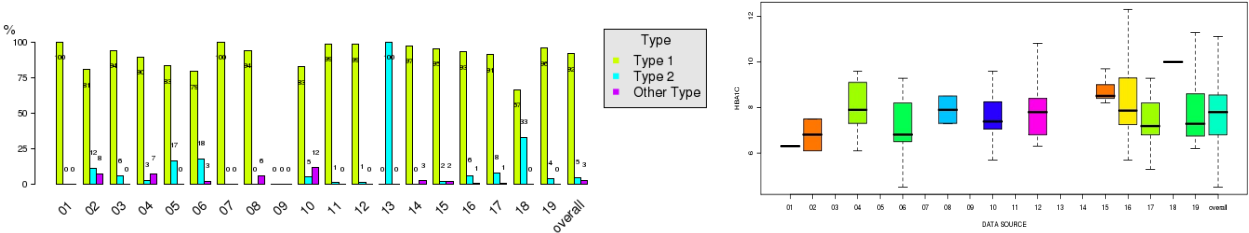
$$Y_i \text{ exp} = \beta_0 + \beta_1(\text{females}) + \beta_2(\text{age_class1}) + \dots + \beta_k(\text{age_class4})$$

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

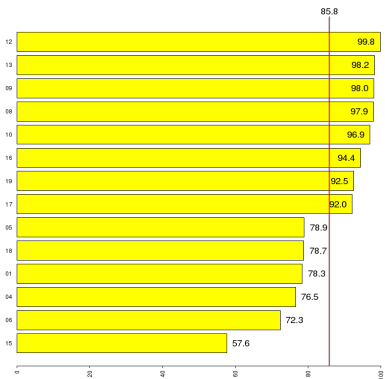
$$\text{Standardized Rate} = (\text{observed rate} / \text{expected rate}) * \text{pop.rate}$$



Flexible Reporting

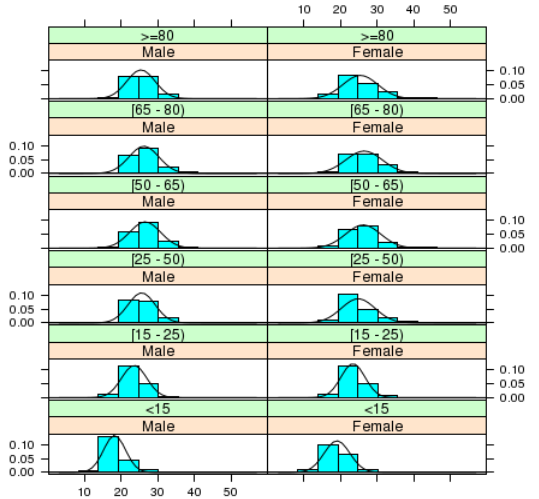


Assessing Data Quality / Variability across Sources



Benchmarking EU-Adjusted Standardized Indicators

Automated Outputs available in multiple formats (HTML, PDF, PNG, JPF, SVG)



Distribution of Risk Factors



Independent Evaluation

Euroreach WP2: Coordination with 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...”

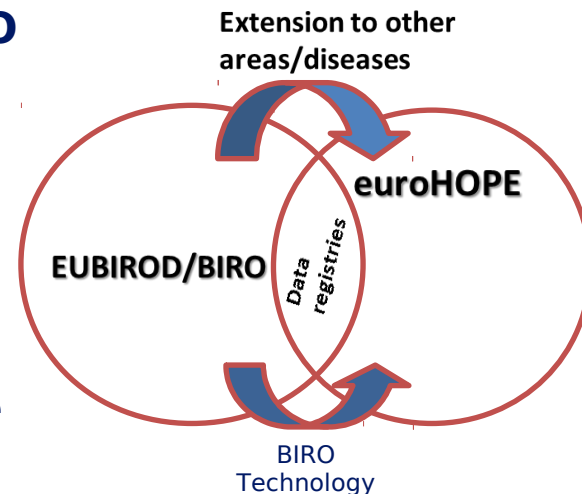
Recommendation: BIRO can be extended to further diseases and has even been specifically conceived and realized for that, since the entire platform may be parameterized to allow the computation of health indicators for a wide range of diseases”



EuroREACH



Improved access to health care data through cross-country comparisons



**B.Zander, R.Busse
(TUB Berlin)
2011**



Fabrizio Carinci - The EUBIROD Project



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An avenue for the future: the BIRO Academy

<http://www.eubiroad.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
Diabetes report to: Guest User (France)
Your Guest User

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

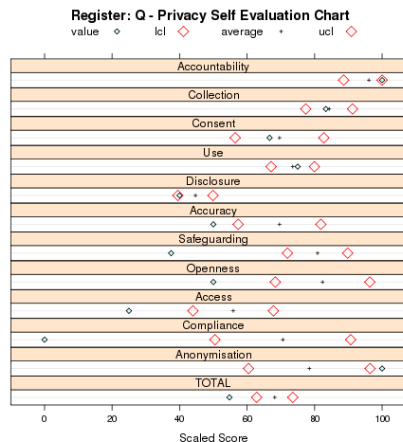
The details for a specific data source, once duly completed, will be used to create a national compilation for France to be included in the integrated BIRO software.

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.
- The use of the integrated BIRO software requires a validated **BIRO Unique Data Source Identifier**. To provide you with maximum flexibility we require a "predefined code" for each catchment area identified. The temporary ID will be validated by the BIRO Central Administrator and stable entered 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 in 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 national register. Your results will never be disclosed to third parties. Overall figures will be used automatically format to analyze variation in practice and to identify pathways for quality improvement.

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

BIRO Academy Developed by: Massimo Belloni - University of Modena



BIRO EUBIROD

You are not logged in (0:00)

Navigation

- Home
- My courses
- Courses

Site news

Welcome to the Eubirod E-learning platform

The portal contains self-administrated 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 on 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

part (0:00)

Home

Courses

- Eubirod Core
- Common Database
- Common Profiles
- EU Diabetes Platform
- International Diabetes Platform
- 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)



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”