



Using health information without buying the data

Analysis of quality of care indicators from diabetes registries of 19 European countries

Fabrizio Carinci
Technical Coordinator
EUBIROD Project Consortium

"Innovations in the measurement of quality of care in Europe"
Canadian Institute for Health Information
Toronto 26th September 2013





The problem: making an active use of health information

- Performance reports have become common practice to benchmark and leverage quality, equity and efficiency in health systems
- The aim is measuring to improve health systems and population health
- Data management for large scale system analysis can be extremely complex: massive and ever increasing databases, usually dispersed across jurisdictions, domains, health systems levels, users, etc.
- Privacy legislation may not allow data linkage, even when using pseudonym
- Statistical methods can be complex and results difficult to interpret for policy makers.

- International projects show all the intrinsic limitations of a centralized approach: data transfer, legislative barriers, lack of standardized data....
- Protocols and agreed procedures must be put in place to automatically check data quality, manage information exchange, and deliver results on health care quality indicators at all levels

OECD Health Care Quality Indicators



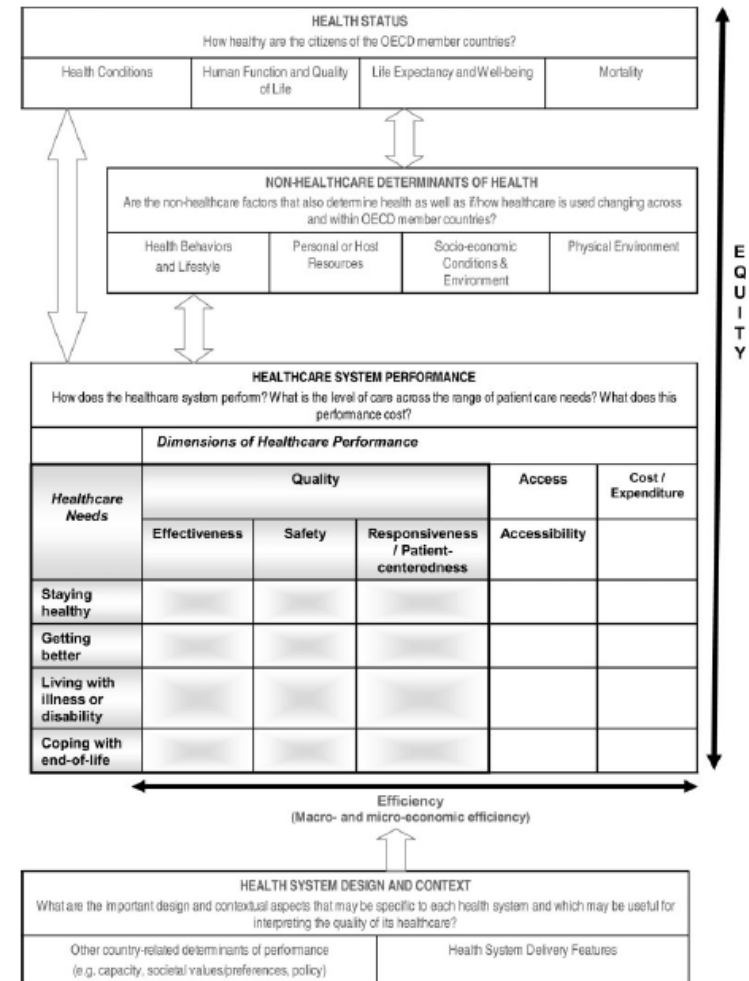
2002

Ministerial Conference, 2004

Conceptual Paper, 2006

Health Care Quality Indicators Report, 2006

Toronto Bureau Meeting 2013



Quality of Care in Diabetes: easier?

[IDF Diabetes Atlas, Fourth Edition, 2009]

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

- Multicentric 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 is so difficult even for a specific disease?

[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.**”*



EU 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**”*

Data sources on quality of care



**Linked
Administrative Data**



Clinical Databases



**Epidemiological
Studies**

Diabetes Registers



Population-based



Disease Management



Research oriented

Unified model: cathedral or bazaar?



VS



Mixed models can be more flexible
...and also more interesting for humans!



L'Aquila (Abruzzo, Italy) – Piazza Duomo before the earthquake



EU BIRO and EUBIROD Projects

BIRO project (2005-2009): DG-SANCO co-funded project in diabetes

- ***Aim: to provide European health systems with an ad hoc, evidence and population-based diabetes information system***

EUBIROD project (2008-2011) builds upon BIRO

- ***Aim: “to implement a sustainable European Diabetes Register through the coordination of existing national/regional frameworks and the systematic use of the BIRO system in 20 European countries***

Project Consortia

University of Perugia (I)
Serectrix snc (I)
University of Dundee (GB)
Joanneum Research (A)
NOKLUS (N)
Paulescu Institute (RO)
University of Malta (M)
Republic of Cyprus (CY)
Sahlgrenska Institute (S)
University of Debrecen (H)
Institute of Public Health (B)
IDF (B)
Adelaide Meath Hospital (IRL)
CBO (NL)
Centre Hospitalier (LUX)
University of Ljubljana (SLO)
IMABIS Foundation (E)
Medical University Silesia (PL)
Havelhoe Hospital (D)
Hillerod University Hospital (DK)
Vuk Vrhovak University (HR)

Participating Institutions:
Ministry of Health, Latvia
IDIBAPS, Spain
Dasman Diabetes Centre, Kuwait



BIRO

11/2005

9/2008

5/2009

3/2012

EUBIROD



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

Duration: 42 months

Total N.Participants: 26

N.Countries: 21

Coordinating Centre: University of Perugia, Italy





The vision

“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

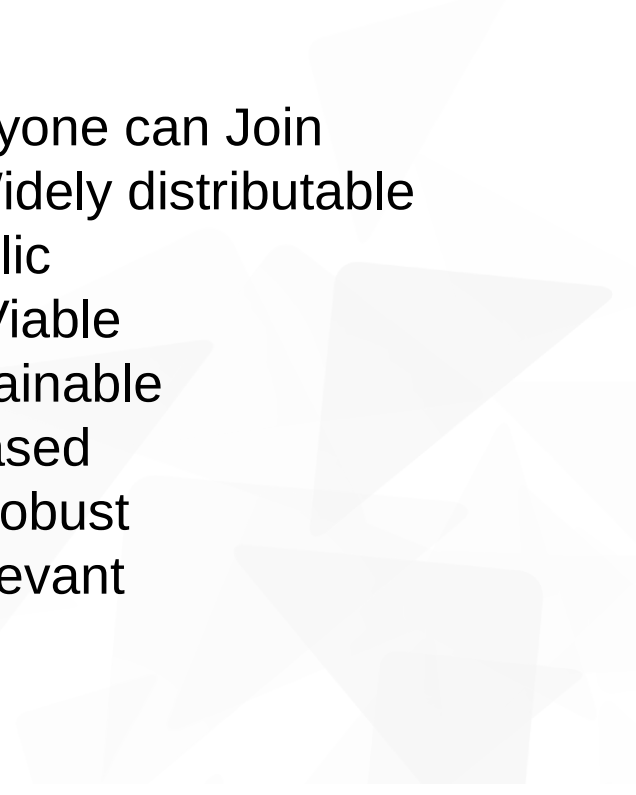
Privacy by Design = Legally Viable

Distributed = Efficient and Sustainable

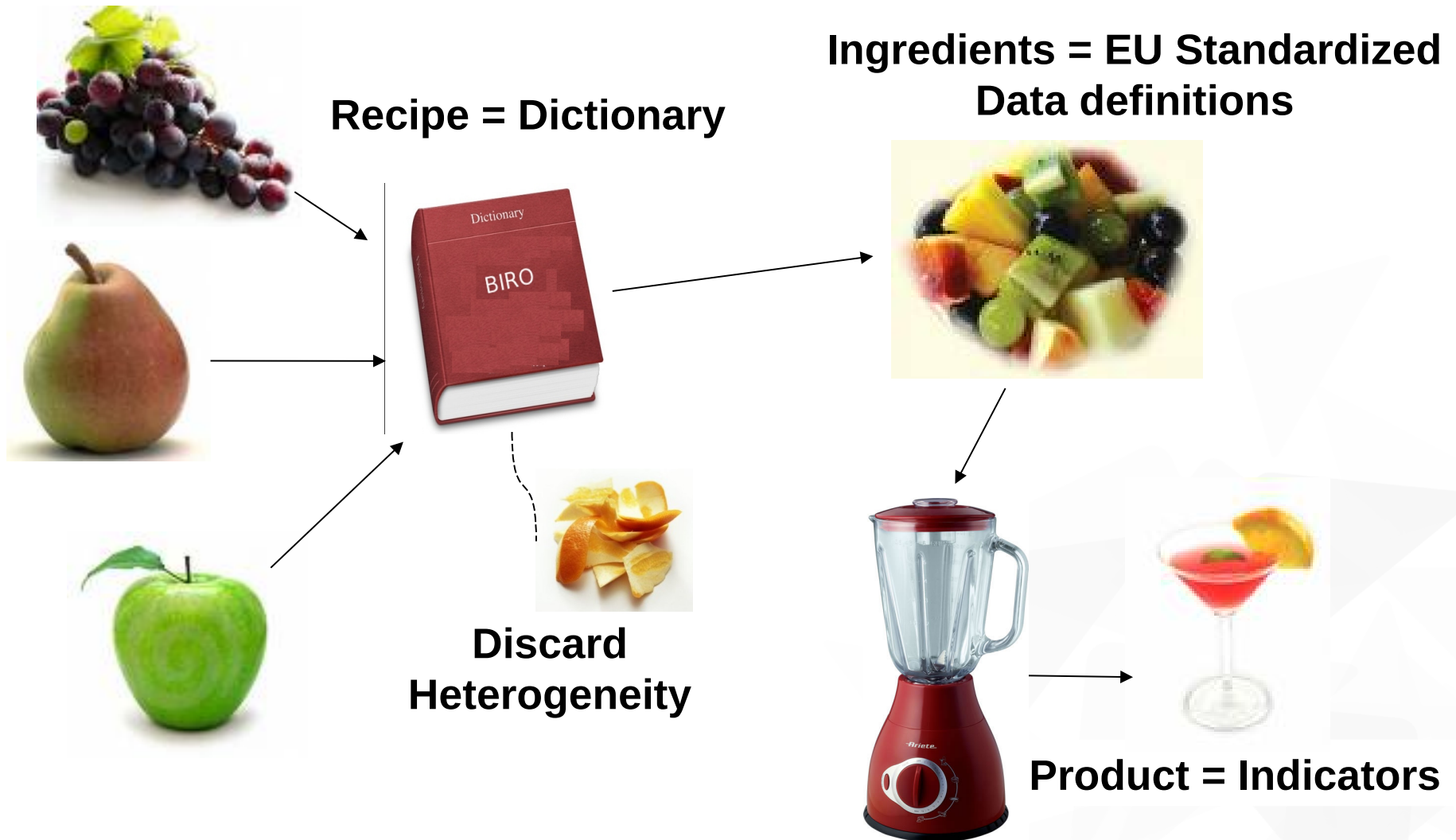
Standardized = Evidence-based

Risk Adjusted = Statistically Robust

Multidimensional = Policy Relevant



Coordination rather than unification: a pragmatic approach



BIRO Data Standards

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



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



BIRO Data Standards

[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
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 g/day
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

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 4-5 June 2010 [read more](#)



BIRO Data Standards

<http://www.eubiroad.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)

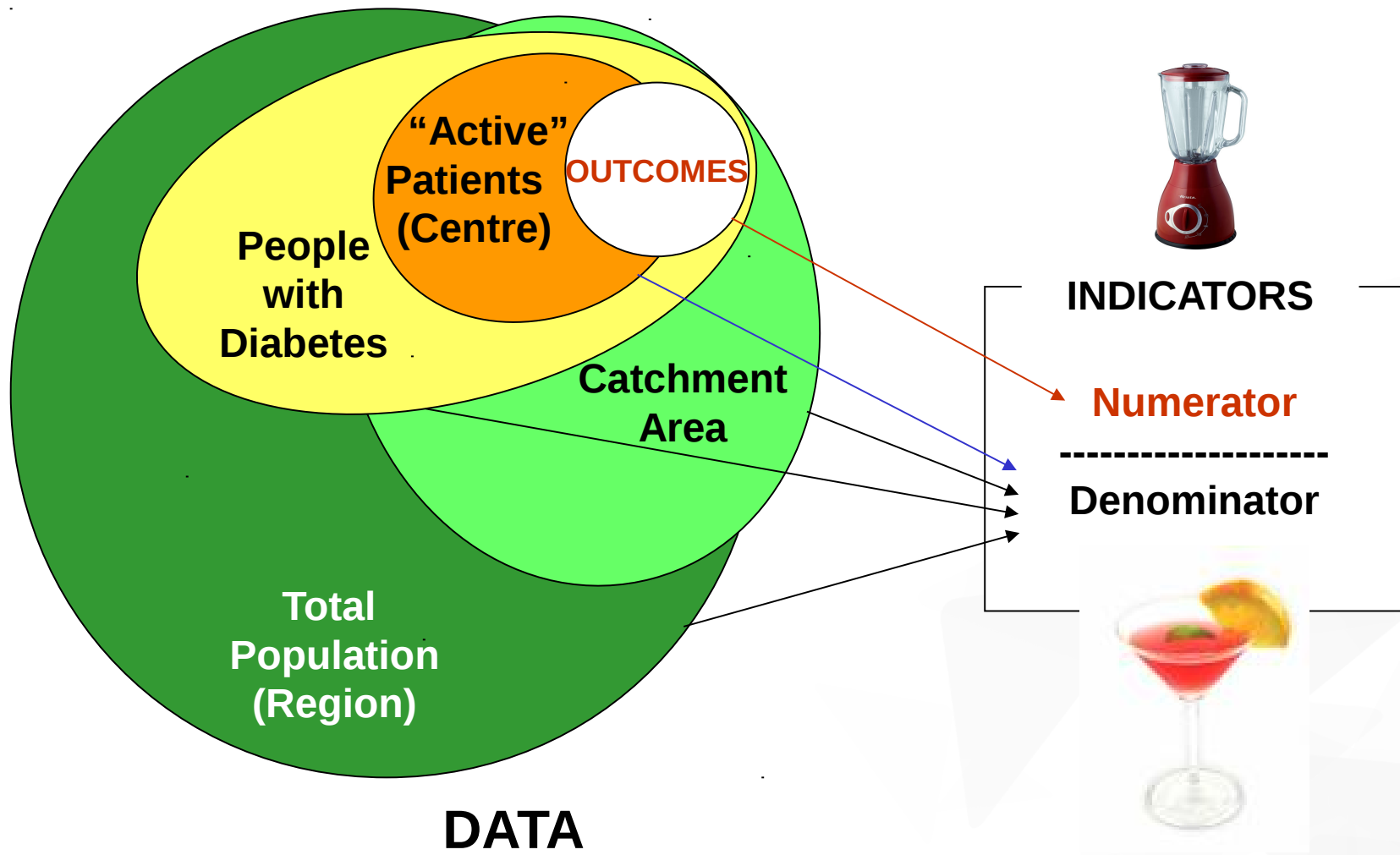
Health System: Structures, Processes (N=20)

Population: Vital Statistics (N=3)

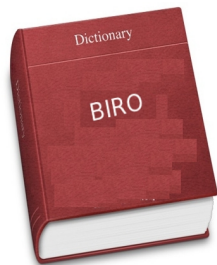
Risk Adjusted: Outcomes (N=31)

Pediatric Section (N=6)

The problem of selection bias in data sources



BIRO Core Dataset



N=48

1. **ID Patient**
2. ID Centre
3. **Type of Diabetes**
4. **Sex**
5. **Date of Birth**
6. **Date of Diagnosis**
7. **Episode Date**
8. Smoking Status
9. N.Cigarettes (x day)
10. Alcohol Intake (g/x day)
11. Weight
12. Height
13. BMI
14. Systolic Blood Pressure
15. Diastolic Blood Pressure
16. HbA1c
17. Creatinine
18. Microalbumin
19. Total Cholesterol
20. HDL
21. Tryglicerides
22. Eye Examination
23. Retinopathy Status
24. Maculopathy Status
25. Foot Examination
26. Foot Pulses
27. Foot vibration
28. End Stage Renal Failure
29. Renal Dyalisis
30. Renal Transplant
31. Stroke
32. Foot Ulceration
33. Acute Myocardial Infarction
34. Laser
35. Hypertension
36. Blindness
37. Amputation
38. Antihypertensive Medication
39. Hypoglicemic Drug Therapy
40. Oral Drug Therapy
41. Pump Therapy
42. Nasal Therapy
43. Average Injections (x day)
44. Self monitoring
45. Diabetes Specific Education
46. Lipid Lowering Therapy
47. Anti-platelet Therapy
48. Patient enrollment in DMP for diabetes

BIRO "Local Mapping"

BIROBox

Help

Best Information through Regional Outcomes

BIROBox Setup

BIRO Database Database Engine

Local Report Statistical Engine

Data Transmission Communication Software

Global Report Central Engine

Global Connection Web Portal

Fields mapping configuration

Configure mapping between BIRO fields and local fields

BIRO field: **Type of Diabetes**

BIRO field name: TYPE_DM

BIRO field description: Type of Diabetes

Extract from local database

Local field name: tipoDiabetelnt

BIRO category	Expression	Local value	BIRO Value
Type 1	if is custom text	1	1
Type 2	if is custom text	2	2
Other Types	if is custom text	0	3

Previous Finish

Building the BIRO architecture: Privacy by Design (EU Data Directive)

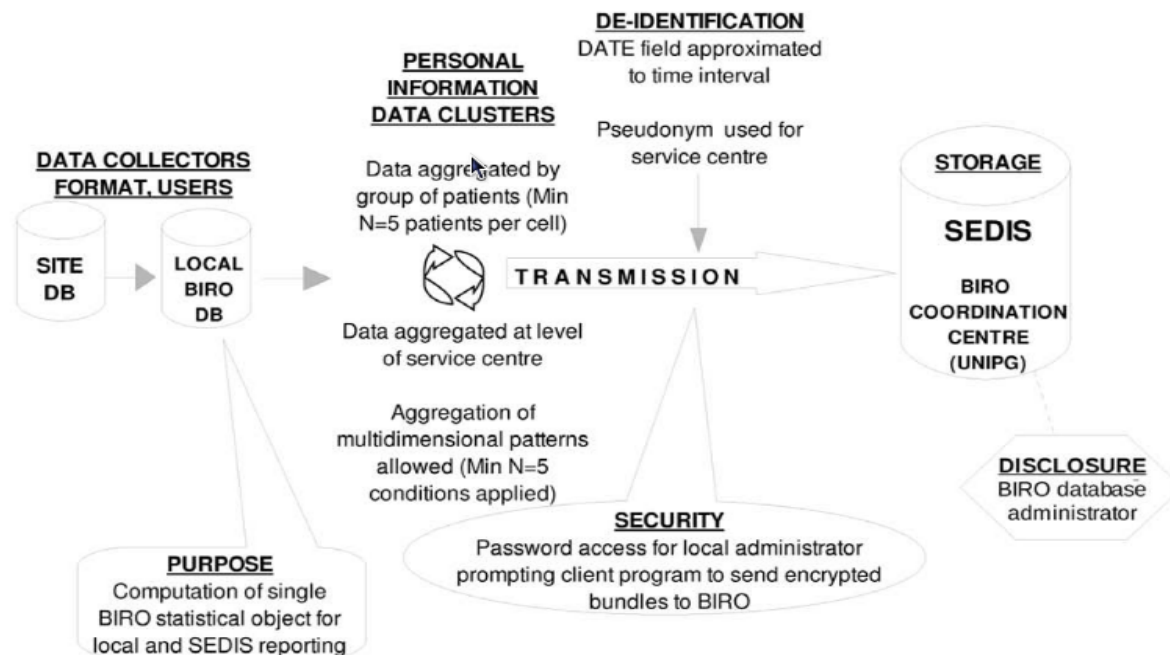
Di Iorio CT et al, J Med Ethics. 2009 Dec;35(12):753-61

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 F S Skeie,⁸ P Taverner,⁸ V Traynor,⁶ M Massi Bene

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



BIRO Privacy impact assessment

Delphi Procedure

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

Data Flow Table

CANDIDATE ARCHITECTURE 2: AGGREGATION BY GROUP OF PATIENTS

Scenario 1: Grouping condition directly set by statistical object (e.g. ordered frequency distribution of LOS by CENTRE to compute variability of medians)

Description of personal information / Data clusters	Collected by	Type of format	Used by	Purpose of collection	Transmission to BIRO: de-identification	Security mechanisms for data transmission	Format of BIRO Database	Disclosed to	Storage or retention site
NO aggregation size limit OR min aggregation N=5 patients per cell OR min aggregation N=5, only applicable for high critical privacy variables e.g. service centre, geographical site etc Aggregation across service centres	BIRO partner	One Record for each aggregation level	BIRO partner (local engine), BIRO Consortium (central engine)	Computation of single BIRO statistical object for local and SEDIS reporting	OPTION 1: All DATE fields transmitted as in original OPTION 2: DATE fields approximated to time interval (e.g. months)	OPTION 1: Password access for local administrator prompting client program to send encrypted bundles to BIRO OPTION 2: Client program automatically sending encrypted data (agent)	Separate sets of aggregated tables linkable by predefined statistical criteria	OPTION 1: BIRO database administrator OPTION 2: All local database administrators	OPTION 1: BIRO Coordinating Centre OPTION 2: EU (DG-SANCO)

Data Flow Questionnaire

SCENARIO 1:
Question 1. PERSONAL INFORMATION/DATA CLUSTER: DECISION 1

Option	Privacy				Information Content	Technical Complexity
	Identifiability	Linkability	Observability	Overall	Overall	Overall
No Aggregation size limit						
Min aggregation N=5 patients per cell						
Min aggregation N=5 patients per cell, only applicable for high critical privacy variables e.g. service centre, geographical site etc						

Overall Consensus Table

A	Personal Data	No Aggregation size limit	3.5	4	3
B	Personal Data	Min Aggregation N=5 patients per cell	2	3	2
C	Personal Data	Min aggregation N=5 patients per cell, only applicable for high critical privacy variables e.g. service centre, geographical site etc	2	4	3
1	Personal Data	Aggregation across service centres	2	2	2.5
E	Personal Data	Data aggregated at the level of service centre	2.5	3	3
F	Personal Data	Aggregation of multidimensional patterns (e.g. risk adjustment) NOT allowed	2	2	2
T	Personal Data	Aggregation of multidimensional patterns (e.g. risk adjustment) allowed	3	3.5	2.5
C	Personal Data	Aggregation of multidimensional patterns (e.g. risk adjustment) allowed, Min N=5 condition applied	2	4	3
R	Transmission	All DATE fields transmitted as in original	3	3	2
E	Transmission	DATE fields approximated to time interval (e.g. months)	2	2	2
3	Transmission	Client program automatically sending encrypted data (agent)	2	2	2



BIRO Fundamental Statistical Principles

Region

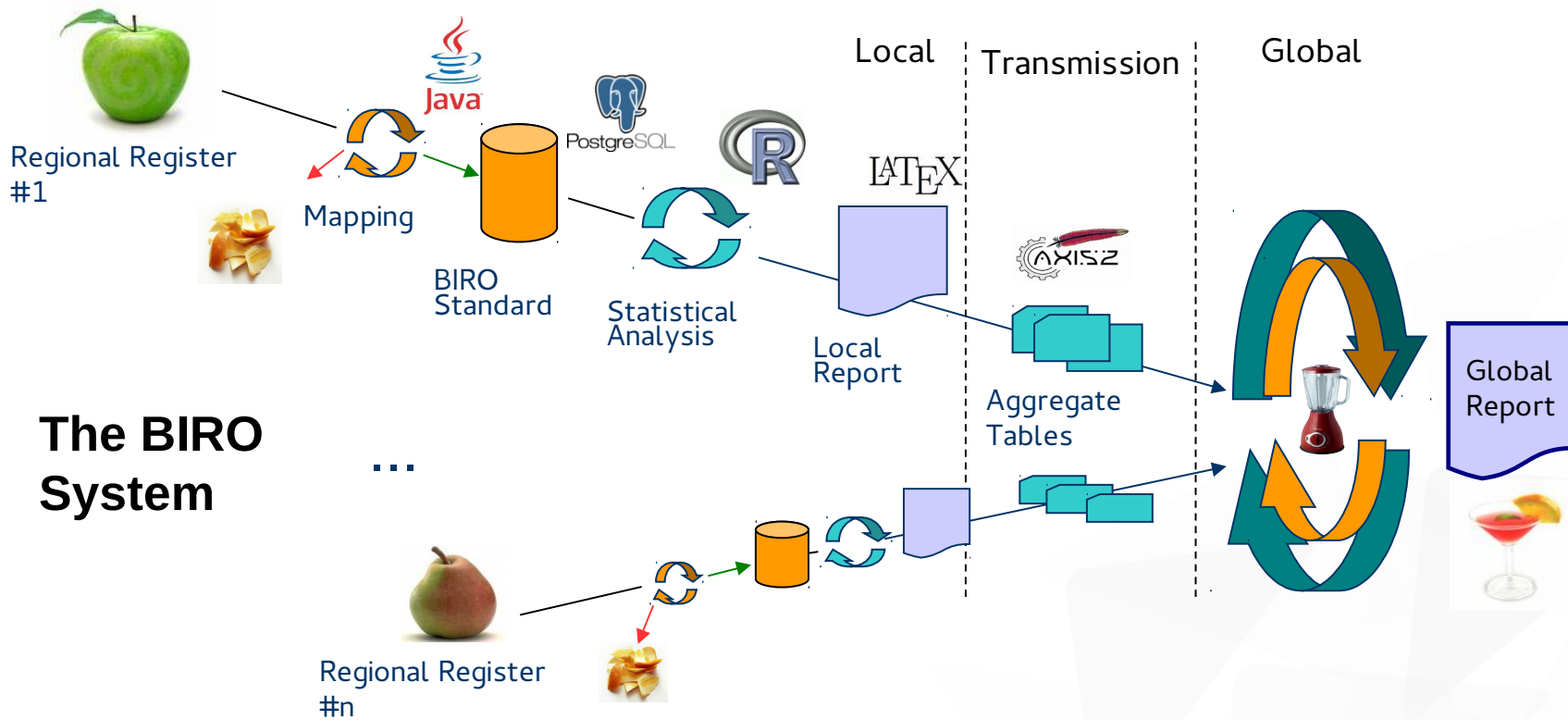
a network sharing a common homogeneous framework for the collection of health information (e.g. group of professionals/centres, local health authority, single provinces, regions, states, or group of states)

Statistical Object

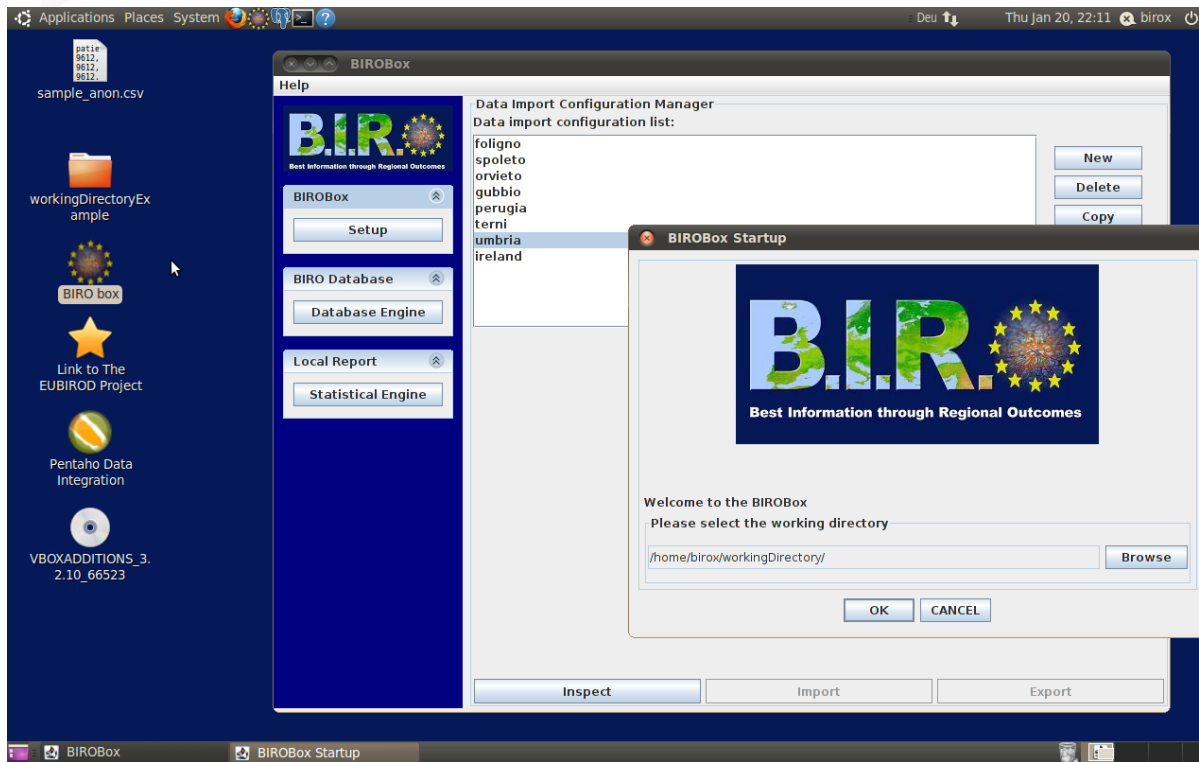
An element of a distributed information system carrying essential data in the form of embedded, partial aggregate components, required to compute a summary measure or relevant parameter for the whole population from multiple sites

The BIRO System

http://www.eubirod.eu/images/eubirod_homepage_mainfigure_explained.png



BIRO System Software Integration



The BIRO System is an open source suite of integrated software tools distributed as a complete Linux operating system running on Virtual Machine: **BIROX**.

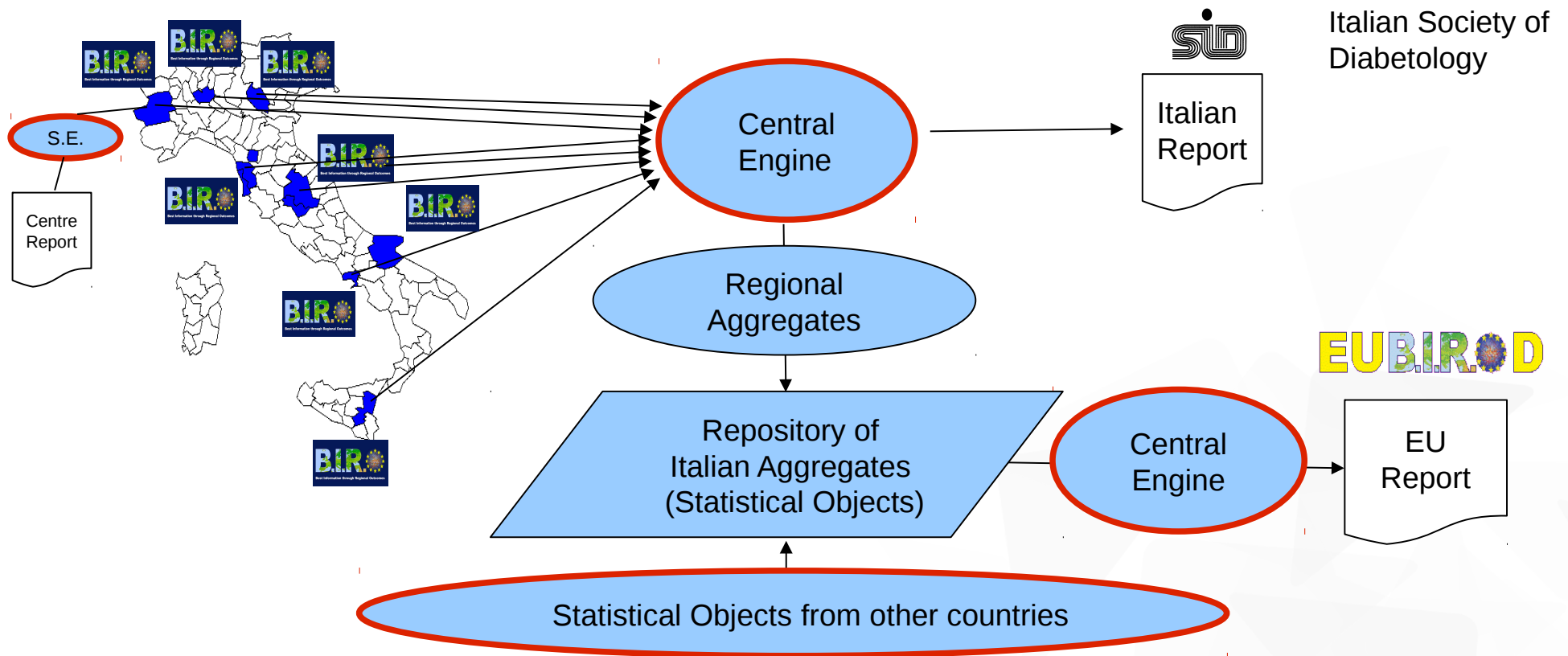
Runs on any platform (Windows, Linux, MacOS) = *no need to change the setup of the local environment!*

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

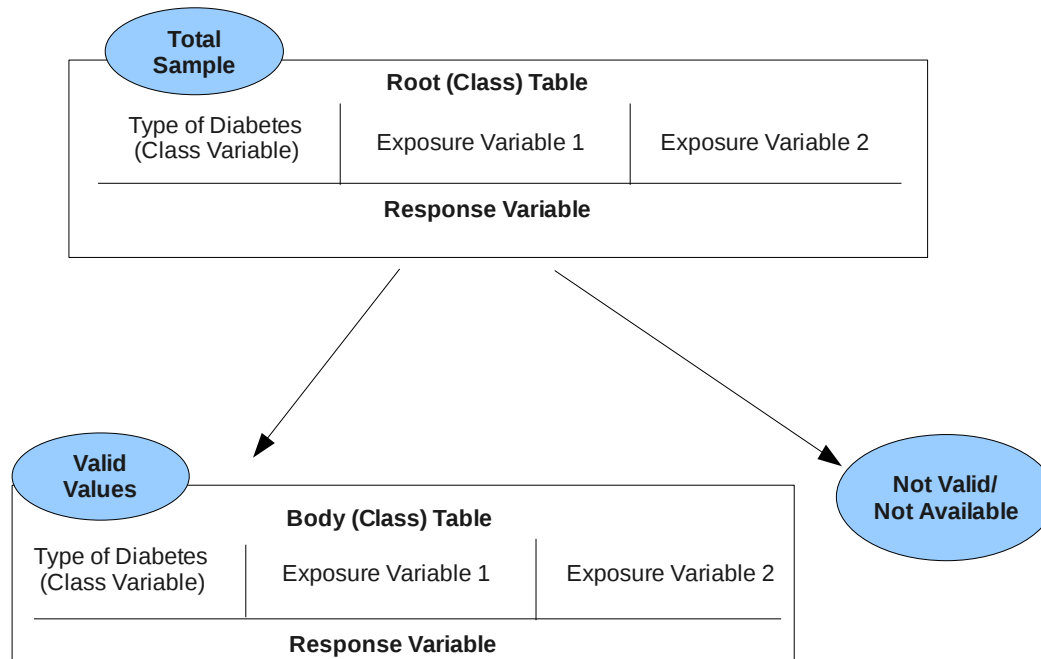
How the BIRO System works in EUBIROD: country example

ITALY: BIRO installed in N=8 centres

DATABASES OF INDIVIDUAL RECORDS STAY WITH THE ORIGINAL DATA CUSTODIAN



Further specifications required: Structure of the Report



Body (Class) Graphs

BARPLOTS

Exposure Variable 1 (Exposure Variable 2)
Data Source

Response Variable=Categorical

TRELLIS / BOXPLOTS

Exposure Variable 1 (Exposure Variable 2)
(Data Source)

Response Variable=Continuous

Standardized (Class) Estimates (Risk Adjusted Estimators)

Data Source
Response Variable

Standardized (Class) Graphs

BARPLOTS

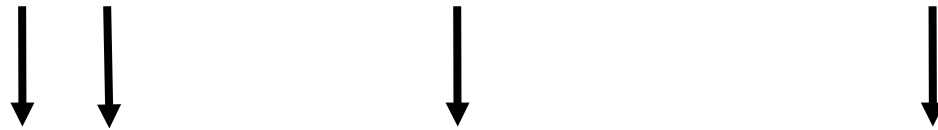
FOREST PLOTS

Data Source
Response Variable

Standardization (AHRQ 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

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

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

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

Logistic regression for risk adjustment: why using individual data?

Box 3.4.2. Output Logistic Model on all observations

The LOGISTIC Procedure
Model Information

Data Set WORK_MODEL_
Response Variable HI_HBA
Number of Response Levels 2
Number of Observations 17102
Model binary logit
Optimization Technique Fisher's scoring

Response Profile

Ordered Value	HI_HBA	Total Frequency
1	1	4856
2	0	12246

Probability modeled is HI_HBA=1.

Analysis of Maximum Likelihood Estimates

Standard Parameter	Wald DF	Estimate	Error	Chi-Square	Pr > ChiSq
Intercept	1	-0.6862	0.1028	44.5243	<.0001
GENDER	1	-0.2297	0.0343	44.7555	<.0001
CL_AGE2	1	0.0916	0.1092	0.7027	0.4019
CL_AGE3	1	-0.1465	0.1040	1.9842	0.1589
CL_AGE4	1	-0.2491	0.1086	5.2637	0.0218

Complete Sample

Box 3.4.3. Output Logistic Model on aggregate data

The LOGISTIC Procedure
Model Information

Data Set WORK.IN_SEDIS
Response Variable HI_HBA
Number of Response Levels 2
Number of Observations 16
Weight Variable COUNT
Sum of Weights 17102
Model binary logit
Optimization Technique Fisher's scoring

Response Profile

Ordered Value	HI_HBA	Total Weight	Total Frequency
1	1	8	4856.000
2	0	8	12246.000

Probability modeled is HI_HBA=1.

Analysis of Maximum Likelihood Estimates

Standard Parameter	Wald DF	Estimate	Error	Chi-Square	Pr > ChiSq
Intercept	1	-0.6862	0.1028	44.5243	<.0001
GENDER	1	0.2297	0.0343	44.7555	<.0001
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CL_AGE3	1	-0.1465	0.1040	1.9842	0.1589
CL_AGE4	1	-0.2491	0.1086	5.2637	0.0218

Combinations of Levels of Covariates

Box 3.4.4. Observed/expected rates by centre using logistic regression

Centre	Den.	Num.	% Observed	% Expected	95% Lower	95% Upper
1	7699	2189	28.4	28.5	27.5	29.5
2	2360	1000	42.4	28.0	26.1	29.8
3	3422	916	26.8	28.4	26.9	29.9
4	1239	222	17.9	28.3	25.8	30.8
5	2382	529	22.2	28.4	26.6	30.2

Same results !

Statistical Objects Data



The image shows a desktop file browser window titled "Desktop - File Browser". The address bar shows the path "fabrizio Desktop". The main pane displays a directory tree with the following structure:


- testrun-2.0.7 (folder)
 - workingDirectory (folder)
 - _se (folder)
 - output (folder)
 - reports (folder)
 - data (folder)
 - #231010090913 (folder)
 - 2008 (folder)
 - 2 (folder)
 - i5_3_3_type_dm_d4_1a.csv (307 bytes, CSV document)
 - i5_3_3_type_dm_d1_3b.csv (100 bytes, CSV document)
 - i5_3_3_type_dm_d1_3a.csv (334 bytes, CSV document)
 - i5_3_3_sex_type_2_d4_1a.csv (303 bytes, CSV document)
 - i5_3_3_sex_type_2d1_3b.csv (101 bytes, CSV document)
 - i5_3_3_sex_type_2d1_3a.csv (376 bytes, CSV document)

The file "i5_3_3_type_dm_d1_3a.csv" is selected. A secondary window titled "i5_3_3_type_dm_d1_3a.csv - /home/fabrizio/Desktop/testrun-2.0.7/workingDirectory/_se/output/data/#231" is open, displaying the following CSV content:

```
1 "type dm", "sum", "sbp c140", "n", "id", "perc", "start", "end", "dbname"
2 "Type 1", 83, "[0 - 140)", 50, "2", 60.2, 2007-12-31, 2008-12-31, "terni"
3 "Type 2", 2511, "[0 - 140)", 1150, "2", 45.8, 2007-12-31, 2008-12-31, "terni"
4 "Type 1", 83, "[140 +)", 33, "2", 39.8, 2007-12-31, 2008-12-31, "terni"
5 "Type 2", 2511, "[140 +)", 1361, "2", 54.2, 2007-12-31, 2008-12-31, "terni"
6
```

EUBIROD Privacy Performance Assessment





Welcome Scotland [LOGOUT](#)

[Questionnaire](#) [P.I.A.](#) [Data Manager](#) [Table Manager](#) [Admin](#) [User Guide \(PDF\)](#)

Privacy Impact Assessment (PIA) Questionnaire

[P.I.A.](#) [Section 1](#) [Section 2](#) [Section 3](#) [Section 4](#) [Section 5](#) [Section 6](#) [Section 7](#) [Section 8](#) [Section 9](#) [Section 10](#) [Page 11](#) [Summary](#)

You are currently in section 1

PLEASE NOTE:
For each question not answered, a value of "Missing" will be automatically applied
If you want to save this section **without answering any of these questions**, you can do so by simply clicking on the "Save" Button. Be Aware that by doing so, each question will be given the value of "Missing"

Accountability for Personal Information


Code	Question for Analysis	Answer	Provide Details
1.1	Has the custody and control of personal information been determined?	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> ND/NA	
1.2	Has the accountability of the registry/database custodian of personal information been documented?	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> ND/NA	
1.3	Are third parties involved in the custody or control of the personal information?	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> ND/NA	
1.4	If third parties are involved, do you have an agreement in place that establishes privacy requirements?	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> ND/NA	
1.5	Are there any requirements in registry/database legislation or policies on the management of personal information that affect the EUBIROD project?	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> ND/NA	



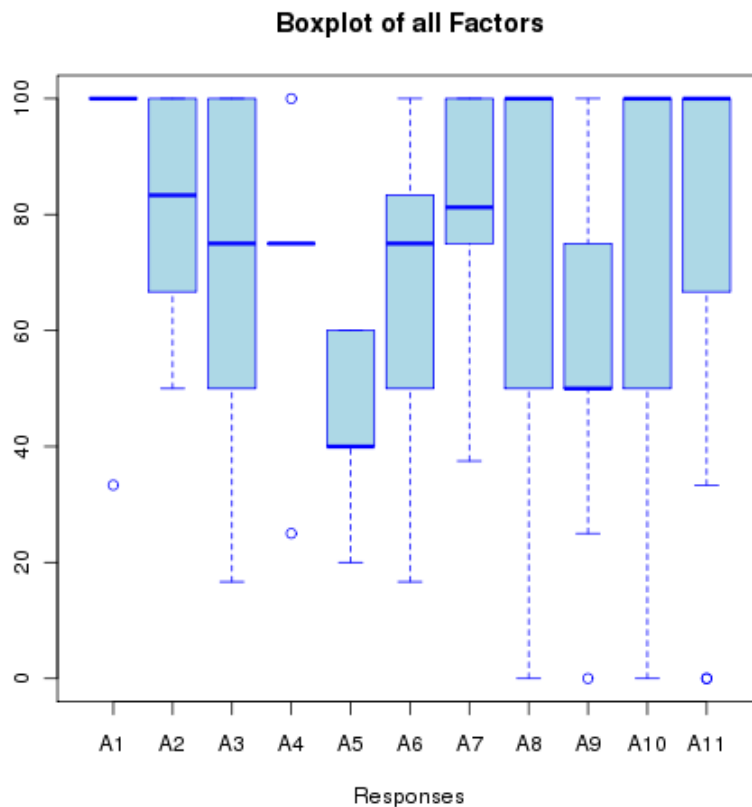
EUBIROD Privacy Performance Assessment

Includes N=11 sections - one for each **factor** identified.
Each section (factor) includes various questions (**sub-factors**)

FACTORS:

- A1.** Accountability of personal information
 - A2.** Collection of Personal Information
 - A3.** Consent
 - A4.** Use of Personal Information
 - A5.** Disclosure and Disposition of Personal Information
 - A6.** Accuracy of Personal Information
 - A7.** Safeguarding Personal Information
 - A8.** Openness
 - A9.** Individual Access to Personal Information
 - A10.** Challenging Compliance
 - A11.** Anonymization Process for Secondary Uses of Health Data
- 

EUBIROD Privacy Performance Assessment



Low average (median):

A5: Disclosure and Disposition (40%)

A9: Individual Access (50%)

A3: Consent (75%)

A4: Use of Personal Information (75%)

A6: Accuracy (75%)

High Variability (standard deviation, range):

A10: Challenging Compliance (39%, 0-100%)

A11: Anonymisation (35%, 45-100%)

A8: Openness (30%, 0-100%)

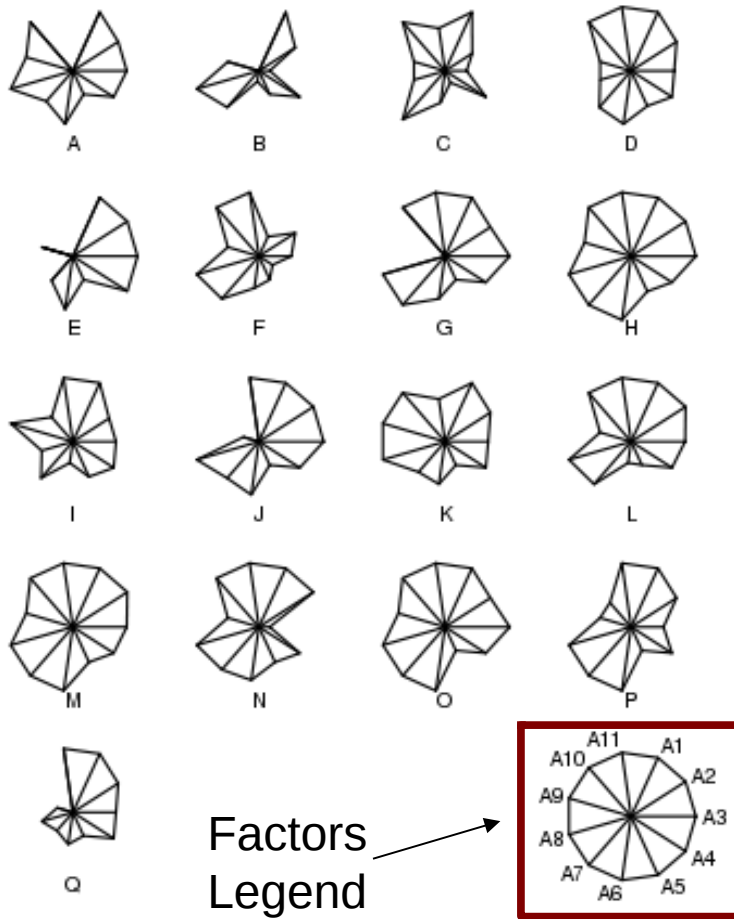
A3: Consent (28%, 17-100%)

A6: Accuracy (26%, 17-100%)

A9: Individual Access (25%, 0-100%)

EUBIROD Privacy Performance Assessment

PIA Factors by Diabetes Register



- **Starplots** summarize the “Privacy Profile” of each EUBIROD register included in the database

EUBIROD Privacy Performance Assessment

DI IORIO CT, CARINCI F et al, European Journal Public Health, 4 May 2012

The European Journal of Public Health Advance Access published May 4, 2012

European Journal of Public Health, 000-000

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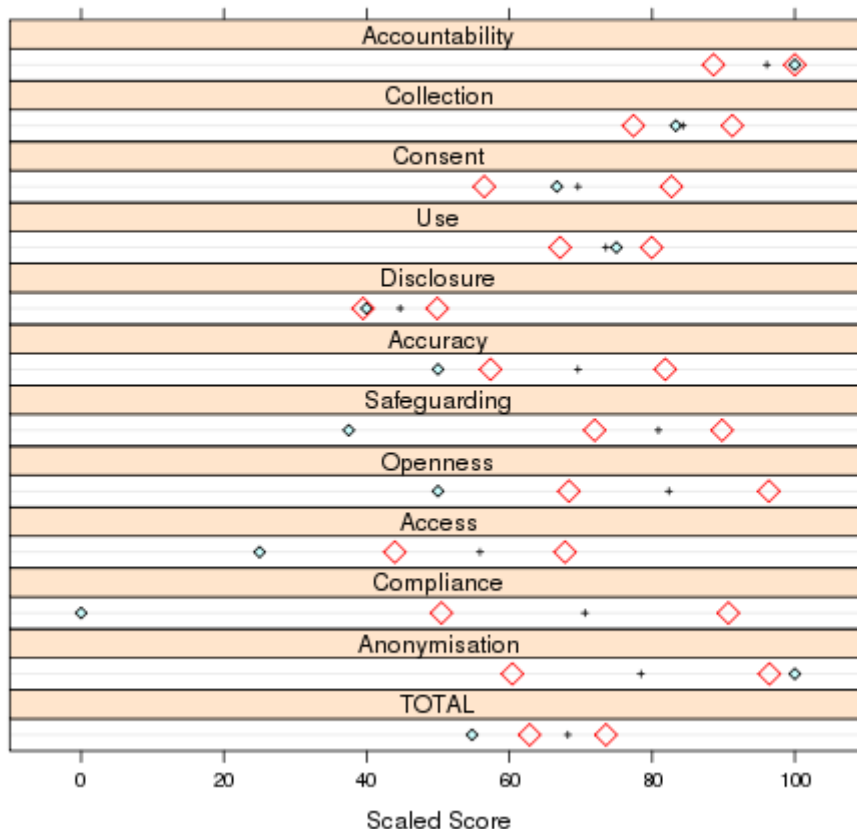
doi:10.1093/eurpub/cks043

Cross-border flow of health information: is 'privacy by design' enough? Privacy performance assessment in EUBIROD

Concetta Tania Di Iorio¹, Fabrizio Carinci¹, Massimo Brillante², Joseph Azzopardi³, Peter Beck⁴, Natasa Bratina⁵, Scott G. Cunningham², Carine De Beaufort⁶, Noemi Debacker⁷, Przemyslaw Jarosz-Chobot⁸, Michael Jecht⁹, Ulf Lindblad¹⁰, Tony Moulton¹¹, Želiko Metelko¹², Attila Nagy¹³, George Olympios¹⁴, Simion Pruna¹⁵, Michael Roder¹⁶, Svein Skeie¹⁷, Fred Storms¹⁸, Massimo Massi Benedetti¹⁹


Register: Q - Privacy Self Evaluation Chart

value \diamond lcl \diamond average $+$ ucl \diamond





- Each register can compare own practice against the average of the overall sample and the maximum attainable score
- Example:
 - Maximum score in terms of accountability and anonymisation
 - Acceptable levels for collection, consent, use and disclosure
 - All other factors show poor privacy performance

EUBIROD Meta-Registry



Meta Registry of Diabetes Data Sources



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

Logout

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 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 duly 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 "proposed 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 variation in practices and to identify pathways for quality improvement.

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



Please Select a Registry within the list below to display/edit the appropriate data.


[Bourgogne]

Select

Your Profile:

Total number of data sources: 2

Total target population: 0



EUBIROD Report 2010

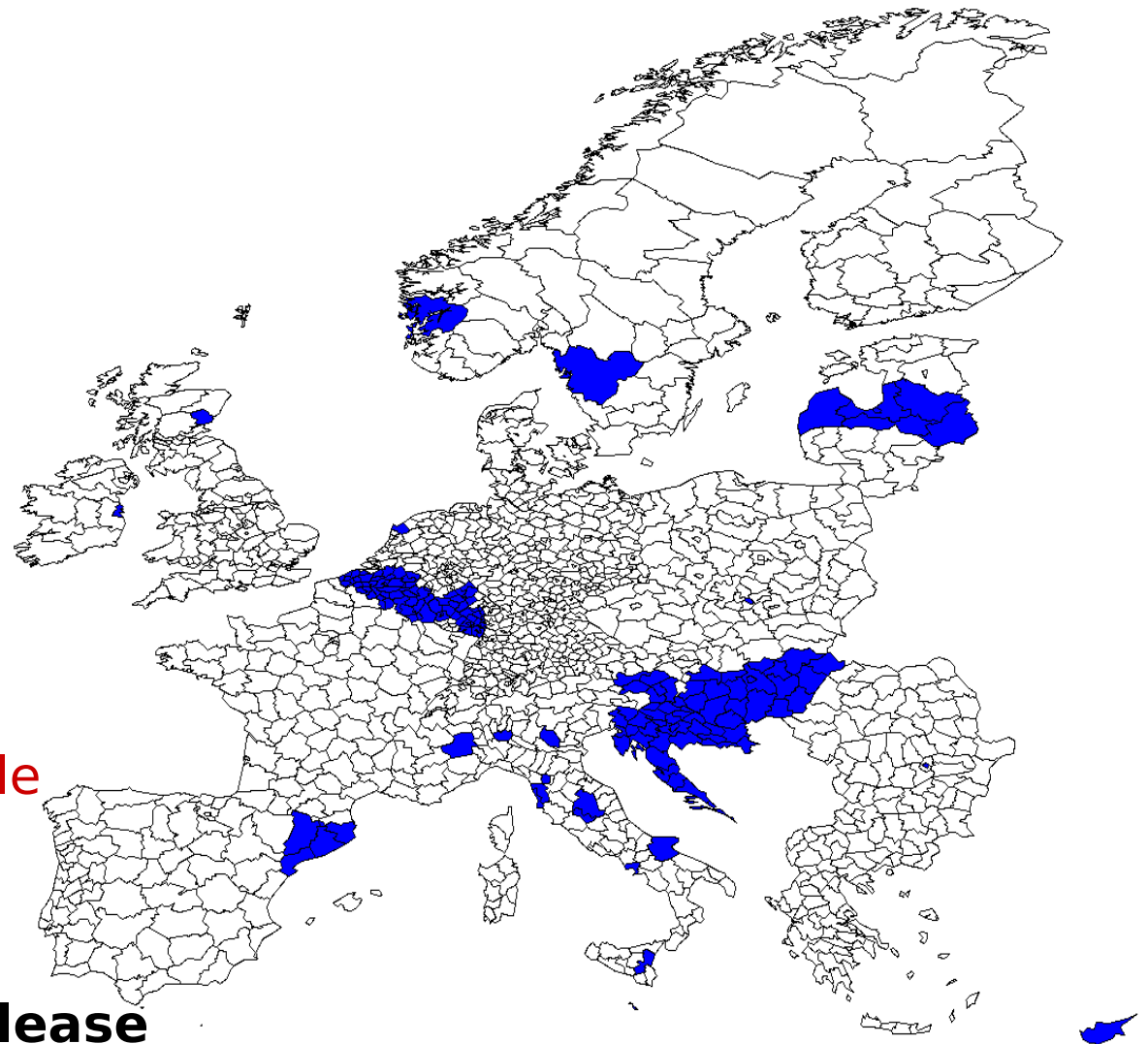
8/2/2012: New BIRO
Release 2.1.12

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 !**

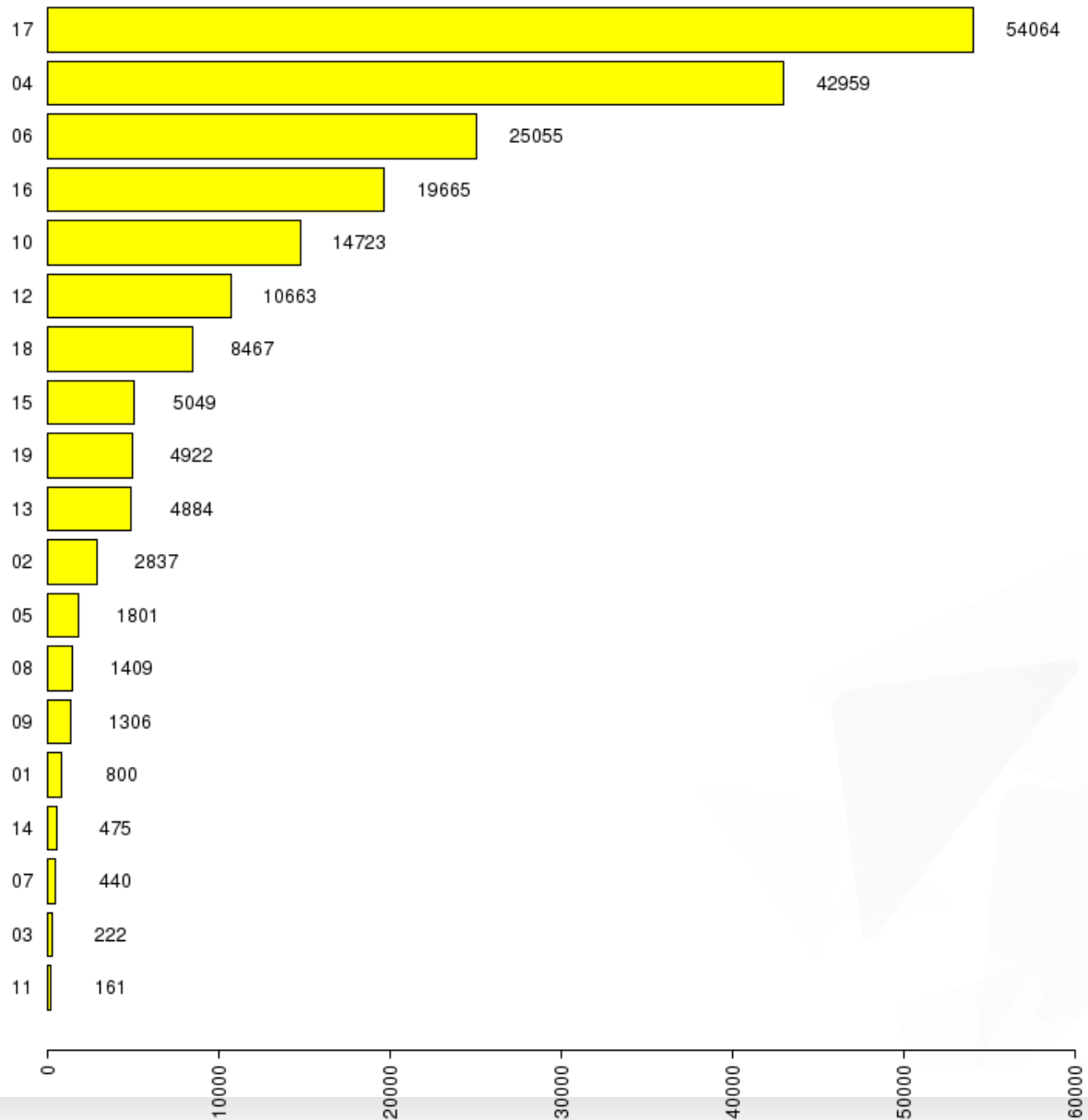
[Previously: 52 days (8/2011), 60 days (1/11)]



Total Cohort

EUBIROD Diabetes Report 2010

TOTAL No. Subjects by Data Source (Year 2010 - N=199902)

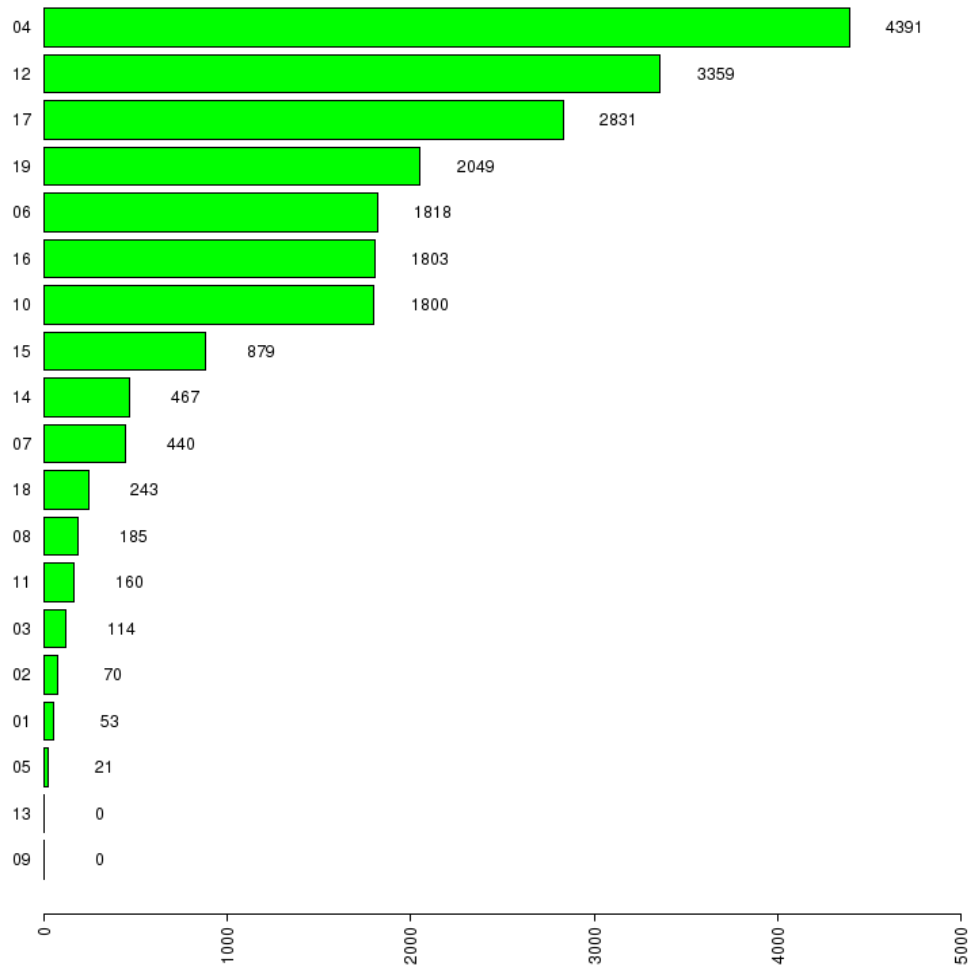




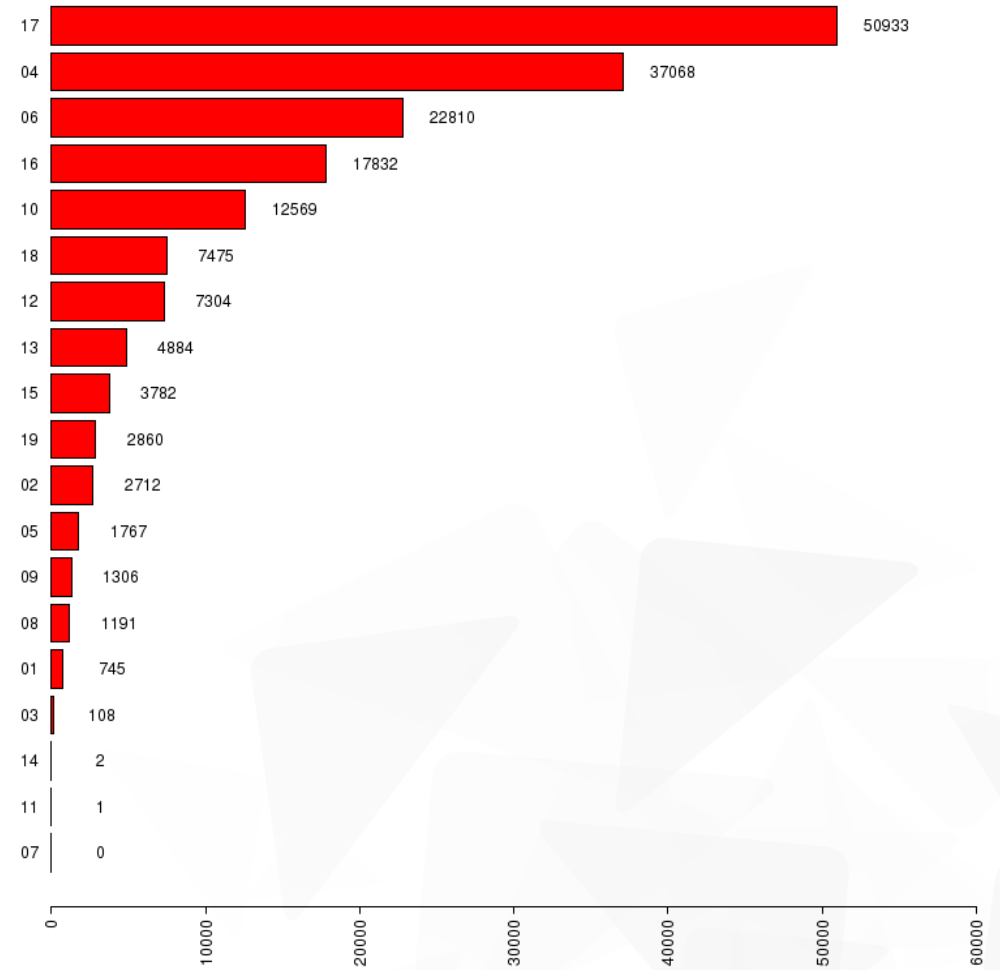
Total Cohort by Diabetes Type

EUBIROD Diabetes Report 2010

Diabetes Type: Type 1 - No. Subjects by Data Source (Year 2010 - N=20683)



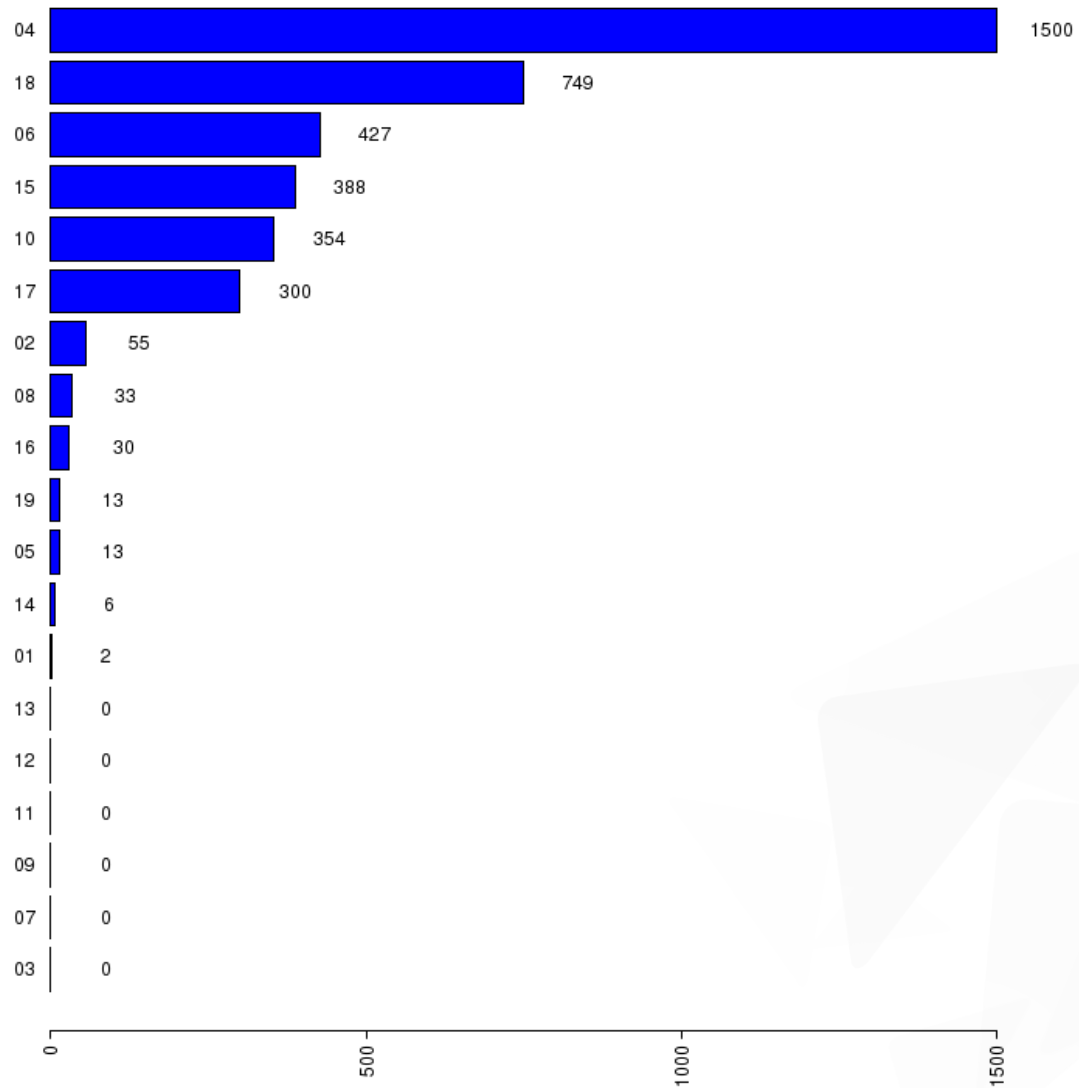
Diabetes Type: Type 2 - No. Subjects by Data Source (Year 2010 - N=175349)



Total Cohort by Diabetes Type

EUBIROD Diabetes Report 2010

Diabetes Type: Other Type - No. Subjects by Data Source (Year 2010 - N=3870)



Demographics and Clinical characteristics

EUBIROD Diabetes Report 2010

Summary

Demographic characteristics

1.1 Basic demographics

Indicator	Code	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19
Age	1.1.1	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X

Clinical characteristics

2.1 Diabetes status

Indicator	Code	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19
Type of diabetes	2.1.1	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Diabetes Duration	2.1.2	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X

2.2 Risk factors

2.2.1 Obesity

Indicator	Code	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19
Weight	2.2.1.1	X	X	X	X	X	X	X	X	X	X		X	X	X	X	X	X	X	X
BMI	2.2.1.2	X		X	X	X	X						X	X	X	X	X	X	X	X

2.2.2 Lifestyle

Indicator	Code	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19
Smoke	2.2.2.1	X	X		X	X	X		X	X	X		X	X	X	X	X		X	X

Clinical measurements

EUBIROD Diabetes Report 2010

Clinical measurements

Indicator	Code	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19
SBP	2.2.3.1	X	X		X	X	X	X	X	X	X		X	X	X	X	X	X	X	X
DBP	2.2.3.2	X	X		X	X	X	X	X	X	X		X	X	X	X	X	X	X	X
Cholesterol	2.2.3.3	X	X		X	X	X	X	X	X	X		X	X	X	X	X	X	X	X
HDL	2.2.3.4	X	X		X	X	X		X	X	X	X	X	X	X	X	X	X	X	X
Creatinine	2.2.3.5	X	X		X	X	X		X	X	X		X	X	X	X	X	X	X	X
HbA1c	2.2.3.6	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X

Diabetes Complications

Indicator	Code	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19
Retinopathy	2.3.1	X			X		X		X		X				X	X	X		X	
ESRF	2.3.2	X	X		X		X		X		X		X	X	X		X	X		
Foot Ulcer	2.3.3	X			X		X		X	X	X		X		X	X	X	X	X	
Amputation	2.3.4	X	X		X		X		X	X	X		X		X	X	X	X	X	X
Stroke	2.3.5	X	X		X		X		X	X	X		X		X		X	X	X	X
Miocardial Infarction	2.3.6	X	X		X		X		X	X	X		X				X	X	X	
Hypertension	2.3.7	X	X		X	X	X		X	X	X			X	X		X		X	X

Risk-adjusted indicators

EUBIROD Diabetes Report 2010

Outcome Indicators

Intermediate

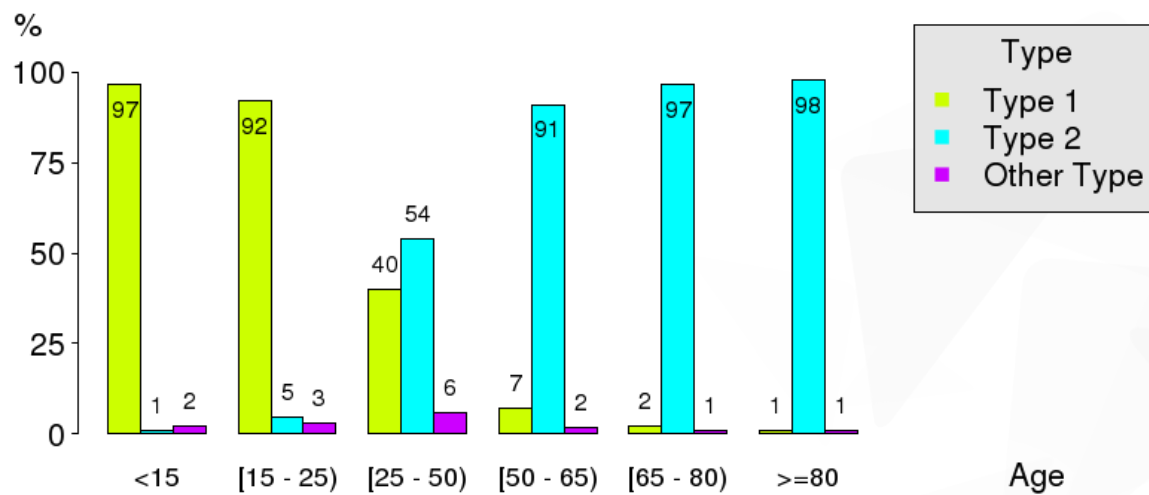
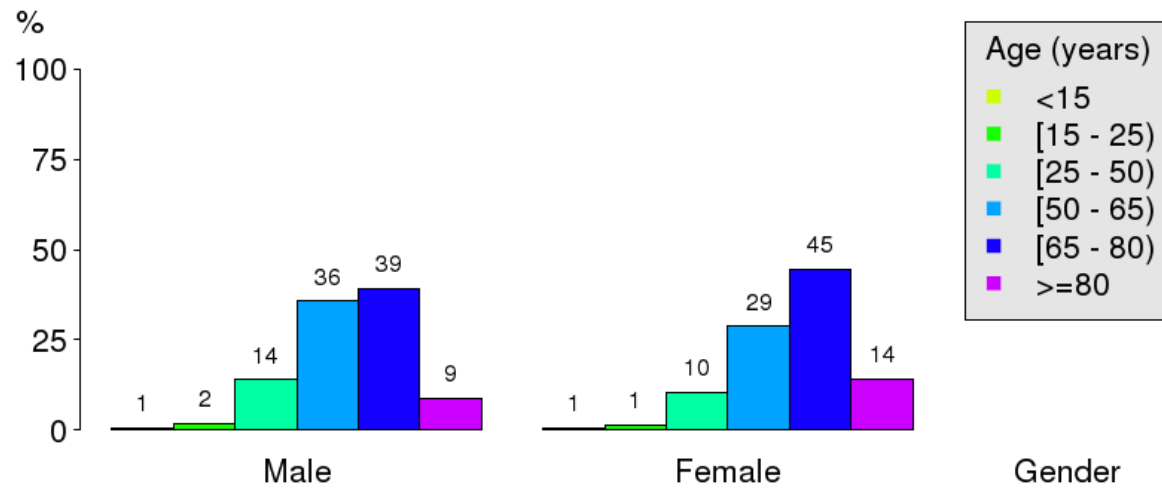
Indicator	Code	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19
HbA1c	5.3.1	X		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
HbA1c	5.3.2	X		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
BP	5.3.3	X			X	X	X	X	X	X			X	X	X	X	X	X	X	X
BMI	5.3.4	X		X	X	X	X						X	X	X	X	X	X	X	X
Microalbuminuria	5.3.5	X			X		X	X	X		X		X	X	X	X	X			X
Current Smokers	5.3.6	X			X	X	X		X	X	X		X	X	X	X	X		X	X
Foot Ulceration	5.3.7	X			X		X		X	X	X		X		X	X	X	X	X	X

Terminal

Indicator	Code	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19
Dialysis	5.4.1	X													X		X			X
ESRF	5.4.2	X			X		X		X		X		X	X	X		X	X		

Gender – Age

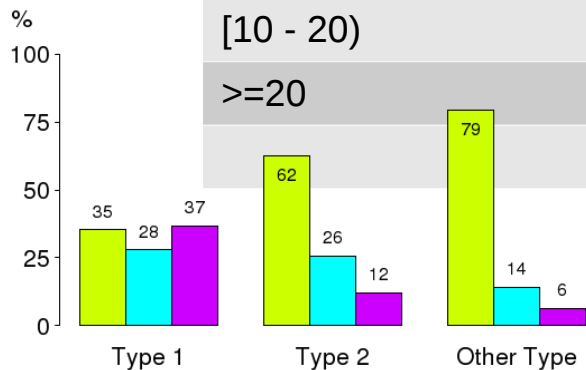
EUBIROD Diabetes Report 2010



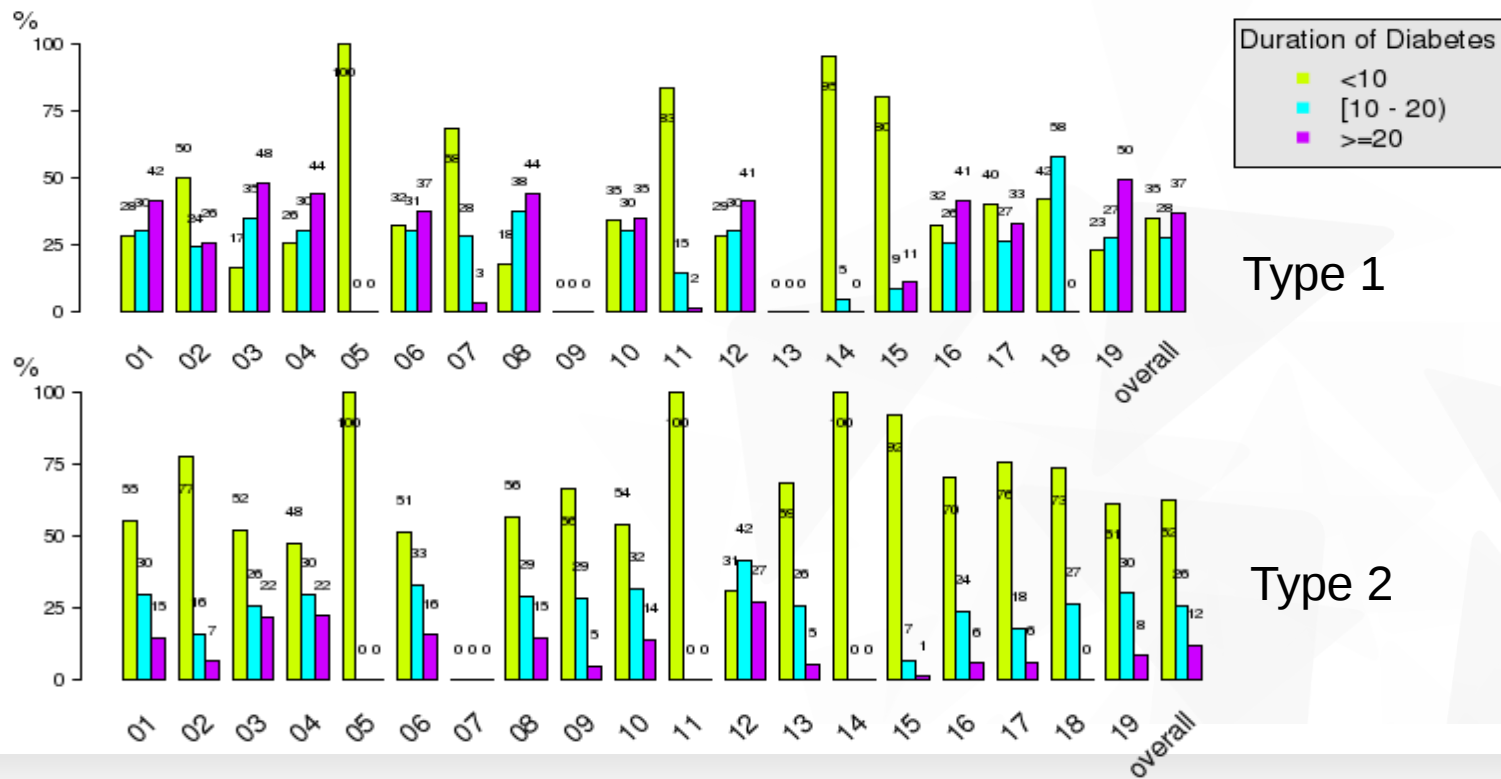
Duration of Diabetes

EUBIROD Diabetes Report 2010

Duration of Diabetes	Type 1 (%)	Type 2 (%)	Other Type (%)	
<10	7300 (35.3)	109365 (62.4)	3076 (79.5)	119741 (59.9)
[10 - 20]	5768 (27.9)	44948 (25.6)	546 (14.1)	51262 (25.6)
>=20	7615 (36.8)	21036 (12.0)	248 (6.4)	28899 (14.5)
	20683 (10.3)	175349 (87.7)	3870 (1.9)	199902 (100.0)



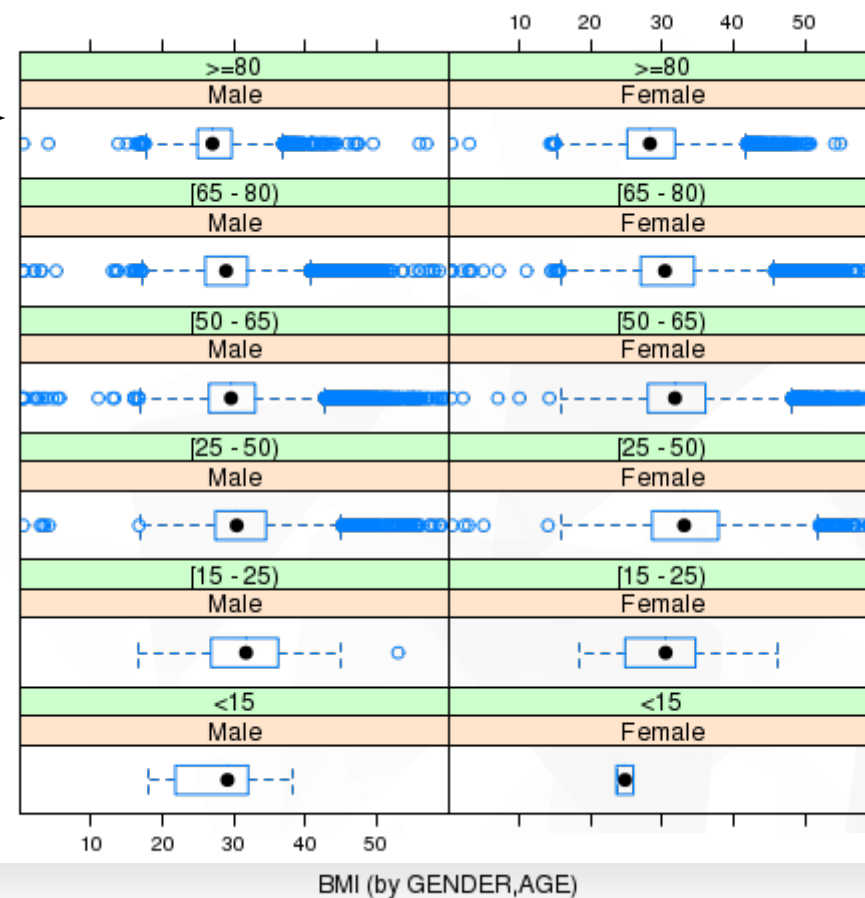
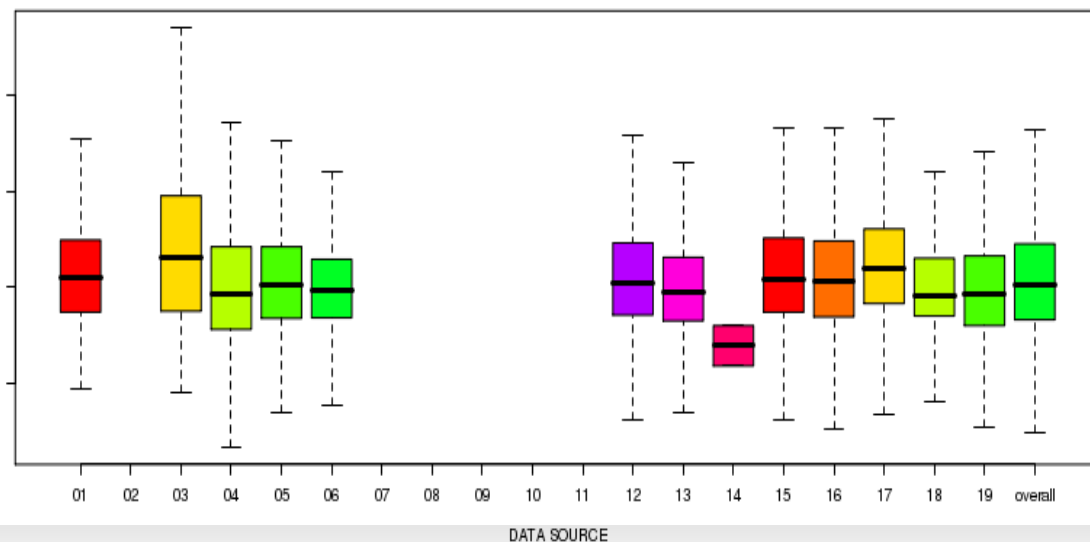
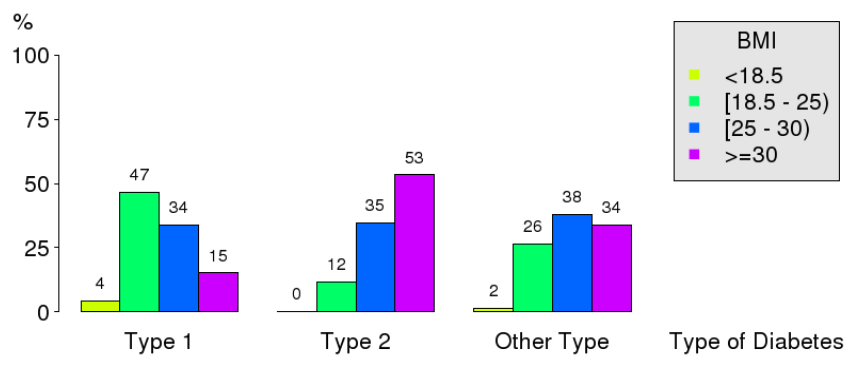
by Data Source



Body Mass Index

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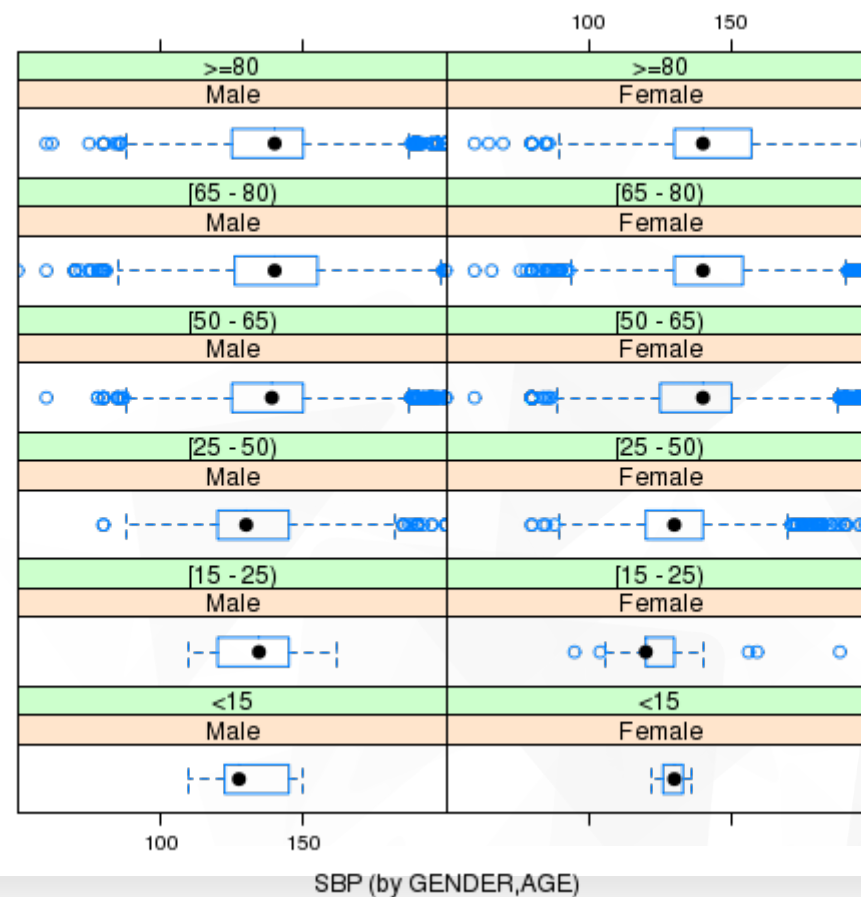
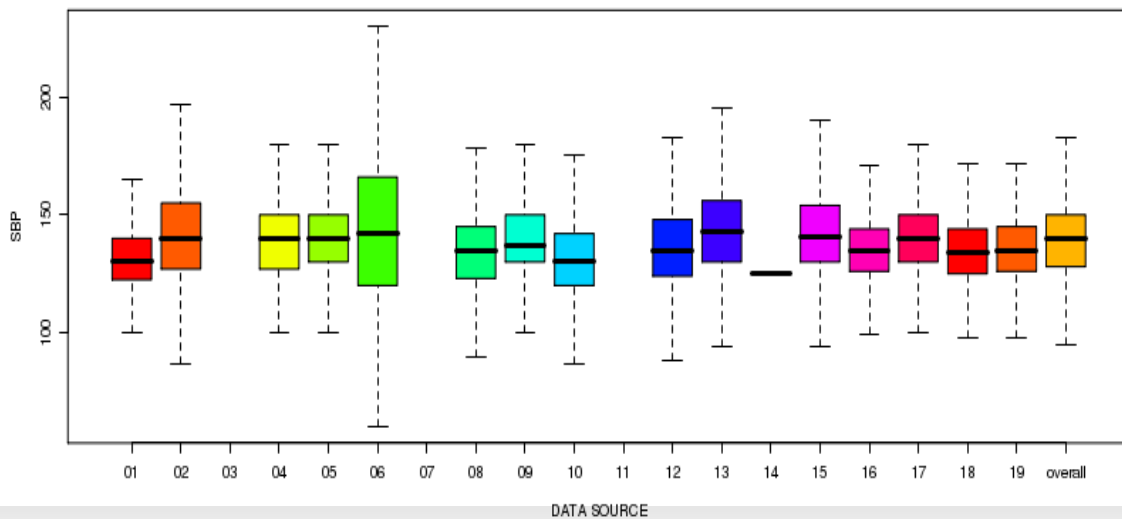
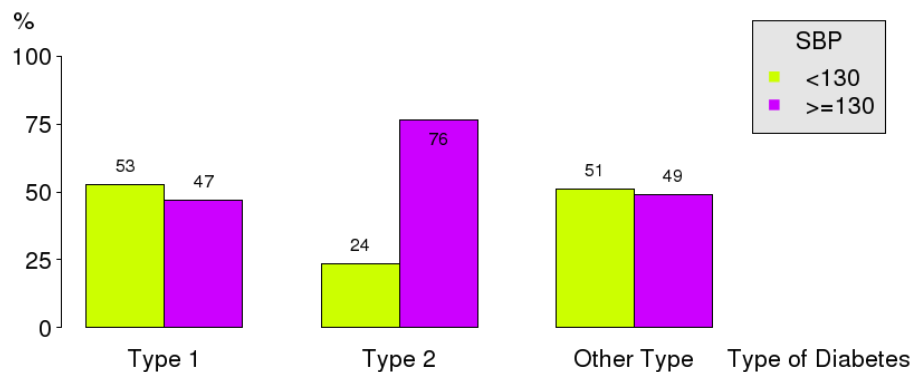
BMI	Type 1 (%)	Type 2 (%)	Other Type (%)	
<18.5	622 (4.4)	372 (0.3)	36 (1.6)	1030 (0.7)
[18.5 - 25)	6671 (46.7)	14680 (11.8)	597 (26.4)	21948 (15.6)
[25 - 30)	4825 (33.8)	42893 (34.5)	862 (38.1)	48580 (34.5)
>=30	2164 (15.2)	66286 (53.4)	770 (34.0)	69220 (49.2)
	14282 (10.1)	124231 (88.2)	2265 (1.6)	140778 (100.0)



Systolic Blood Pressure

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SBP	Type 1 (%)	Type 2 (%)	Other Type (%)	
<130	8944 (52.8)	35408 (23.5)	1407 (51.1)	45759 (26.9)
>=130	7980 (47.2)	114960 (76.5)	1347 (48.9)	124287 (73.1)
	16924 (10.0)	150368 (88.4)	2754 (1.6)	170046 (100.0)

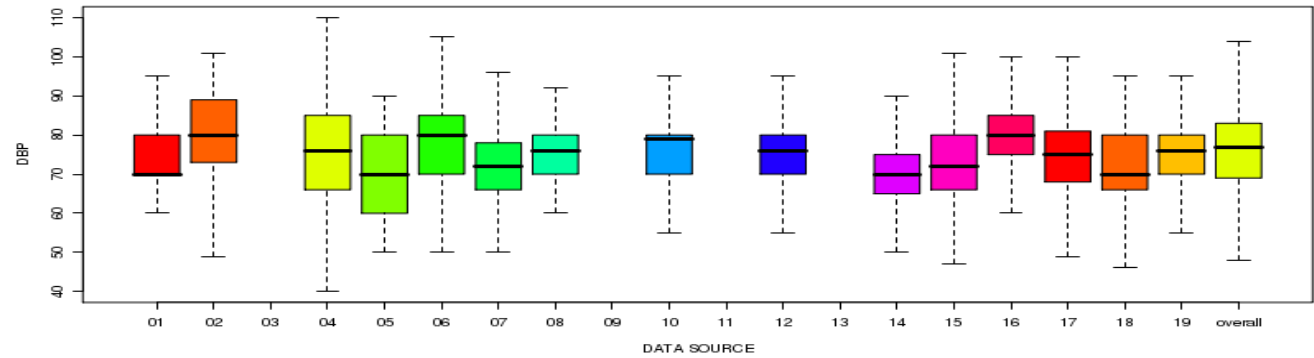


Diastolic Blood Pressure

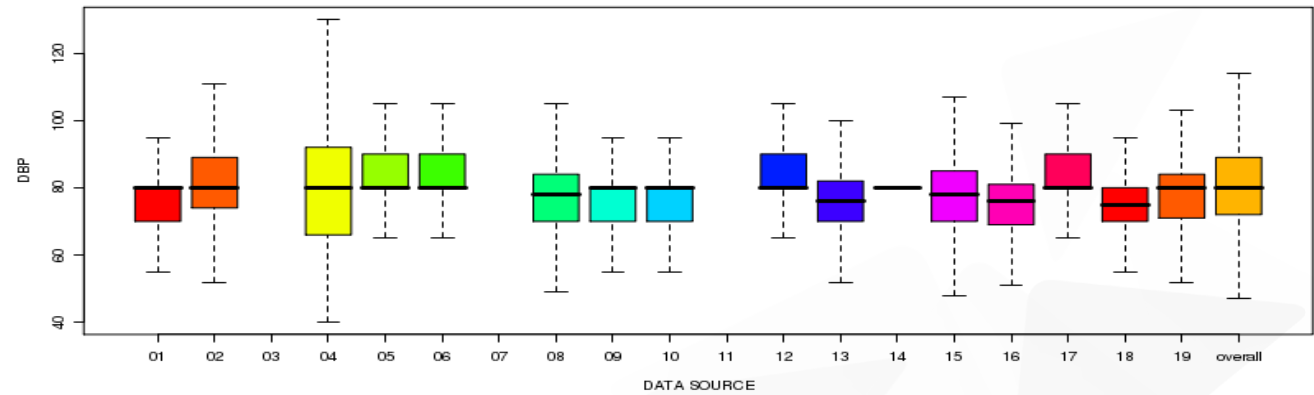
N=169,910

EUBIROD Diabetes Report 2010

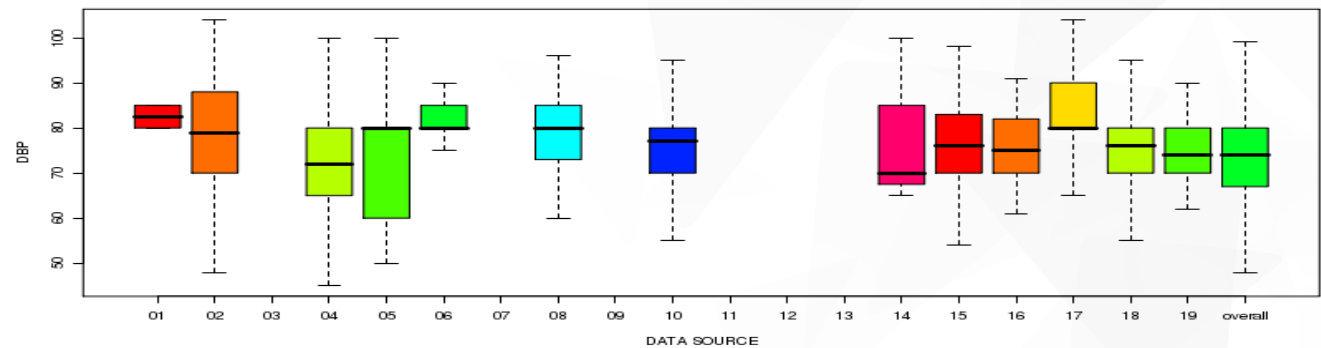
Type 1



Type 2



Other Type

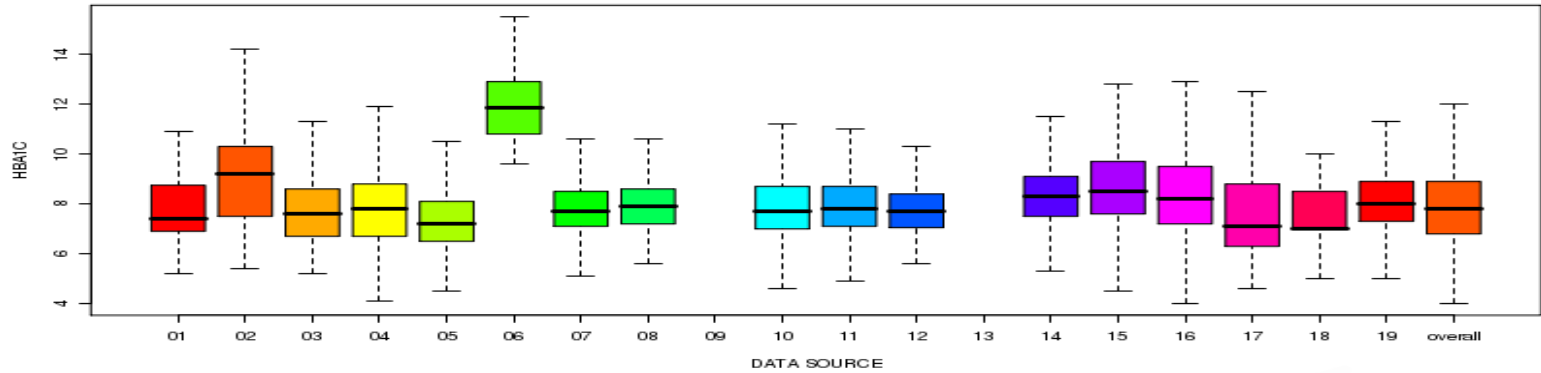


Glycated Haemoglobin (HbA1c)

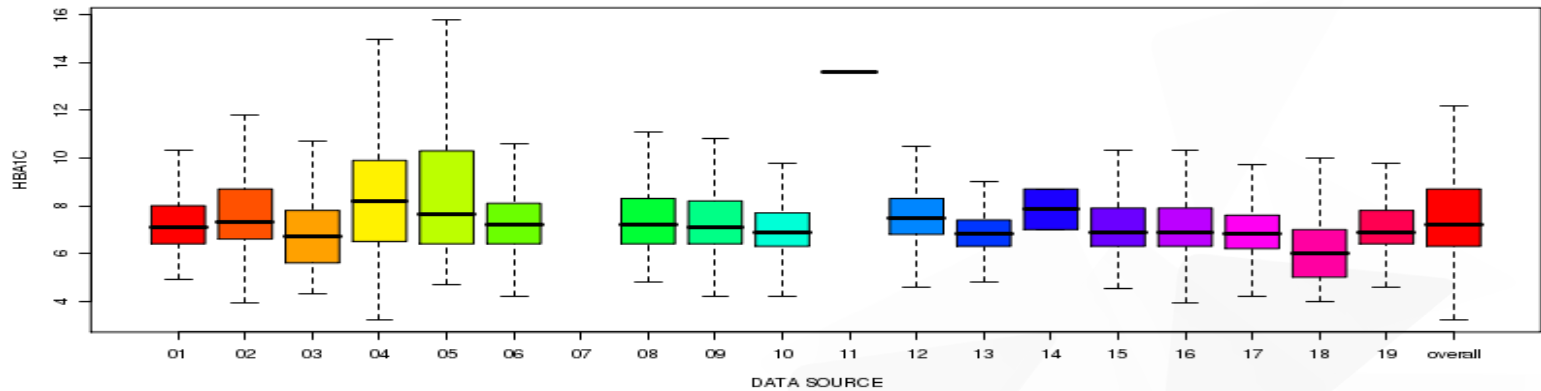
N=168,948

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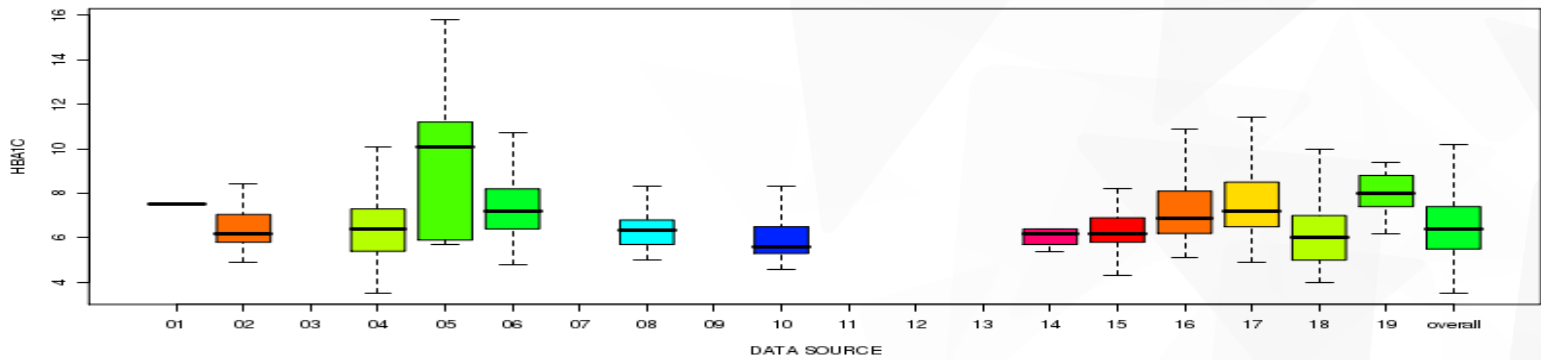
Type 1



Type 2



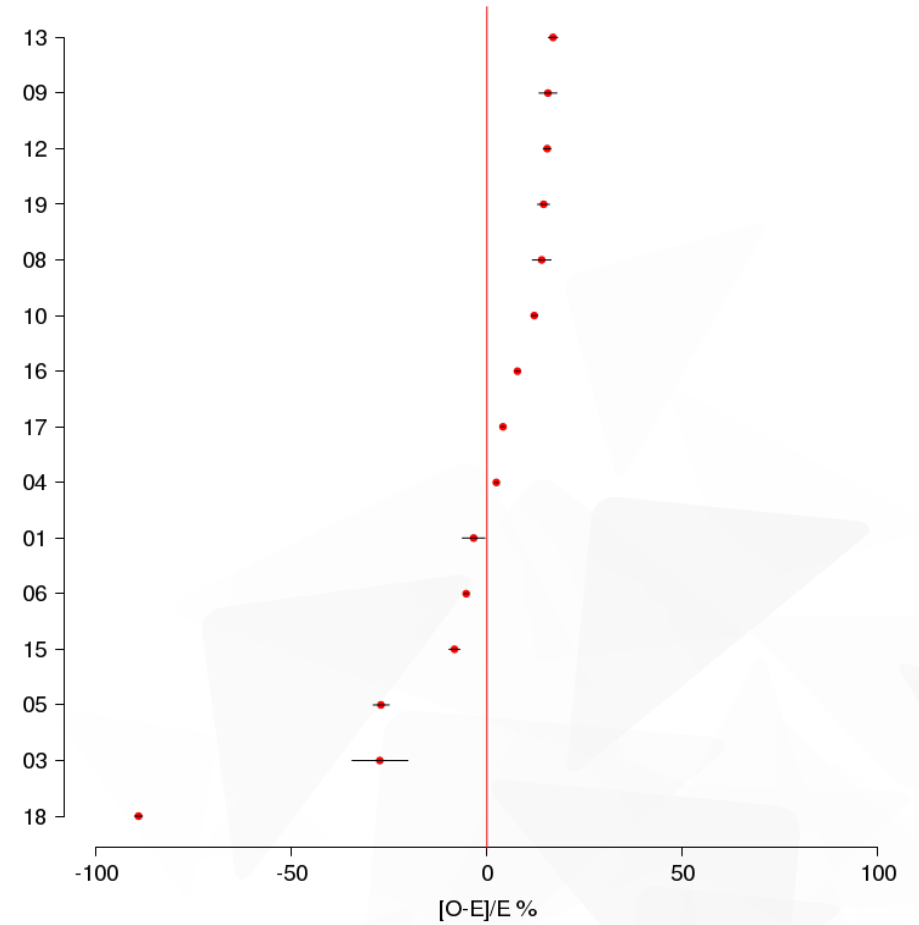
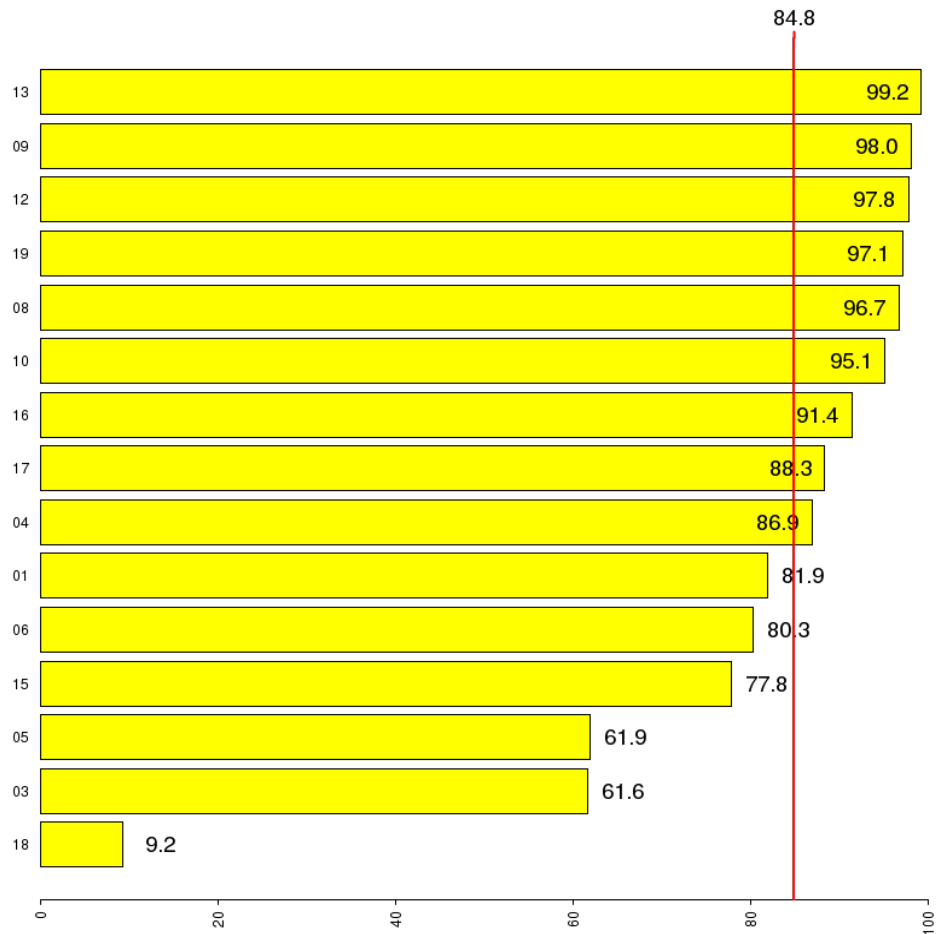
Other Type



Percentage of Adults with 1+ HbA1c tests in 12 mts

Type 2 (N=172,605)

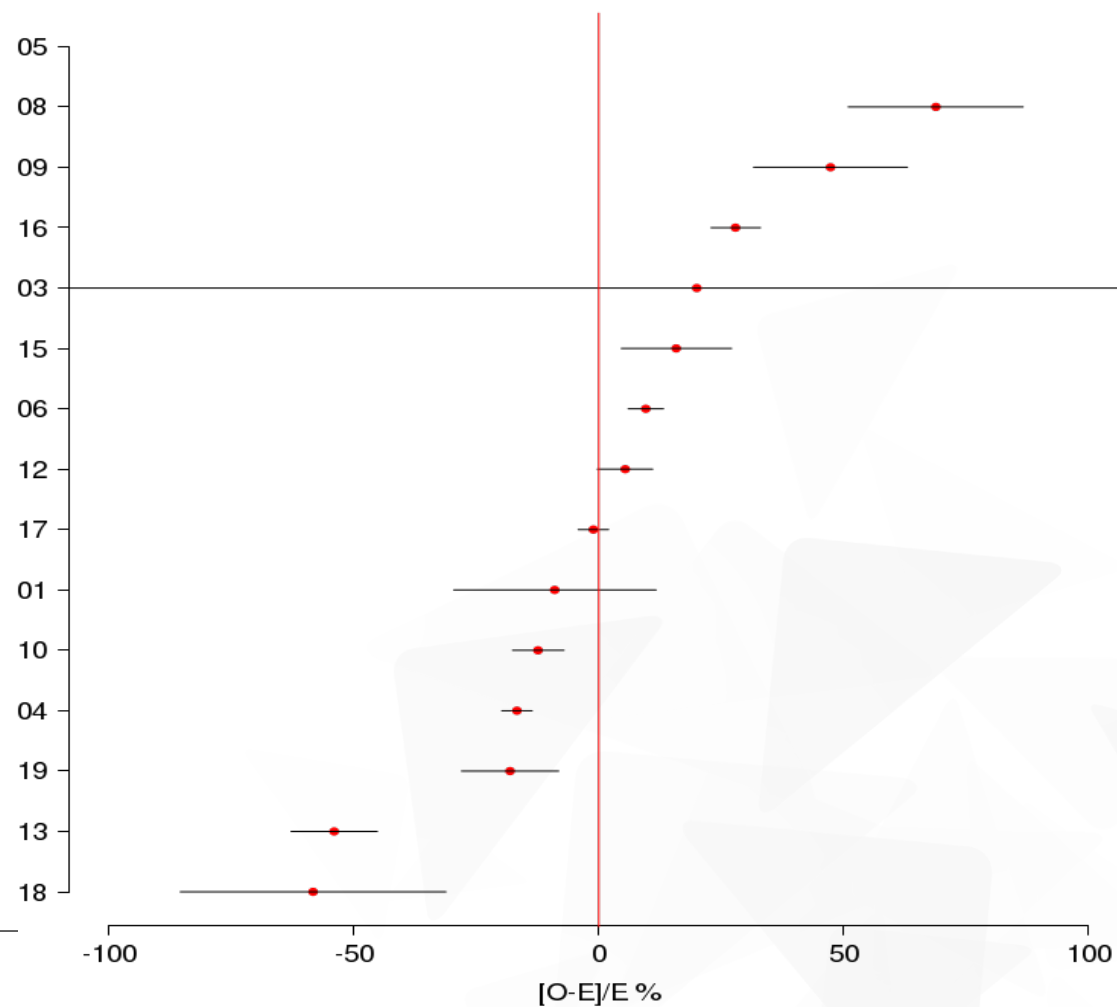
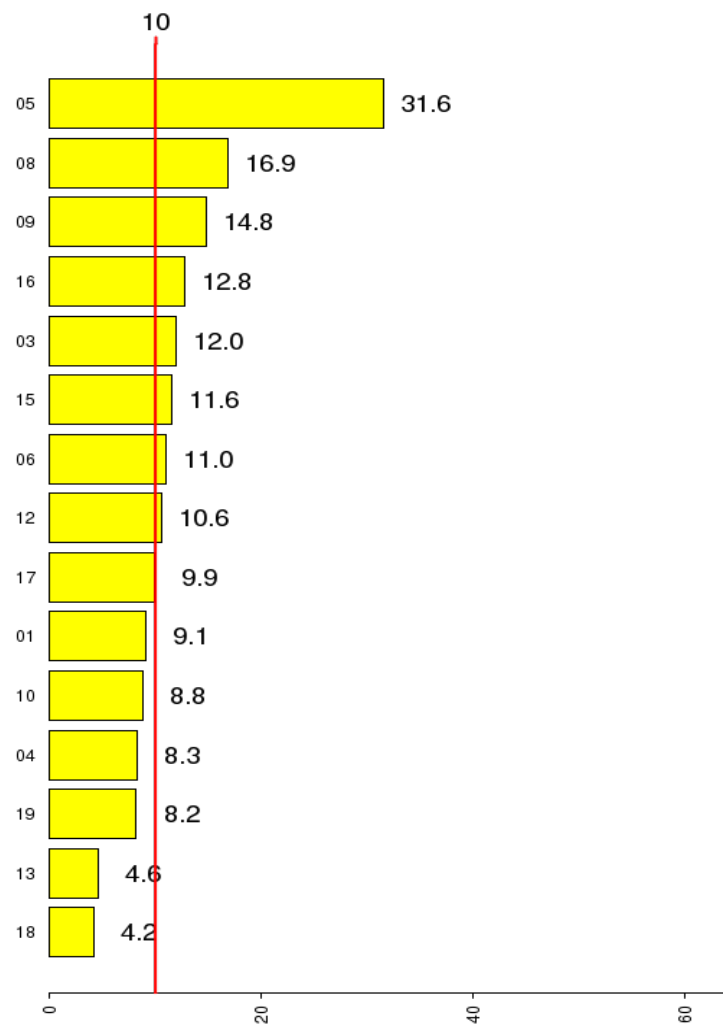
EUBIROD Diabetes Report 2010



Percentage of adults with most recent HbA1c > 9.0%

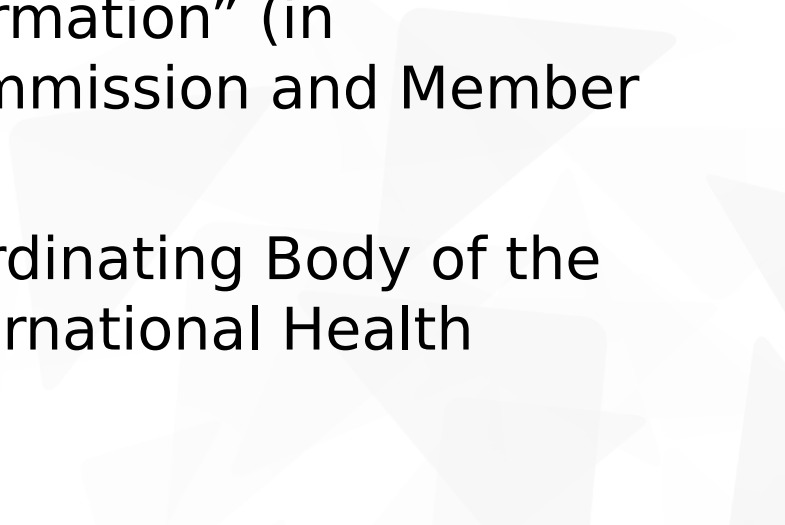
Type 2 (N=146,397)

EUBIROD Diabetes Report 2010





EUBIROD 2013

- Associated Project of the European Joint Action “Cross-border Patient Registries Initiative” (PARENT)
 - Involvement in the program of the European Joint Action on Chronic Diseases (JA-CHRODIS)
 - Preparation of the proposal for a “European Research Infrastructure Centre on Health Information” (in collaboration with the European Commission and Member States)
 - New Foundation established as Coordinating Body of the EUBIROD Network: the “Hub for International Health reSearch” (HIRS Perugia, Italy)
- 



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 now automatically linked to official EU platforms in diabetes and across other chronic diseases
- Our experience paves the way for a new generation of transnational/translational evidence-based information systems that can use distributed models with a higher efficiency and minimal impact on data privacy, ownership, and overall cost of information management
- The implementation of distributed statistical systems e.g. BIRO may be initially complex, but once automated it can show all its advantages, particularly relevant for federal/decentralized health systems and large international partnerships



Thanks for your attention!



Pescara, Abruzzo, Italy