



**IGEA: dal progetto al  
sistema  
L'integrazione delle cure  
per le persone con malattie  
croniche  
Roma, 22 - 23 aprile 2013**

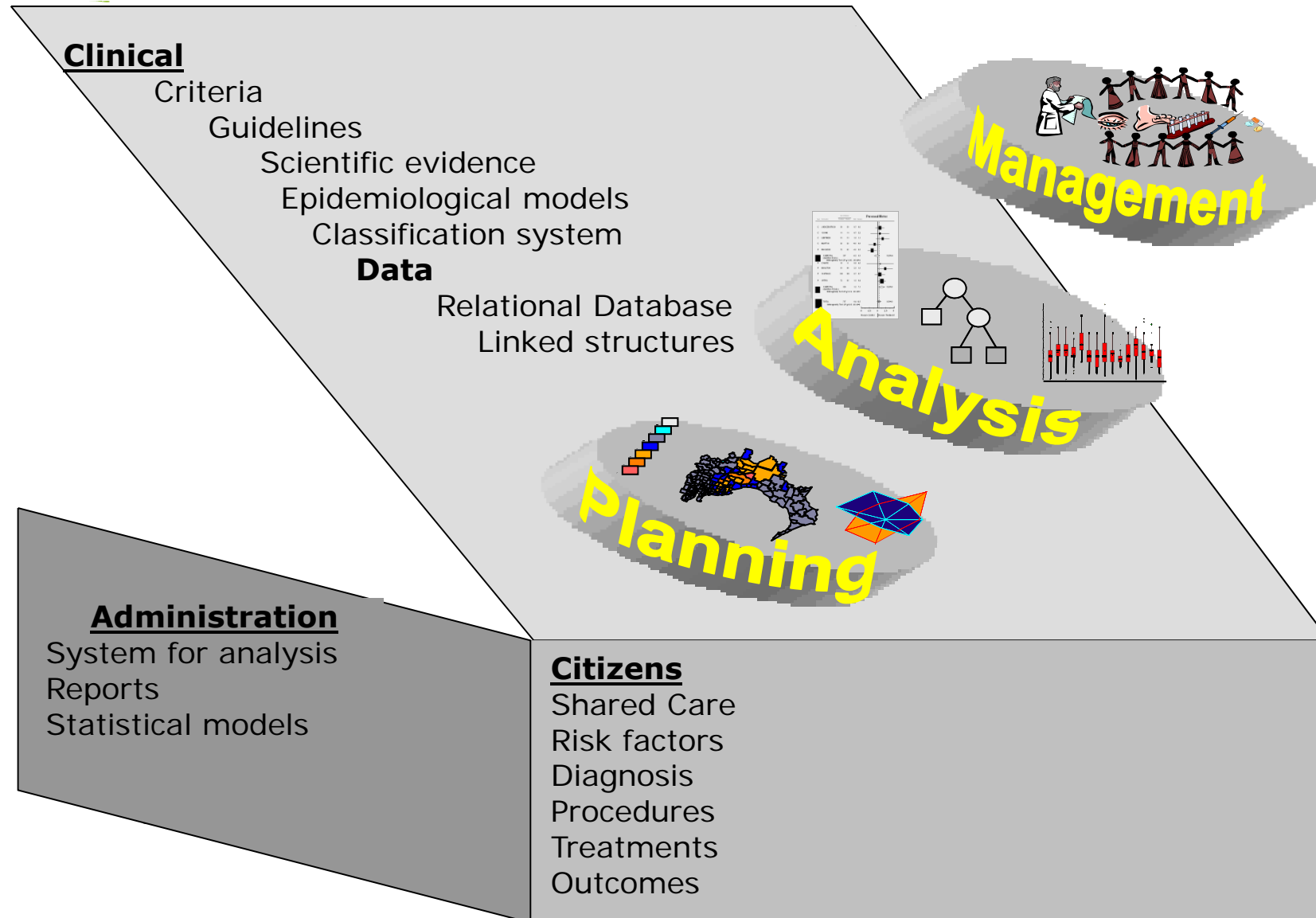
Prospettive di uso a livello nazionale e  
globale del progetto EUBIROD

Prof. Massimo Massi Benedetti

Scientific Coordinator

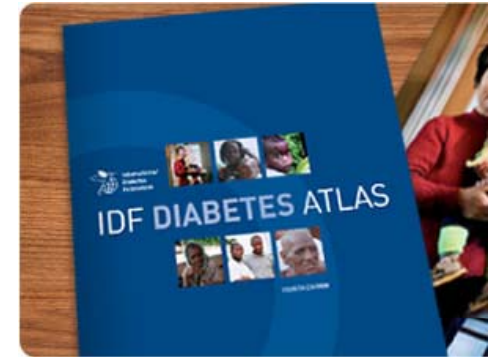
EUBIROD Project

# What is a Register for



# Qualità della cura nel diabete

[IDF Diabetes Atlas, Fourth Edition, 2009]



2004-2008: >1,500 publications **on quality of care**

- Multicentre data in a single country
- Analysis on a single centre
- Only N=3 studies comparing quality across countries

1999-2003: sample of 50% papers:

- N=5 international studies

OECD "Health Care Quality Indicators Project"

N=9 diabetes indicators originally identified

- N=2 computed:
  - Annual eye examination, Amputation rates

# Why are international comparisons so difficult?

[IDF Diabetes Atlas, Fourth Edition, 2009]



*“So, why is it that there is a large number of studies of diabetes care within countries, many based on multiple sites, yet so few international comparisons? The simple answer is **lack of consistently applied standards that would enable international comparisons**. Standard systems and definitions, applied to comparable populations result in data that can be collected and compared relatively easily. The more unified systems are, the easier these comparisons become.”*



# Perchè è importante riferire ogni dato ad uno specifico soggetto (REGISTRO DI POPOLAZIONE)

- PER CONSENTIRE DI **CONTROLLARE E VALIDARE LE INFORMAZIONI** ATTRAVERSO PIU' FONTI (Data Linkage per conferma diagnosi, etc.)
- PER **EVITARE SOVRASTIME** DI PREVALENZA
- PER DETERMINARE **RUOLO E IMPATTO DI OGNI SPECIFICO LIVELLO DI ASSISTENZA** SUL CONTROLLO DEL DIABETE, es. ricoveri ospedalieri per pazienti in carico ai servizi di diabetologia (Valutazione di Struttura)
- PER VALUTARE **L'APPROPRIATEZZA DI UN SERVIZIO** IN BASE AL PROFILO GLOBALE DEL SOGGETTO (Valutazione dei Processi)
- PER ATTRIBUIRE **IL PESO DI ESITI SPECIFICI** (COMPLICANZA, ESITO INTERMEDIO, ESITO FINALE) SU PARTICOLARI GRUPPI DI SOGGETTI A RISCHIO (DENOMINATORI) (Valutazione degli Esiti)



# Limiti nella raccolta e comparabilità dei dati internazionali sul diabete

Indicatori OCSE attualmente calcolati di routine:

- Ricoveri per complicanze a breve termine
- Ricoveri per complicanze a lungo termine
- Ricoveri per diabete non controllato
- Tassi di Amputazione Estremità Inferiori
- Esame annuale dell'occhio

PROBLEMI GLOBALI A LIVELLO OCSE:

- Qualità dei dati ospedalieri eterogenea e difficilmente verificabile
- Limitata disponibilità di dati da cure primarie
- Data Linkage generalmente limitato ed eterogeneo
- Difficile collegamento a dati clinici e di prescrizione tramite registri, integrazione dei livelli di cura, database amministrativi/farmaceutici etc.



# Cosa fare per migliorare il monitoraggio globale del diabete (1)

## **IL DIABETE:**

- **E' UN MODELLO IDEALE PER LA CREAZIONE DI UN SISTEMA DI MONITORAGGIO GLOBALE DELLE MALATTIE CRONICHE**
- **DISPONE DI UNA AMPIA BASE DI INDICATORI CONCORDATI A LIVELLO INTERNAZIONALE E CONVALIDATI DALLA LETTERATURA SCIENTIFICA (IN CONTINUA EVOLUZIONE)**
- **PER OGNI INDICATORE DISPONE DI UNA PRECISA CLASSIFICAZIONE DEGLI ELEMENTI NECESSARI AL CALCOLO**

## **PER ESSERE MISURATO ADEGUATAMENTE A LIVELLO GLOBALE:**

- **OCCORRE CONSIDERARE IN MANIERA PIU' SISTEMATICA I DIVERSI LIVELLI DI CURA COINVOLTI**
- **BISOGNA RACCOGLIERE DATI PUNTUALI (STRATIFICATI) COLLEGANDO ELEMENTI PROVENIENTI DA DIVERSE FONTI IN MANIERA OMOGENEA A LIVELLO INTERNAZIONALE**



## Cosa fare per migliorare il monitoraggio globale del diabete (2)

### **REQUISITI:**

- **INTENSIFICAZIONE DELLA RACCOLTA DI DATI AGGREGATI DA OGNI SINGOLO PAESE, BASATA SU STANDARD DI QUALITA' DEI DATI DI BASE SUFFICIENTEMENTE RESTRITTIVI**
- **INCREMENTO DEL VOLUME E VARIETA' DI INCROCI ATTI A CONSENTIRE DIVERSI TIPI DI ANALISI**
- **APPLICAZIONE DI SPECIFICHE METODOLOGIE STATISTICO-INFORMATICHE VALIDE PER I DIVERSI LIVELLI DI BENCHMARKING**
- **SVILUPPO ED ADOZIONE DI OPPORTUNI STRUMENTI INFORMATICI IN GRADO DI ACCEDERE E PROCESSARE AUTOMATICAMENTE I DATABASE ESISTENTI, RIDUCENDO AL MINIMO IL CARICO DI LAVORO ADDIZIONALE RICHIESTO AI SINGOLI PAESI**



# Progetto Europeo EUBIROD 2008-2012

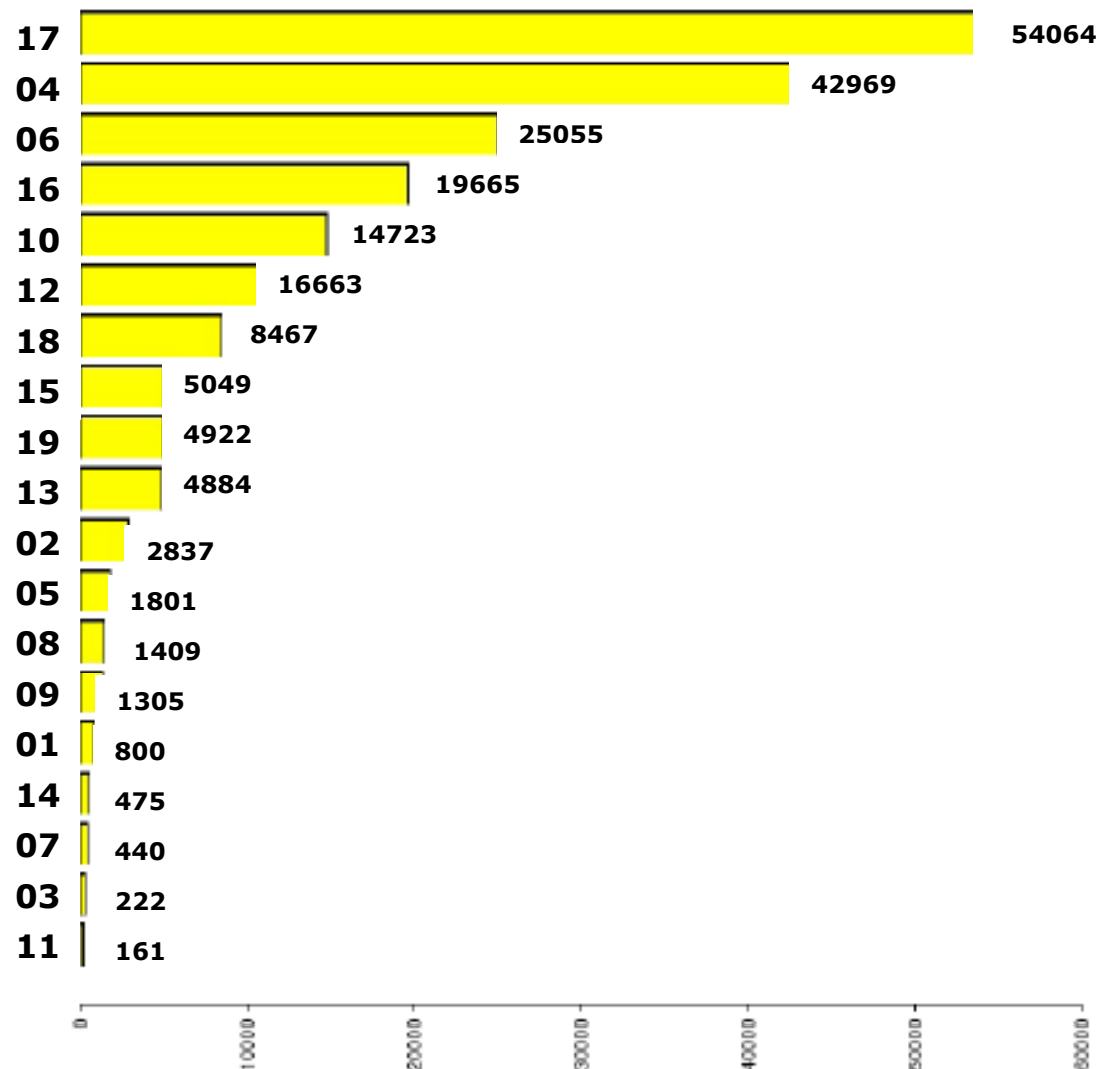
EUBIROD Diabetes Report, YEAR 2010  
19 nazioni, 79 Indicatori - N=199,902



13 Giorni dal rilascio del software open source alla pubblicazione online dei risultati

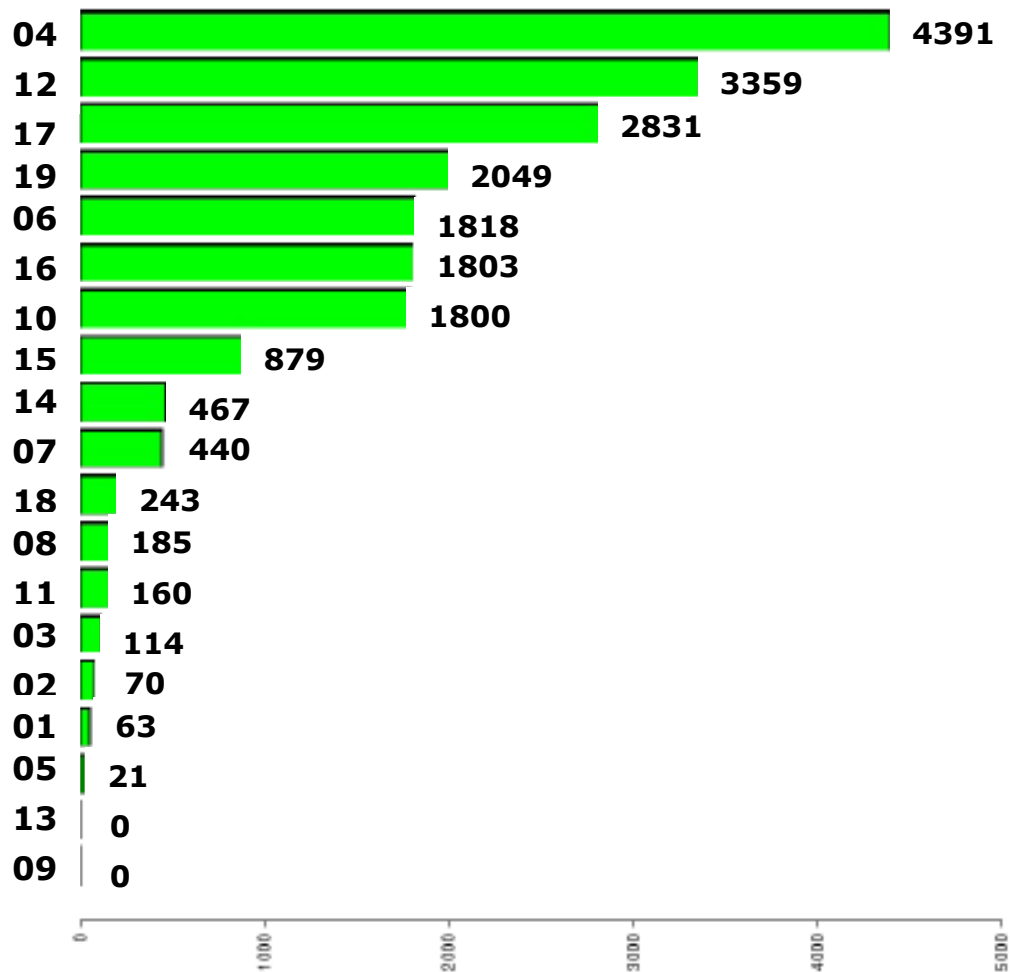
# TOTAL NUMBER OF SUBJECTS BY DATA SOURCE

## N=199902

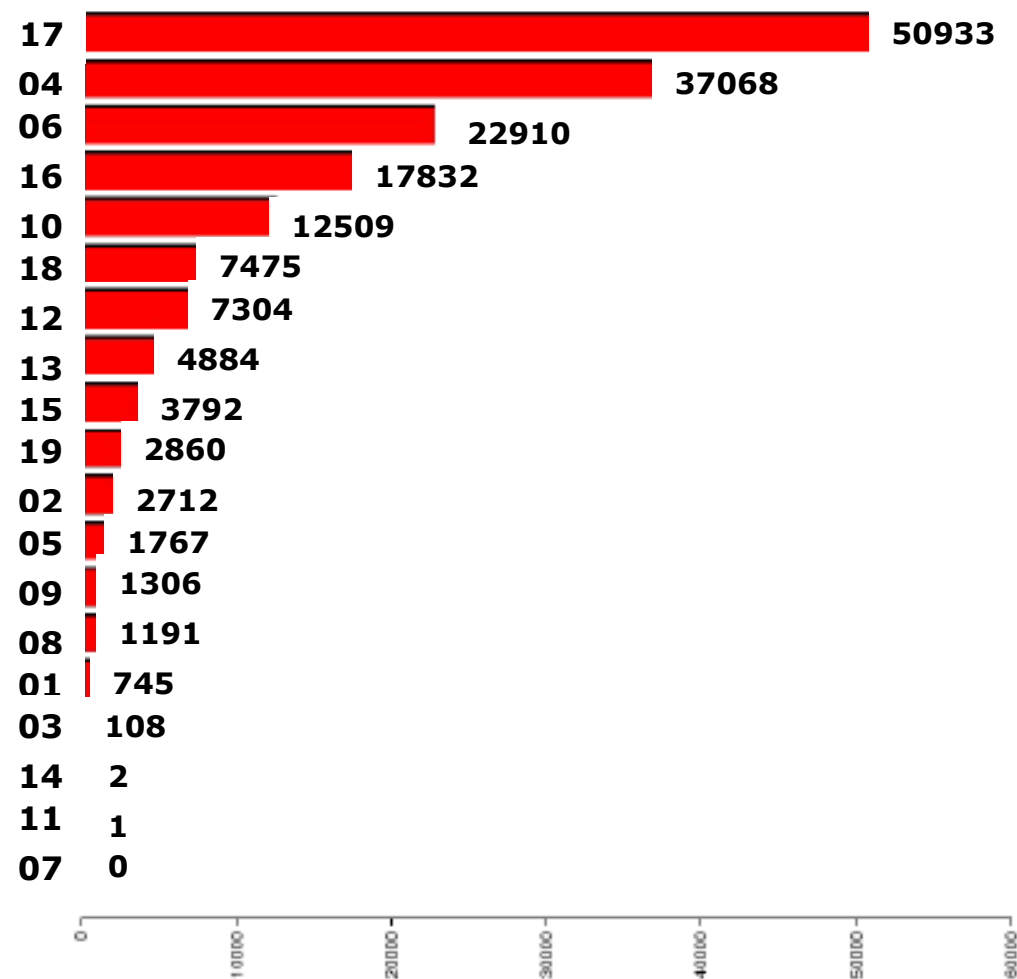


# SUBJECTS BY DATA SOURCE AND DIABETES TYPE

## Type 1



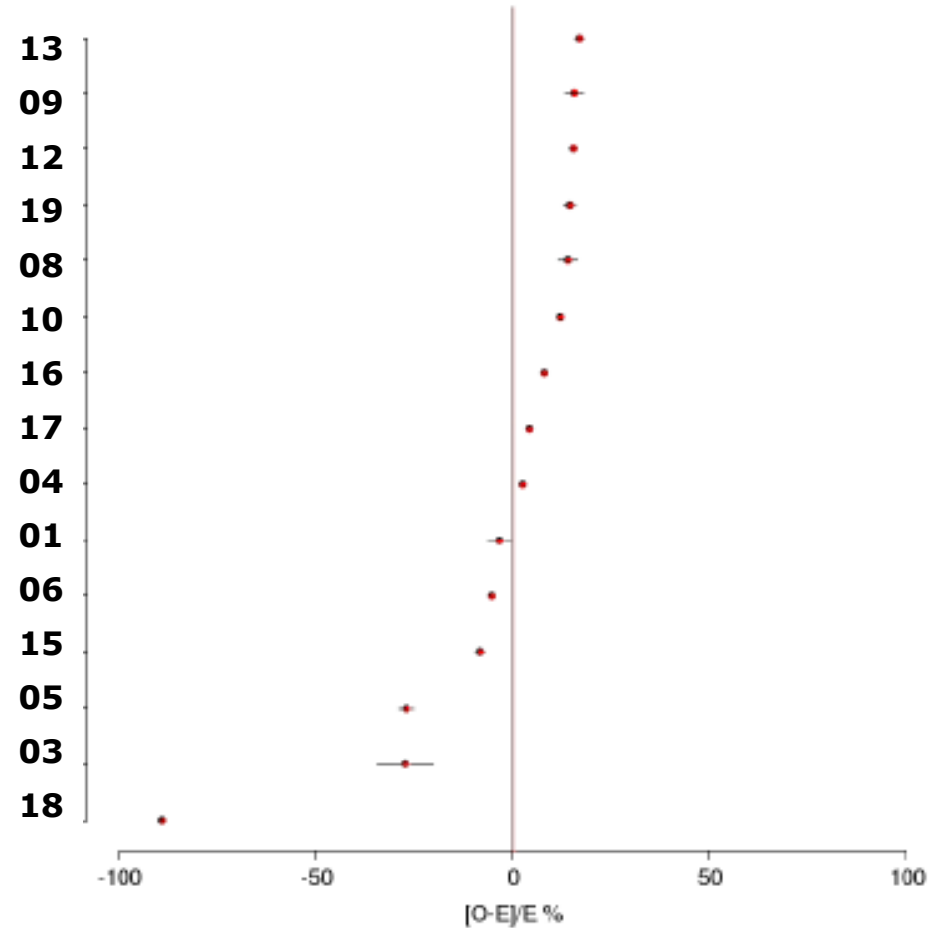
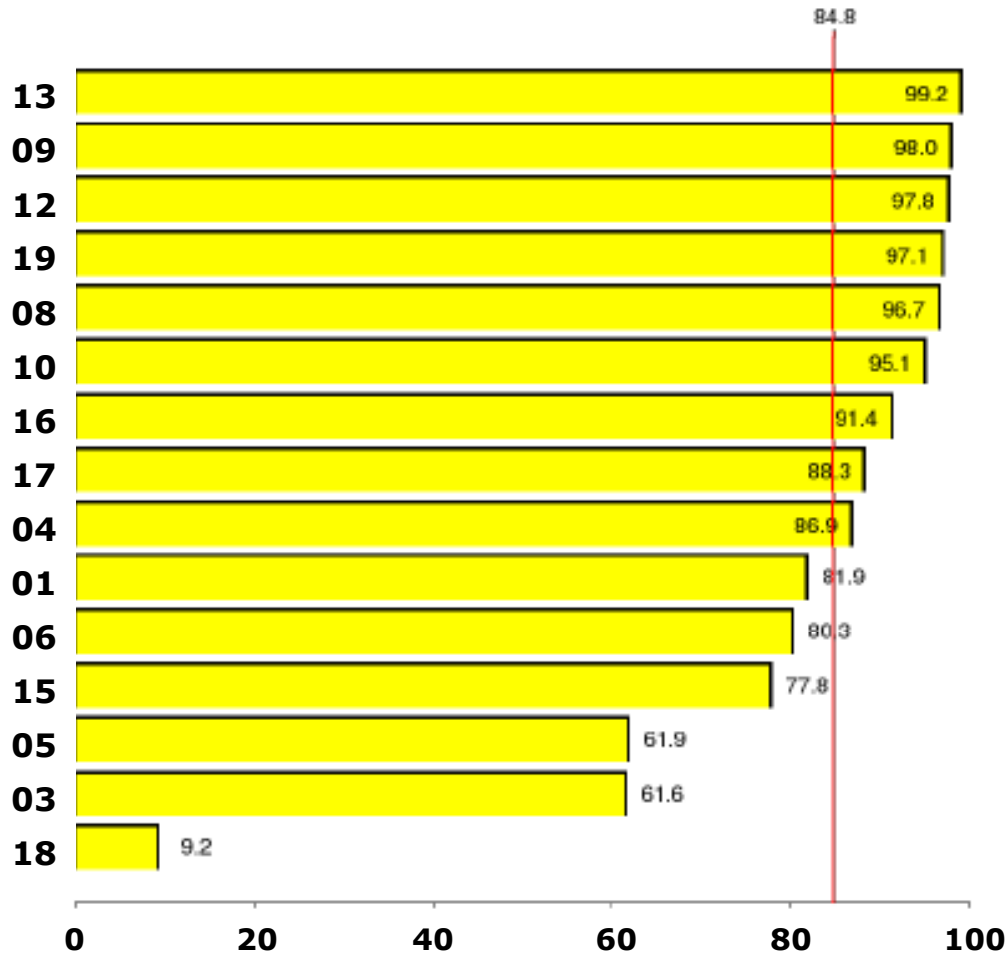
## Type 2



# 5.2.1 Percentage of Adults with 1+ HbA1c tests in 12 mts

## Type 2 (N=172,605)

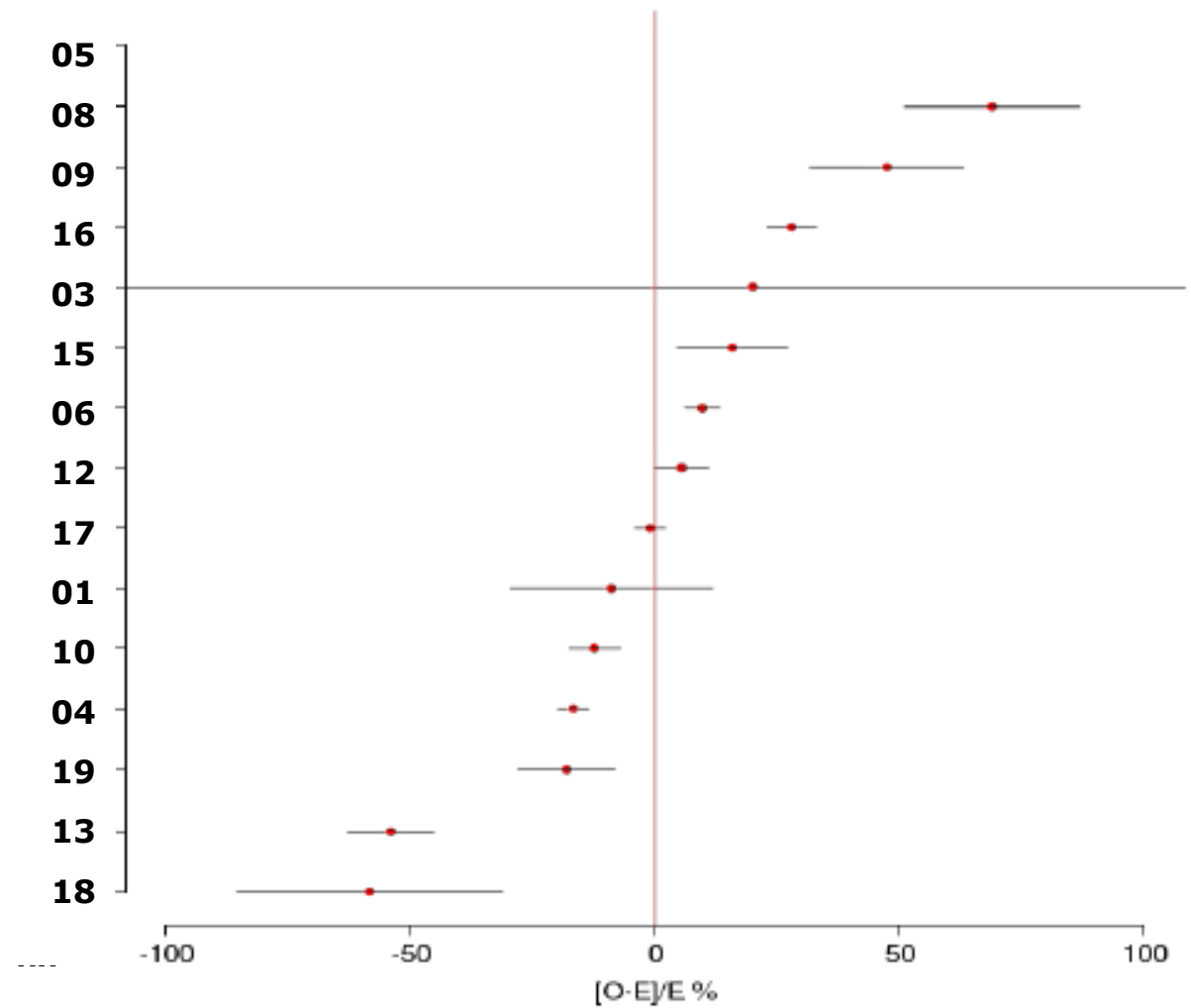
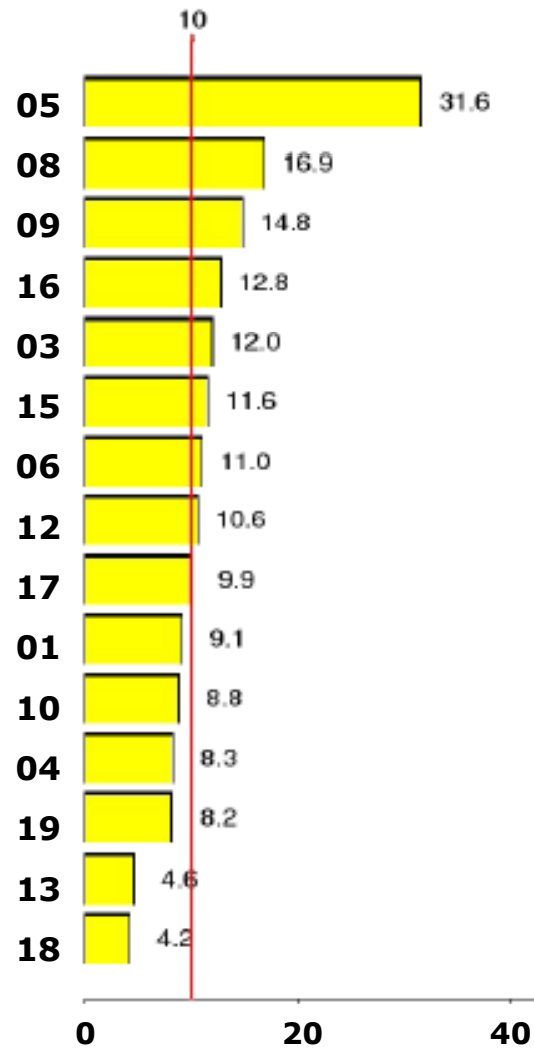
EUBIROD Diabetes Report 2010



# 5.3.1 Percentage of adults with most recent HbA1c > 9.0%

## Type 2 (N=146,397)

EUBIROD Diabetes Report 2010

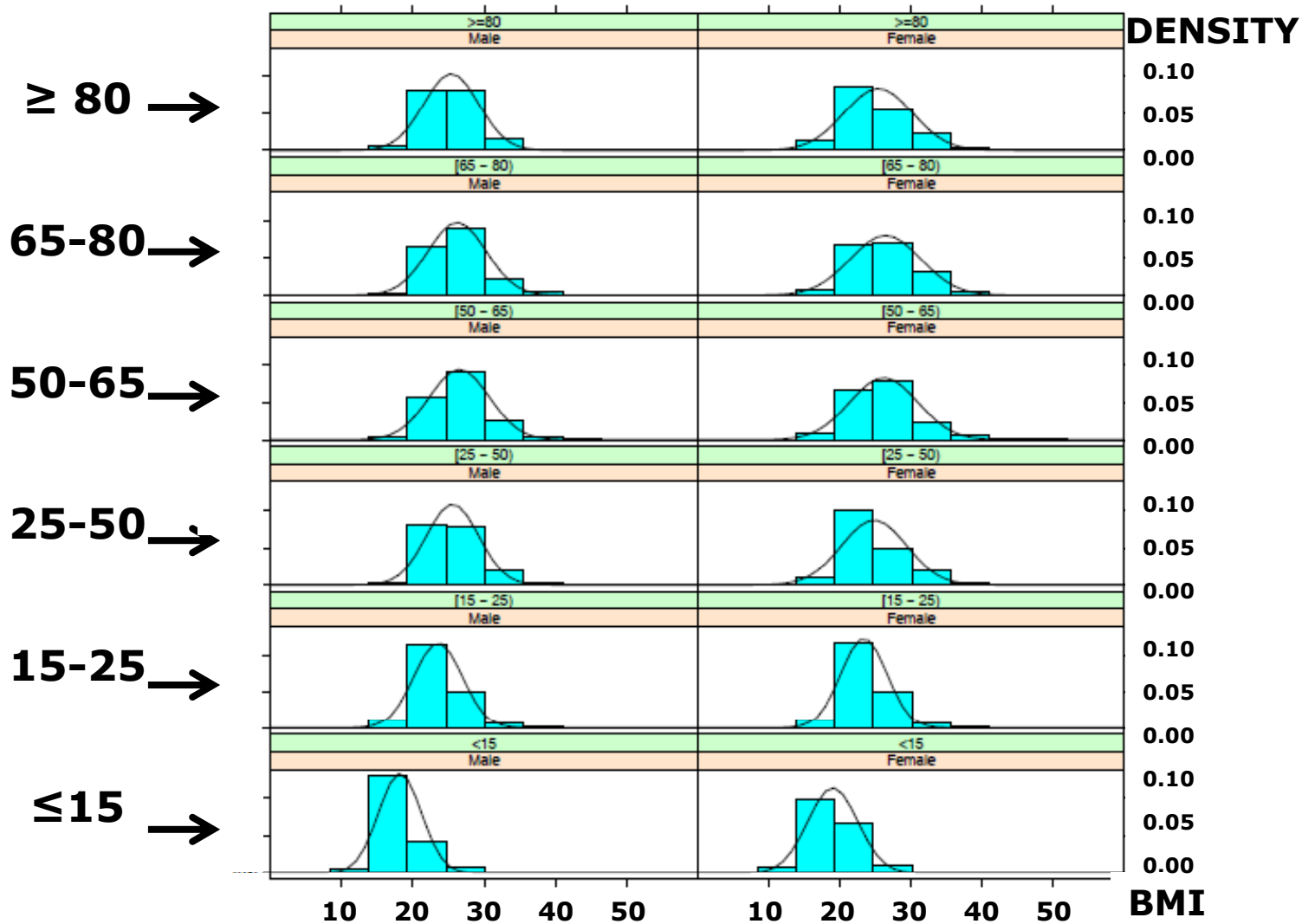


# DISTRIBUTION OF BMI BY GENDER AND AGE IN TYPE 1 DIABETES

Age groups (yrs)

Male

Female

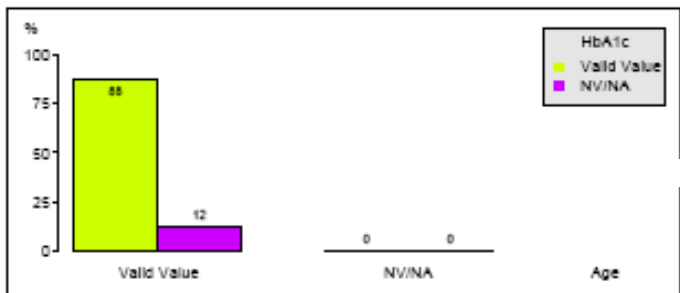


# GLYCATED HbA1c GREATER THAN 7,5%

HbA1c	Valid Value (%)	NV/NA (%)	N (%)
Valid Value	95464 (88.0)	0( 0.0)	95464 ( 88.0)
NV/NA	13055 ( 12.0)	0( 0.0)	13055 ( 12.0)
TOTAL	108519(100.0)	0( 0.0)	108519 (100.0)

Table 5.3.2.5 : HbA1c (by Age)

	CMH Chi-Square	p.value	df
Value	62581.1461	0	1

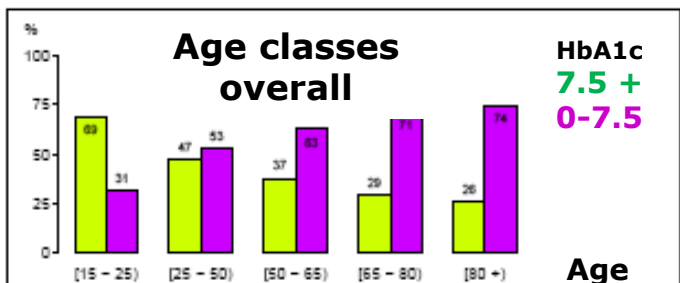


Barplot 5.3.2.5 - HbA1c (by Age)

HbA1c	[15 - 25] (%)	[25 - 50] (%)	[50 - 65] (%)	[65 - 80] (%)	[80 +] (%)	N (%)
(7.5 +)	927 (88.3)	6905 (47.2)	11035 (37.4)	11628 (29.4)	2683 (26.0)	32979 (34.5)
(0 - 7.5)	471 (33.7)	6812 (32.8)	10995 (62.6)	27736 (70.6)	7671 (74.1)	82486 (85.5)
TOTAL	1398 (1.5)	13517 (13.1)	22030 (20.6)	14262 (41.3)	10294 (10.8)	95464 (100.0)

Table 5.3.2.6 : HbA1c (by Age)

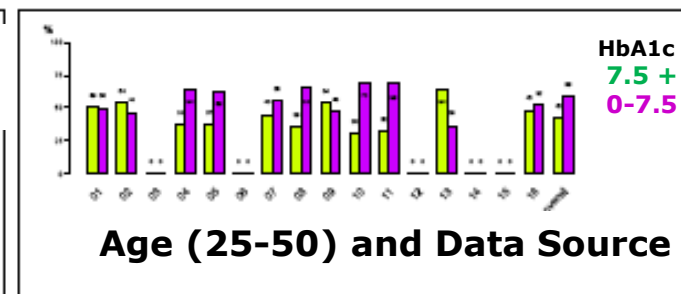
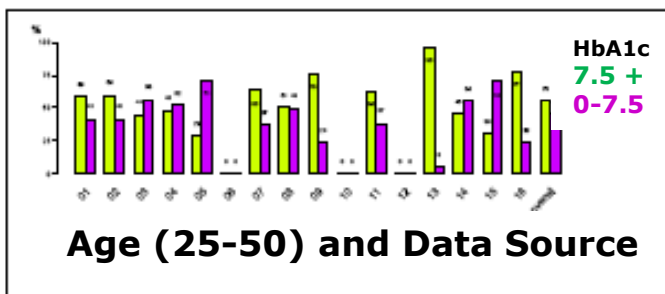
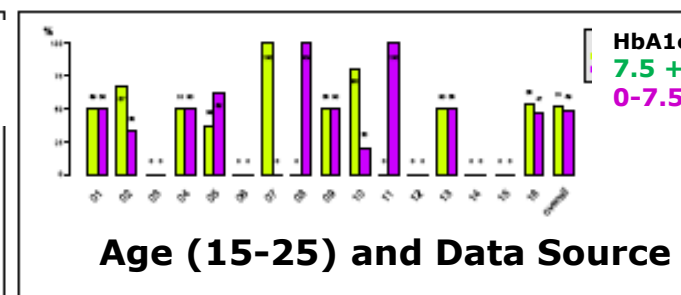
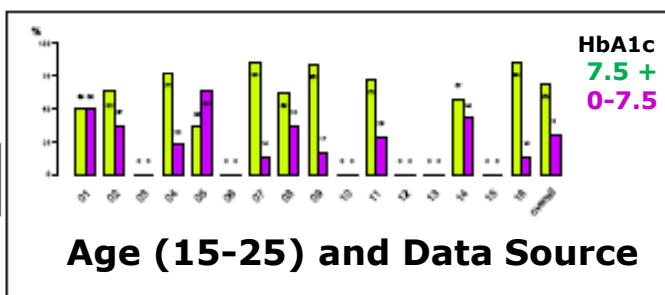
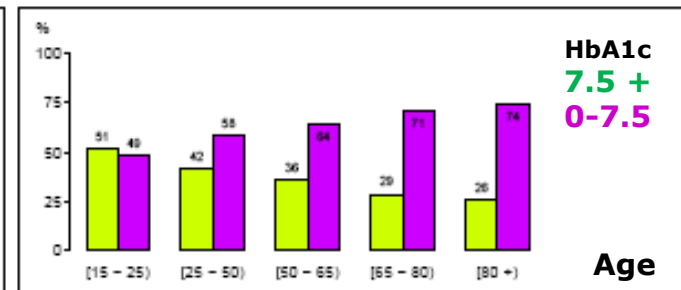
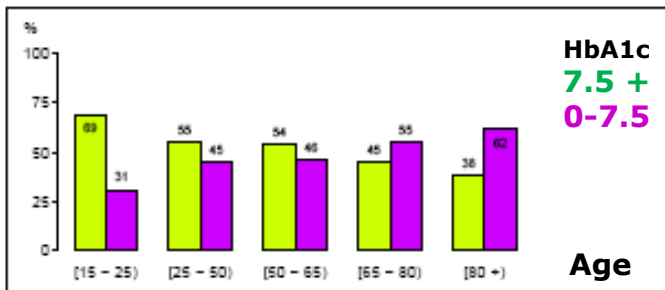
	CMH Chi-Square	p.value	df
Value	2429.4346	0	4



Barplot 5.3.2.6 - HbA1c (by Age)

## Type 1

## Type 2



# MICROALBUMINURIA

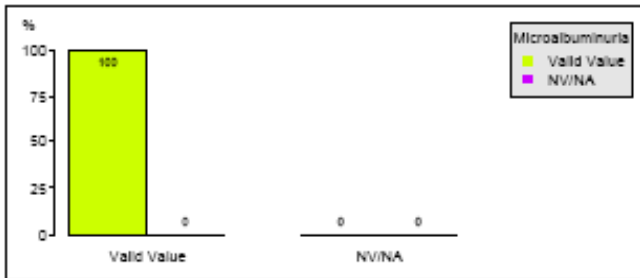
## Type 1

## Type 2

Microalbuminuria	Valid Value ( % )	NV/NA ( % )	N ( % )
Valid Value	44334 (100.0)	0( 0.0)	44334 (100.0)
NV/NA	0 ( 0.0)	0( 0.0)	0 ( 0.0)
TOTAL	44334(100.0)	0( 0.0)	44334 (100.0)

Table 5.3.5.5 : Microalbuminuria (by Age)

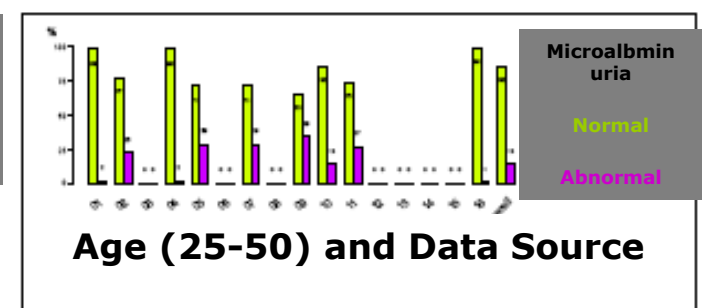
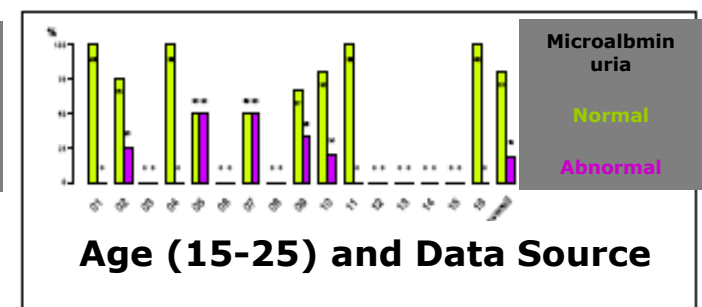
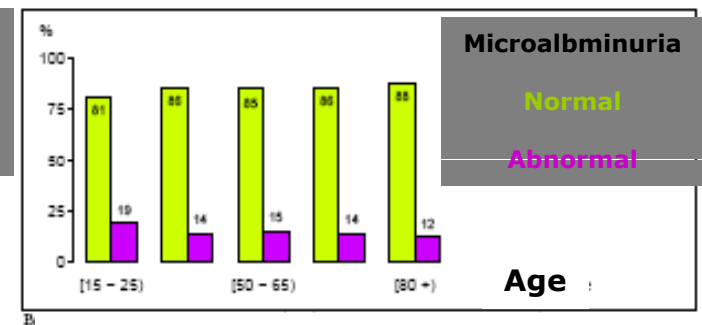
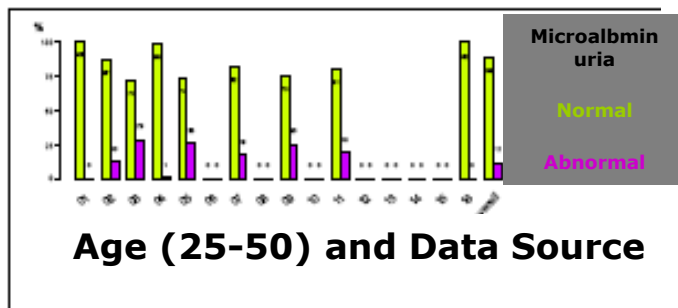
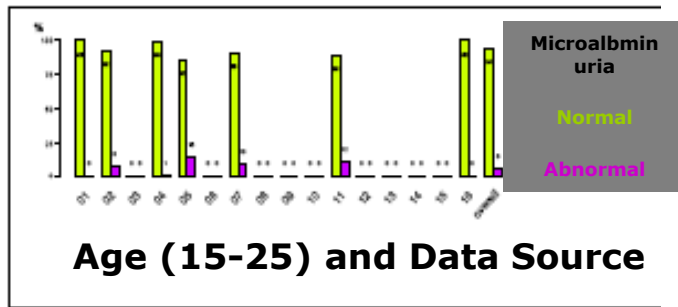
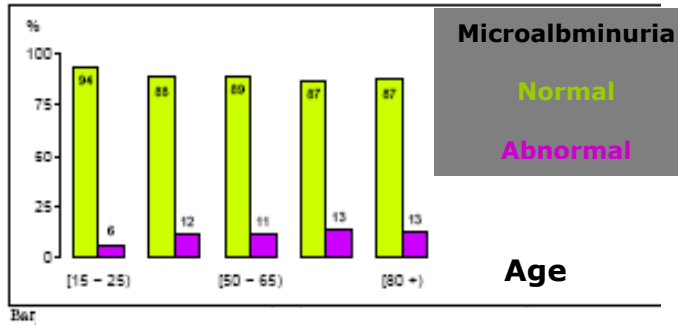
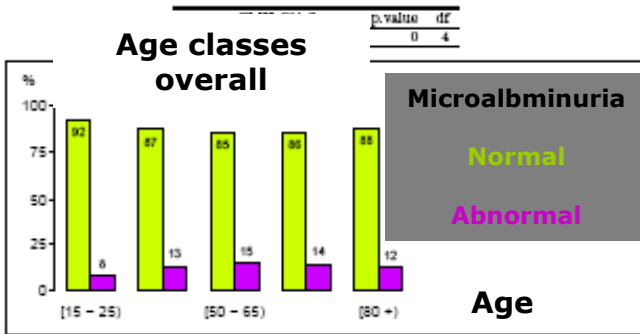
CMH Chi-Square  
Value Too many cells have 0 obs



Barplot 5.3.5.5 - Microalbuminuria (by Age)

Microalbuminuria	[15 - 25] ( % )	[25 - 50] ( % )	[50 - 65] ( % )	[65 - 80] ( % )	[80 +] ( % )	N ( % )
MA Test Normal	611 ( 92.4)	5485 ( 87.1)	12559 ( 85.5)	35267 ( 85.8)	39951 ( 87.9)	39217 ( 88.2)
MA Test Abnormal	50 ( 7.6)	813 ( 12.9)	2137 ( 14.5)	557 ( 1.2)	532 ( 1.1)	6117 ( 13.8)
TOTAL	661 ( 1.5)	6304 ( 14.2)	14696 ( 33.1)	35824 ( 80.9)	40483 ( 91.3)	44334 ( 100.0)

Table 5.3.5.6 : Microalbuminuria (by Age)



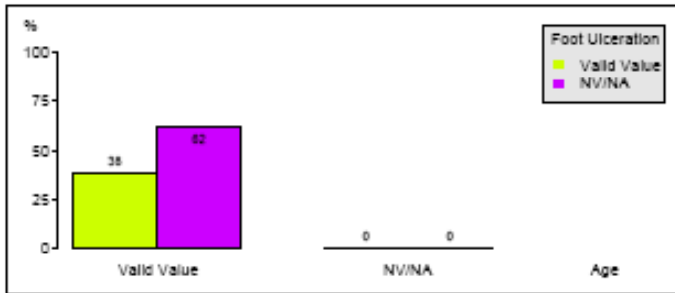


# Foot ulcers

Foot Ulceration	Valid Value ( % )	NV/NA ( % )	N ( % )
Valid Value	33951 ( 38.0 )	0 ( 0.0 )	33951 ( 38.0 )
NV/NA	55343 ( 62.0 )	0 ( 0.0 )	55343 ( 62.0 )
TOTAL	89294 ( 100.0 )	0 ( 0.0 )	89294 ( 100.0 )

Table 5.3.7.5 : Foot Ulceration (by Age)

CMH Chi-Square	p-value	df
Value	5124.5423	0 1



Barplot 5.3.7.5 - Foot Ulceration (by Age)

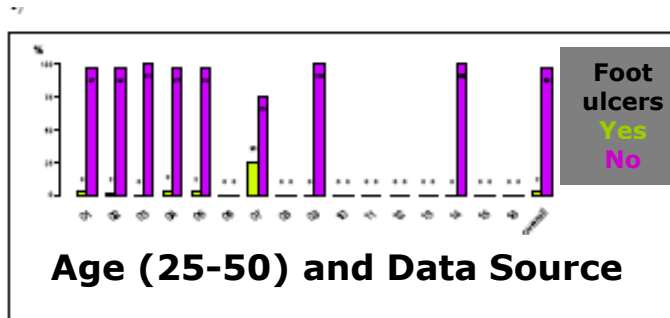
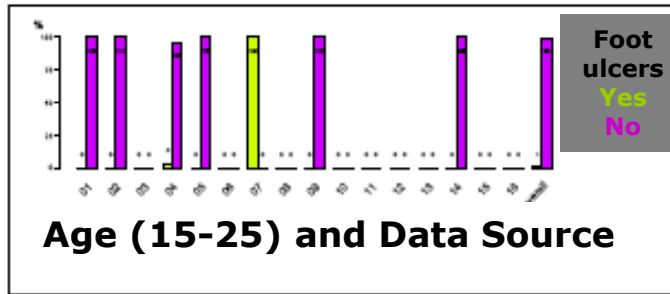
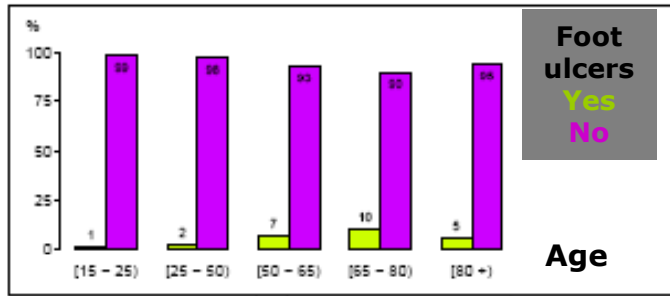
Foot Ulceration	[15 - 25] ( % )	[25 - 50] ( % )	[50 - 65] ( % )	[65 - 80] ( % )	[80 +] ( % )	N ( % )
Yes	5 ( 0.8 )	115 ( 2.6 )	504 ( 4.7 )	1104 ( 7.2 )	493 ( 11.6 )	2399 ( 6.3 )
No	533 ( 99.2 )	4644 ( 97.4 )	10165 ( 95.3 )	12892 ( 82.8 )	3519 ( 88.4 )	31453 ( 83.7 )
TOTAL	538 ( 1.0 )	4759 ( 14.0 )	10669 ( 31.4 )	13996 ( 42.2 )	3992 ( 11.7 )	33951 ( 100.0 )

Table 5.3.7.6 : Foot Ulceration (by Age)

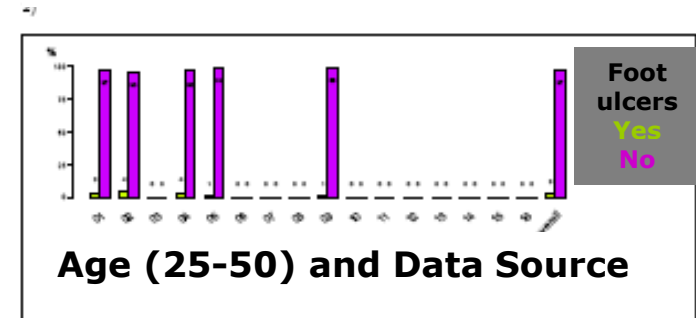
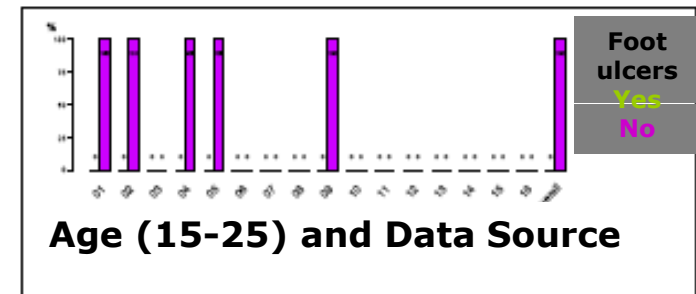
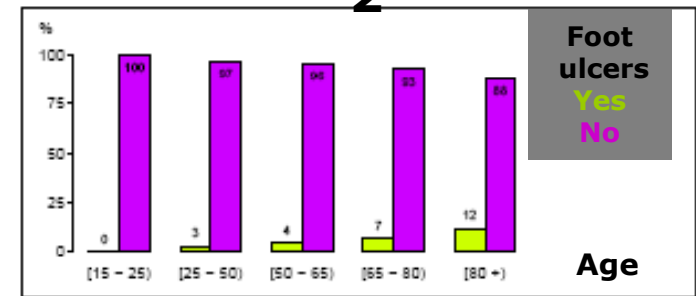


B

## Type 1



## Type 2

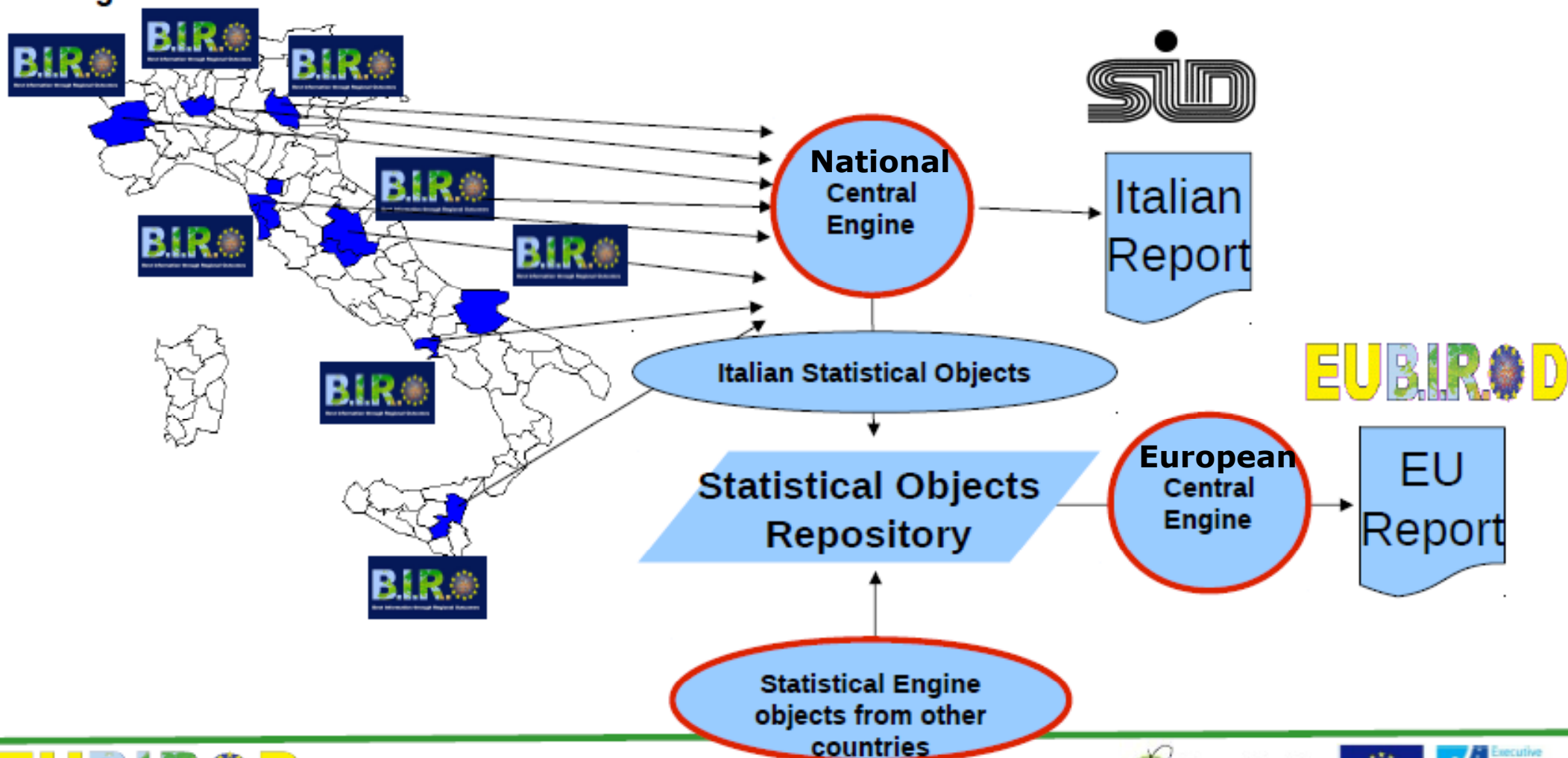


Barplot 5.3.7.12b - Foot Ulceration (by Data Source) - Age - 15 - 50 - Percent of Foot Ulcers - Type 2

2

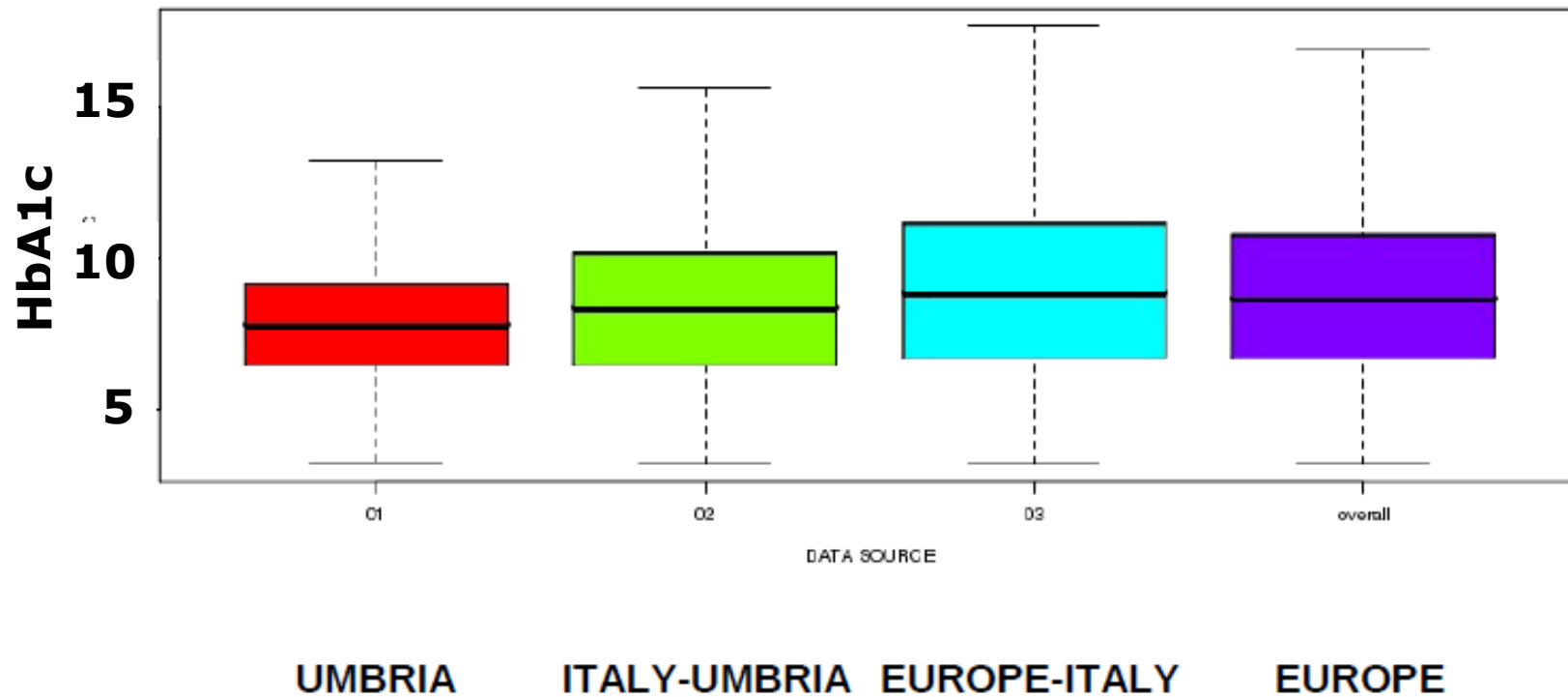
# Recursive central engine on statistical objects (SO)

BIRO installed in N=7 clinical centres + Umbria Register (database split in N=6 sources). Data Import + Statistical Engine



# Recursive Central Engine on SO Repository

## Example of Descriptive Results (1)





European Commission

# HEALTH-EU

Your gateway to trustworthy information on public health

European Commission > Health-EU > News > 2012 > 13

My health

My lifestyle

My environment

Health problems

Care for me

Health in the EU

## News article



### EUBIROD – A European diabetes database

Over 88 million adults in the EU have diabetes and long numbers are believed to remain undiagnosed.

With an increasing prevalence, the impact of diabetes complications is threatening health systems across Europe. The social and economic implications are enormous.

The reason for this is that people are leading more sedentary lives, their eating habits are changing and they don't do enough exercise, if the younger generation continues like this it will increase the spread of diabetes.

It is estimated that already between 5% and 10% of total health expenditure is spent on providing healthcare for the diabetic population.

#### Fighting the epidemic by sharing knowledge

In order to halt the spread of the diabetes epidemic the EU [Public Health Programme](#) has funded the [EUBIROD](#) project, which aims at sharing knowledge about prevention, treatment and patient care.

Despite the large amounts of data and reports available, current information on diabetes in Europe is scattered, fragmented and, more worryingly, underutilised and undervalued. For this reason, the main outcome of the EUBIROD project is a permanent and sustainable online European Diabetes Register for standardised exchange of data and knowledge between EU countries on diabetes.

The register is currently only used by healthcare professionals but a number of ideas have been launched to eventually make this system available to all EU citizens.

Why is a national registry important?

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11 April 2013

e-newsletter

Healthier and safer for European citizens >

Health topics: A-Z

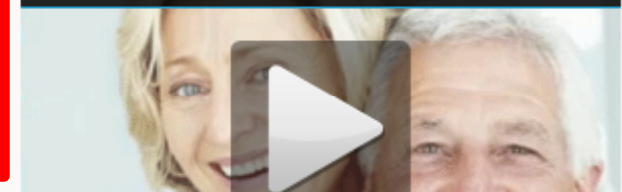
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O P Q R S T U V W X Y Z

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Third Course 2012

Second Course 2011

Special Meeting 2010

First Course 2009

Meta Registry

Software

E-learning

BIRO monograph



## The BIRO Academy



The BIRO Academy is the major dissemination activity of the EUBIROD project. It is aimed at showing the philosophy underlying the BIRO system, the way it has been developed, the results achieved, the products delivered, and the way this approach evolves.

The Academy provides a direct opportunity to interact with a growing international network of distinguished professionals with a high level mix of expertise in the fields of health policy, clinical practice, biostatistics, epidemiology and information technology.

**The BIRO Academy allows developers of diabetes registers to learn from success stories in the field of electronic medical records, participating to the further expansion of the BIRO System to monitor diabetes on a continuous basis, by directly linking providers to the final users of diabetes indicators.**

## Under the spotlight

February 2012  
New Meta Registry  
[available here](#)

February 2012  
New e-learning website  
[available here](#)

February 2012  
New BETA BIROBox 2.1.13  
available in the [BETA Section](#)

November 2010  
The OS BIROX 0.5.1  
[available here](#)

September 2009  
The BIRO Monograph  
[available here](#)

# Prospettive della 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  
Delegates report to: Guest User (France)

Dear 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 Reports.

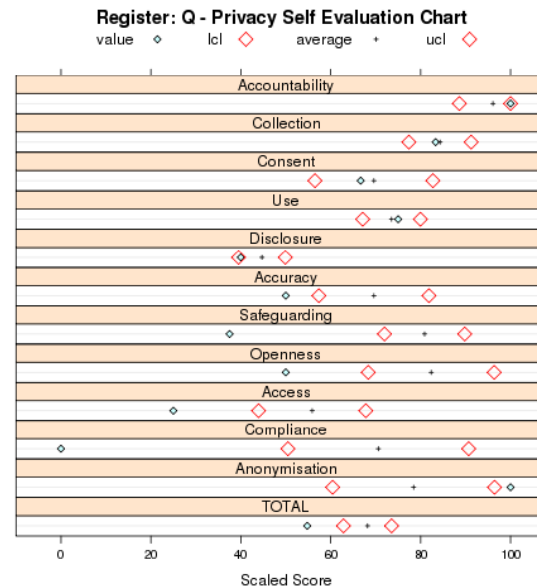
The details for a specific data source, once fully completed, will be used to create a validated configuration file that can be included in the integrated BIRO software.

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.
- use 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 analyze 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: Matthias Brillante (University of Montreal)



**BIRO Academy** **EUBIROD**

You are not logged in. (1/1/13)

Navigation: Home, Courses

Site news: Welcome to the Eubiroad 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) Name

Courses: General Core, Customized Database, Customized ToolBox, EU Diabetes Report, International Diabetes Report, Privacy, Data Protection and Health Information Systems

**1. Rete integrata di Fonti di Dati nel Diabete (Meta-Registry)**

**2. ".dati economici sui costi diretti e indiretti della prevenzione e della gestione della malattia.."**

**3. Promozione delle Best practice nella Protezione della Privacy (validazione di misure oggettive per il "Privacy Performance Assessment (EJPH 2012)")**

**4. Disseminazione dell'approccio BIRO (e.learning)**