



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

**Prof. M. Massi Benedetti, President, HIRS**

**EU network for Best Information  
through Regional Outcomes in Diabetes  
(EUBIROD)**

**THE 2014 EU SUMMIT ON CHRONIC DISEASES  
Addressing the medical, social and economic burden of  
chronic diseases in the EU  
Brussels, 3-4 April 2014**

# 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” (EUBIROD PROJECT, February 2009, [www.eubirod.eu](http://www.eubirod.eu), )**

## THE EUBIROD NETWORK 2014

<http://www.hirs-research.eu/eubirod.html>

**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)

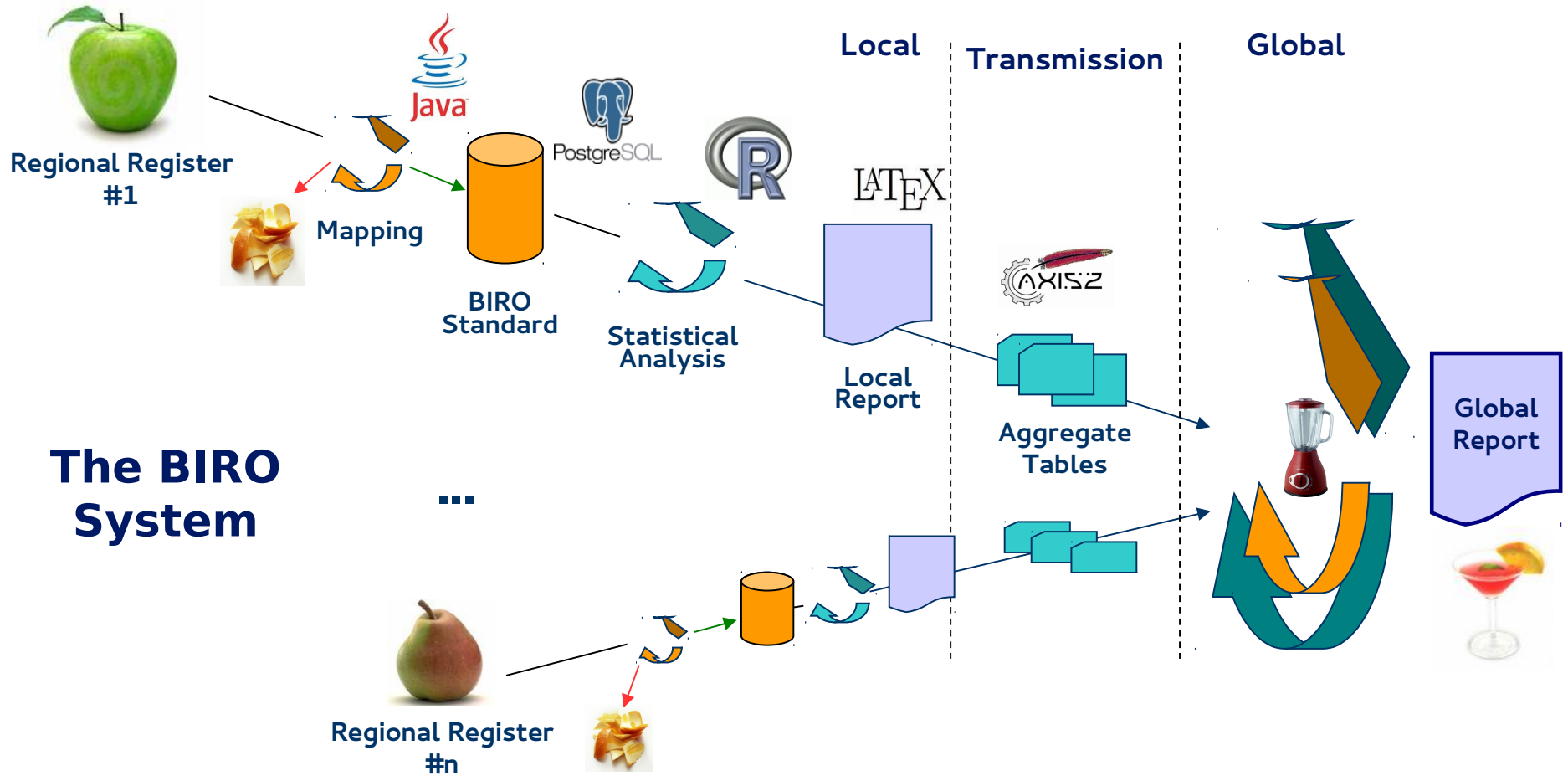
## BIRO Data Standards

The screenshot shows the EUBIROD website interface. The main content area is titled "BIRO Data Standards" and includes a link to "Download BIRO Definitions as a pdf Document". Below this, there is a section titled "1. The BIRO Common Dataset" which contains a table of indicators.

Ref.	BIRO Name	Description	Data Type	Enumerated Values/ Measurement Units
BIRO001	PAT_ID	Patient ID	String(12)	
BIRO002	DS_ID	Data Source ID	String(10)	
BIRO003	TYPE_DM	Type Of Diabetes	Enumerated	1=Type 1 2=Type 2 3=Other
BIRO004	SEX	Sex	Enumerated	1=Male 2=Female
BIRO005	DOB	Date of Birth	Date/Time	
BIRO006	DT_DIAG	Date of Diagnosis	Date/Time	
BIRO007	EPI_DATE	Episode Date	Date/Time	
BIRO008	SMOK_STAT	Smoking Status	Enumerated	1=Current Smoker 2=Non-Smoker 3=Ex-smoker
BIRO009	CIGS_DAY	Cigarettes per day	Integer	
BIRO010	ALCOHOL	Alcohol Intake	Integer	g/week
BIRO011	WEIGHT	Weight	Real	Kg
BIRO012	HEIGHT	Height	Real	m cm
BIRO013	BMI	Body Mass Index	Real	
BIRO014	SBP	Systolic Blood Pressure	Integer	mmHg
BIRO015	DBP	Diastolic Blood Pressure	Integer	mmHg

# “..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)

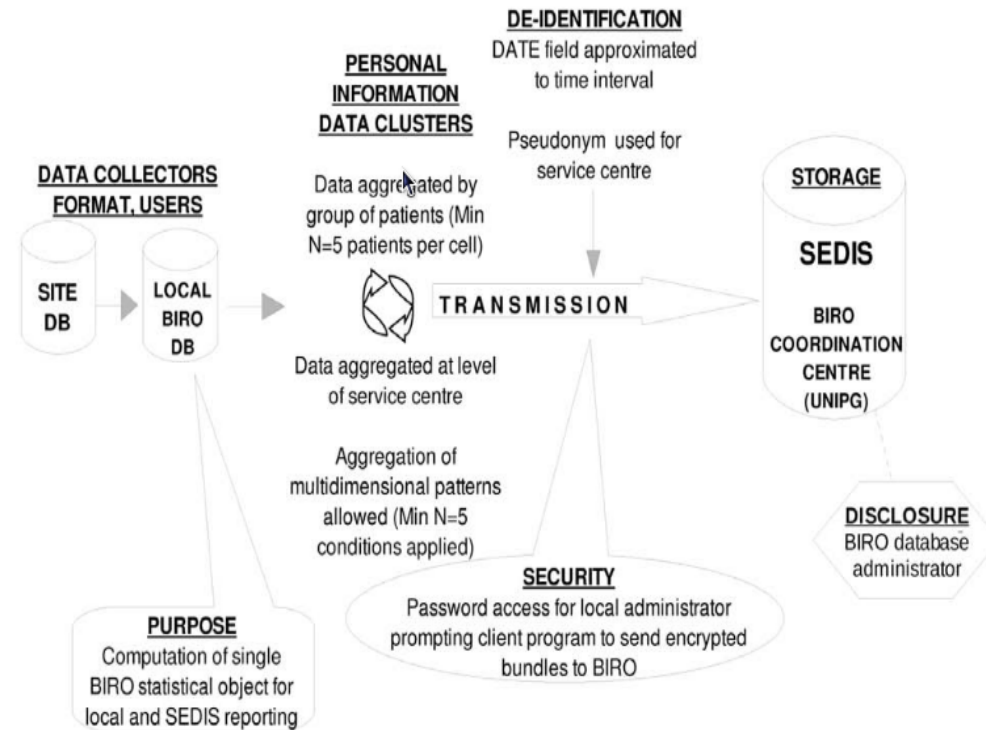
DI IORIO CT et al, J Med Ethics. 2009 Dec;35(12):753-61

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**



## ***“..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 1<sup>st</sup> 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 2<sup>nd</sup> 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.**

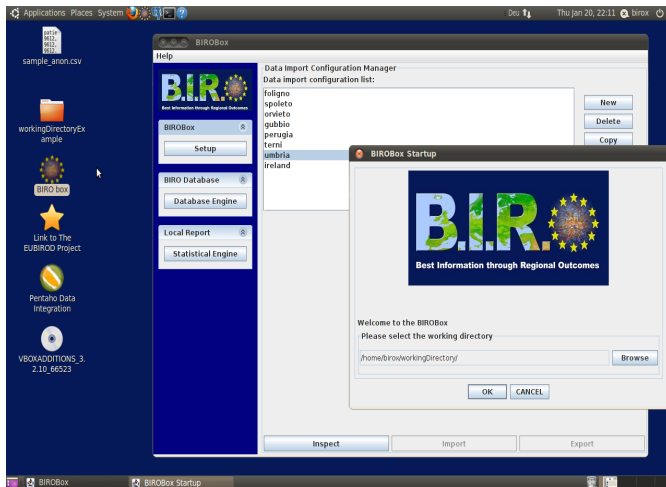


***“..collect, register, monitor and manage..”***

<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..”***

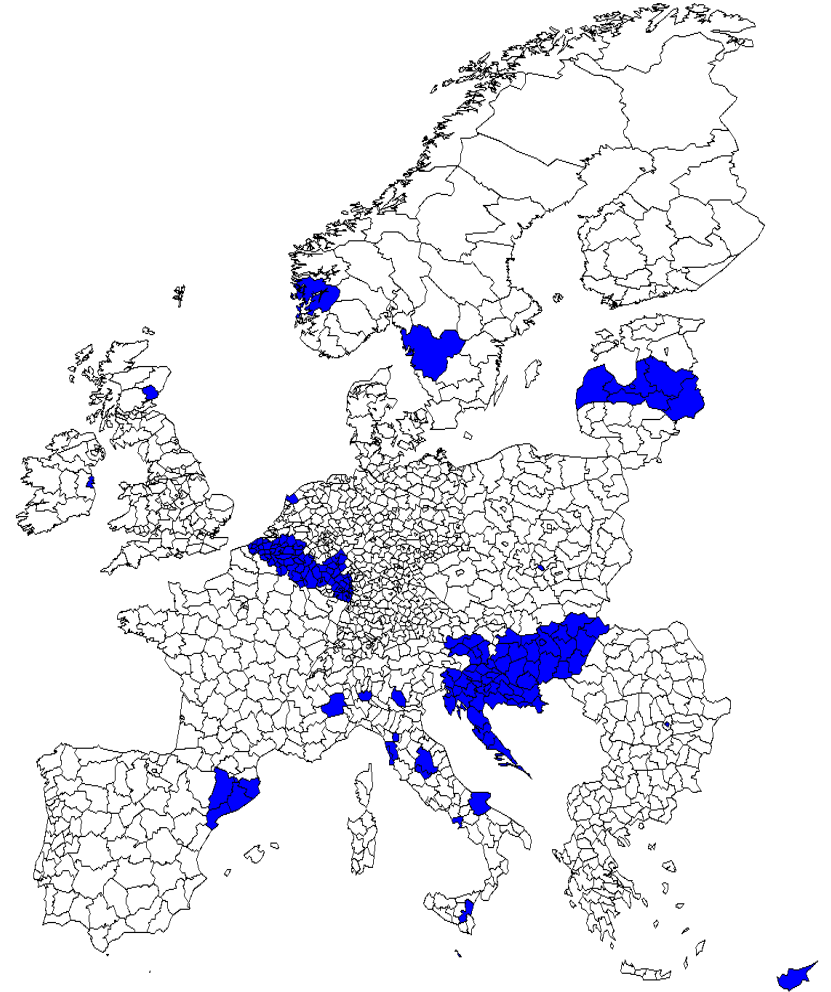
**EUBIROD Diabetes Report, YEAR 2010 - N=199,902**

**8/2/2012: First BIRO Release 2.1.12**

**15/2/2012: Collection of statistical objects**

**21/2/2012: EU Report (N=79 indicators)**

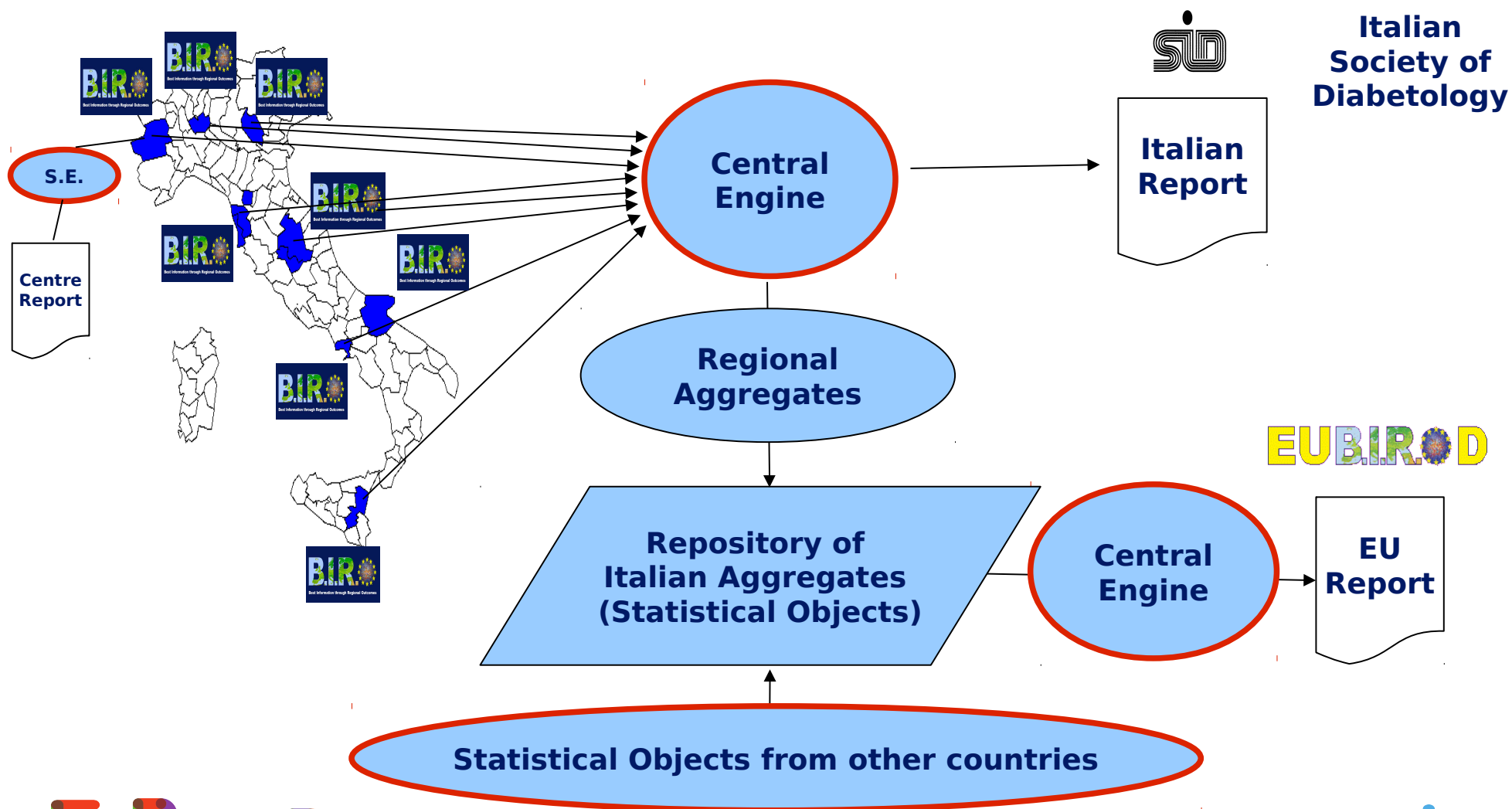
**13 Days from Software  
Release  
to Online Delivery of the full  
report !**



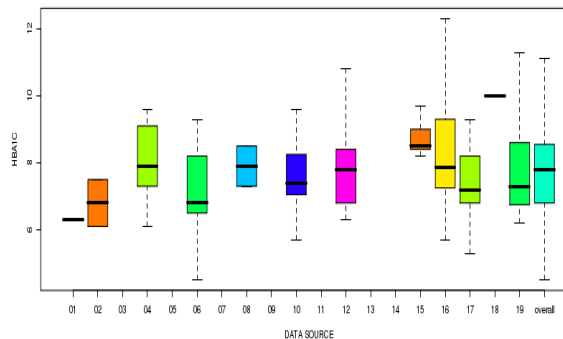
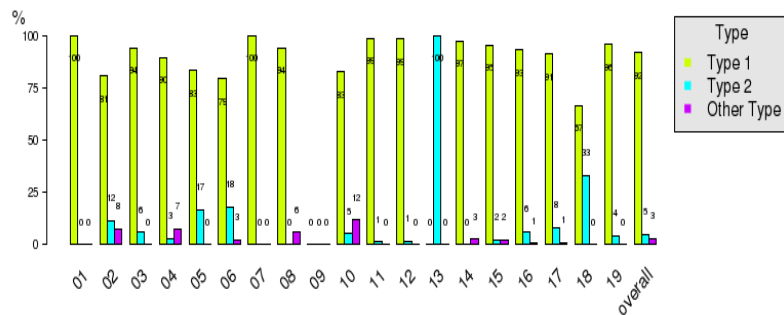
# How EUBIROD works: country example

ITALY: BIRO installed in N=8 centres

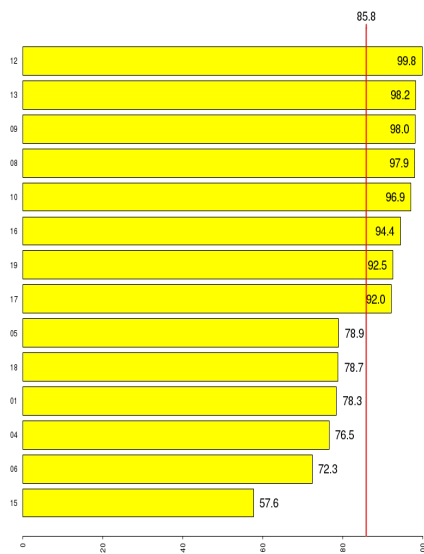
DATABASES OF INDIVIDUAL RECORDS STAY WITH THE ORIGINAL DATA CUSTODIAN



# Flexible Reporting

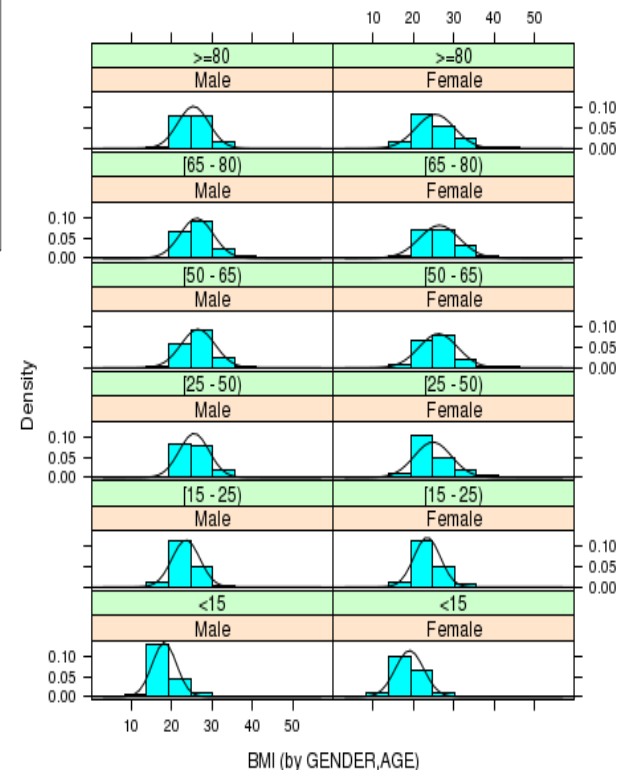


**Assessing Data Quality / Variability across Sources**



**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**

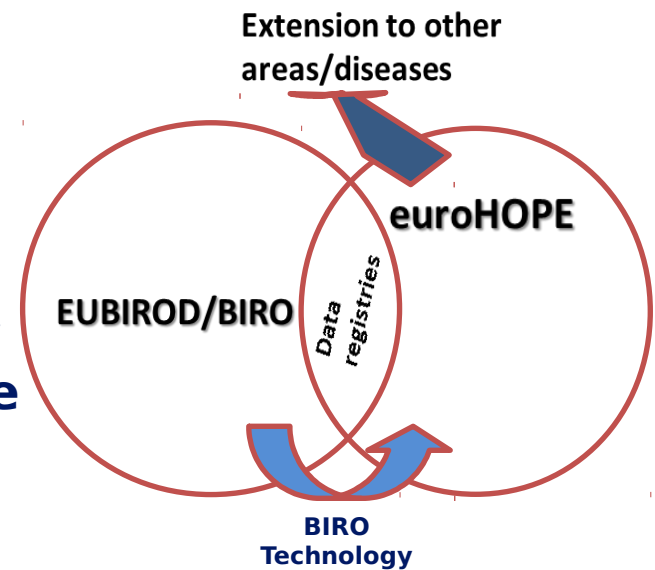
<http://www.euroreach.net/activities/workpackages/w2>

**“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”**



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

# Current Activities at EU level

## The EUBIROD Network

<http://www.hirs-research.eu/eubiroad/members.html>

### *Coordinating Centre*

**Hub for International Health Research, Italy**

### *Members*

**Joanneum Research, Austria**  
**Scientific Institute of Public Health, Belgium**  
**National Institute of Public Health, Croatia**  
**University of Zagreb, Croatia**  
**Ministry of Health, Cyprus**  
**University of Debrecen, Hungary**  
**Serectrix, Italy**  
**Ministry of Health, Latvia**  
**University of Malta, Malta**  
**NOKLUS, Norway**  
**Silesian University of Technology, Poland**  
**Telemedica Consulting, Romania**  
**University of Ljubljana, Slovenia**  
**IDIBAPS, Spain**  
**Foundation for Care Information, The Netherlands**  
**University of Dundee, UK**



**Associated Project**

## **CHRODIS-JA**

**Joint Action addressing chronic diseases and promoting healthy ageing across the life cycle**

**Associated Partner**

## **EGHI**

**Expert Group on Health Information**

**Invited Project to discuss  
a potential ERIC on Health Information**

# Conclusions

- ✓ **The EUBIROD Network is an expanding coalition of diabetes registries in Europe for the construction of a sustainable European Diabetes Register**
- ✓ **The BIRO technology is open, sustainable, generally valid and, most importantly, **it has been proven to work**. The results can be automatically feed EU systems of indicators e.g. the ECHI or future platforms for Health Systems Performance Assessment.**
- ✓ **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”**