

A novel standard to support information delivery for the fulfilment of IDF policy in Europe: results of the EU DG-SANCO funded BIRO project

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on behalf of the BIRO Consortium**

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*IDF World Congress 2009
Montreal, 22nd October 2009*

Increasing interest in the EU

- The EU Health Commissioner's statement in 2004 that he would *"give his full attention to the growing diabetes epidemic"*
- Austrian Presidency decision to make Type 2 diabetes one of its two key public health priorities



Best Information through Regional Outcomes

“Best Information through Regional Outcomes”

- Three years project in the field of diabetes funded by the Health Information Strand, Public Health Program, DG-SANCO
 - Start: 1st December 2005
 - Total cost: 1.2Mn€
 - Total contribution by the European Union: 715,000€
- ***Aim: “to provide European health systems with an ad hoc, evidence and population-based diabetes information system”***
- Seven partners from academia and governmental institutions, sharing an extensive experience in diabetes research/chronic care management
- Novel strategy for the routine collection of base parameters and the regular production of European summary indicators. The proposal targets better collection and integration of national and international data targeting regional networks, optimizing precision at the lowest cost through the active involvement of local users



Best Information through Regional Outcomes

BIRO Consortium



Department of Internal Medicine
University of Perugia, Italy

**COORDINATION, MANAGEMENT, DISSEMINATION
PRIVACY IMPACT ASSESSMENT
DATABASE/STATISTICAL/CENTRAL ENGINES**



Division of Medicine and Therapeutics
University of Dundee, Scotland, UK

**COMMON DATASET
DATA DICTIONARY**



Joanneum Research,
Graz, Austria

**CLINICALREVIEW
COMMUNICATION SOFTWARE**



Department of Medicine,
University of Bergen, Norway

**REPORTS TEMPLATE
WEB PORTAL**



Institute of Diabetes "Paulescu",
Bucharest, Romania

TECHNOLOGY TRANSFER



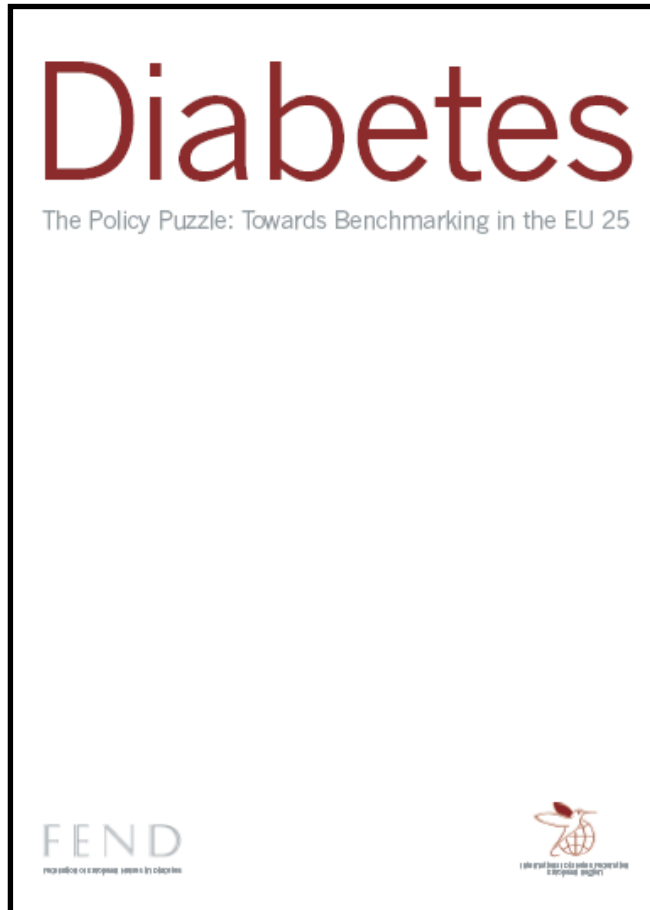
Department of Medicine,
University of Malta, Malta

EVALUATION

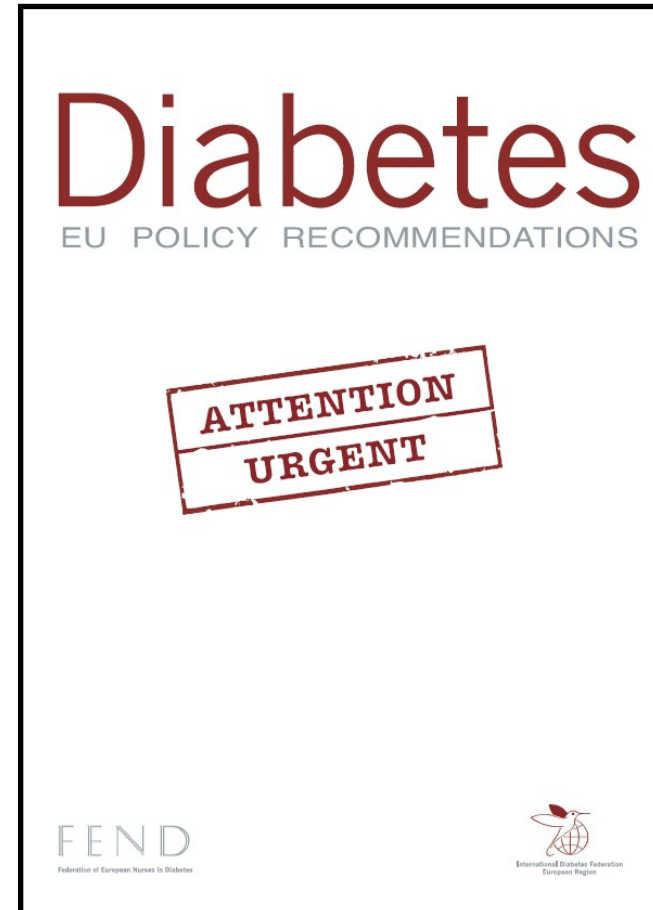


Department of Health Promotion,
Ministry of Health, Republic of Cyprus

IDF/FEND Vienna Declaration 02/2006



The Diabetes Policy Audit



EU Policy Recommendations

EU Council Conclusions June 2006

EU Ministers of Health adopted a set of Health Council Conclusions on the Promotion of Healthy Lifestyles and Prevention of Type 2 diabetes, agreeing that Member States should:

- Develop and implement national diabetes framework plans
- Improve the collection and reporting of diabetes epidemiological and economic data
- Adopt a multi-sectoral, multi-disciplinary approach to managing diabetes
- Develop comprehensive diabetes training for all healthcare professionals.
- The Conclusions also called upon the European Commission to prioritise diabetes, to promote best practice through networking & exchange between Member States and to facilitate and support European diabetes research.

Why Regions?

- A “region” in BIRO logic is not an administrative entity: can be one or more geographical areas characterized by the existence of a common framework for the collection of diabetes data
- In principle can be a group of professionals/centres, a local health authority, single provinces, regions, states, or group of states

Who are the BIRO Users?

Governance

- European Union
- Commission and Parliament
- National and Regional Governments
- Local Health Care Authorities, Management Clinical Networks
- Other local authorities
- Payers
- Social/Private Insurance
- Non Governmental Organizations
- WHO, OECD, IDF, National and Regional Diabetes Associations

Research

- EU Directorates Research and Public Health
- Scientific Organizations

- National and international scientific organizations
- Research institutions
- Universities, Foundations
- Statistical Departments of Local Governements
- Research areas
- Epidemiology, health policy, clinical medicine

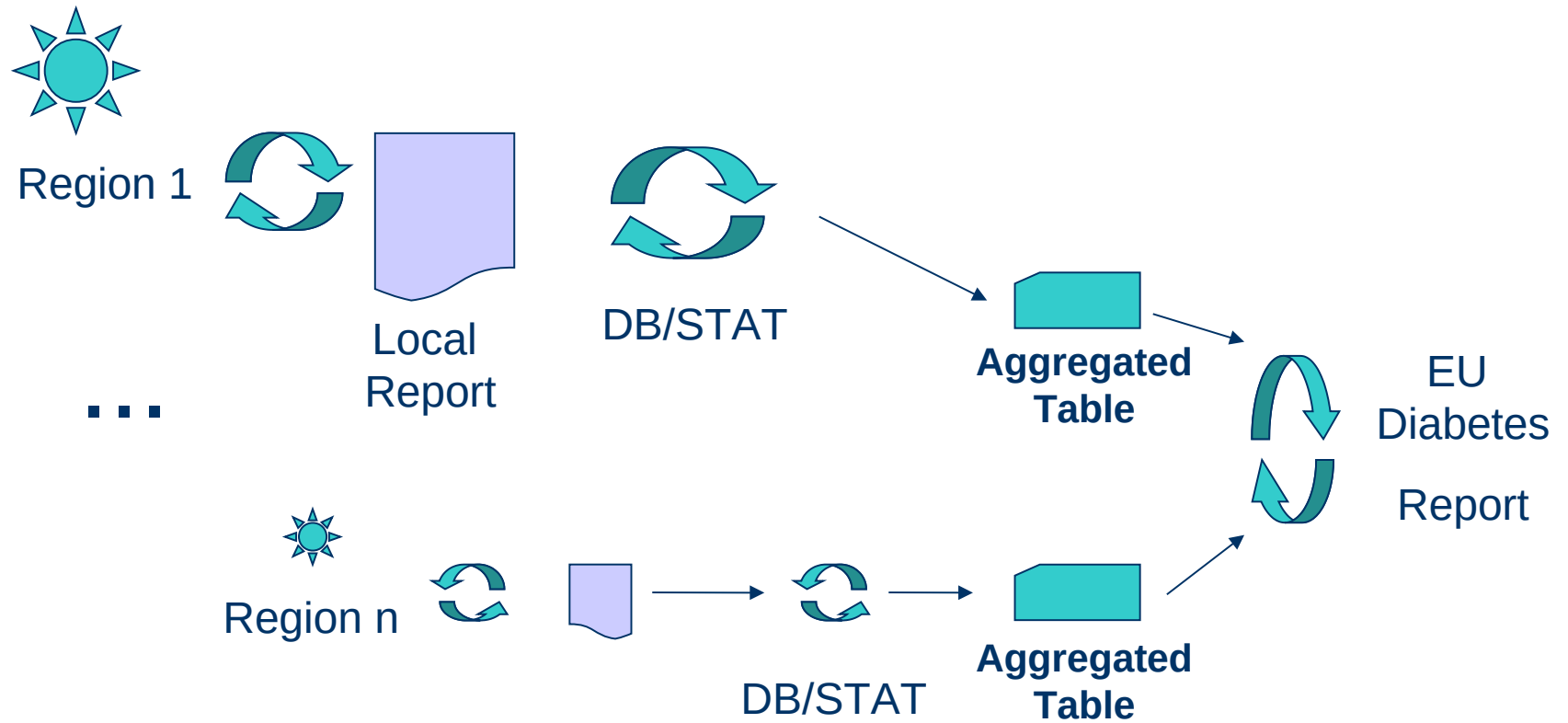
Health Care

- Primary Care Societies
- Diabetes Care Units
- Health Care Professional Associations
- Quality Management Associations

Citizens

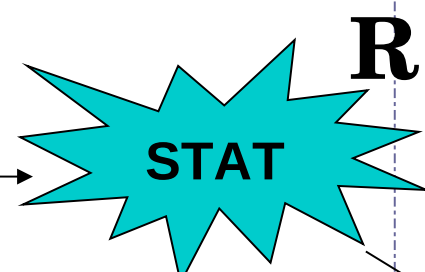
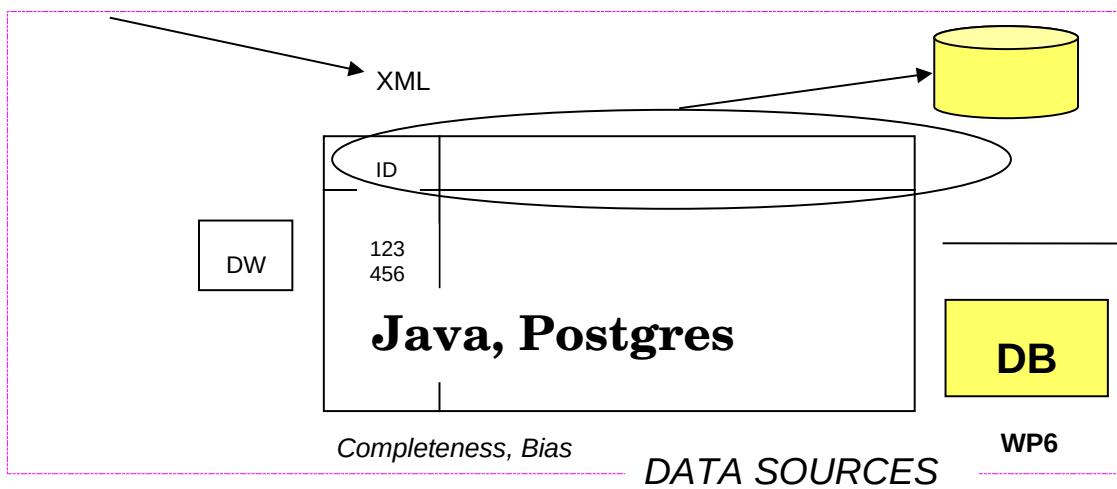
- Consumer organizations
- Patients organizations

BIRO model



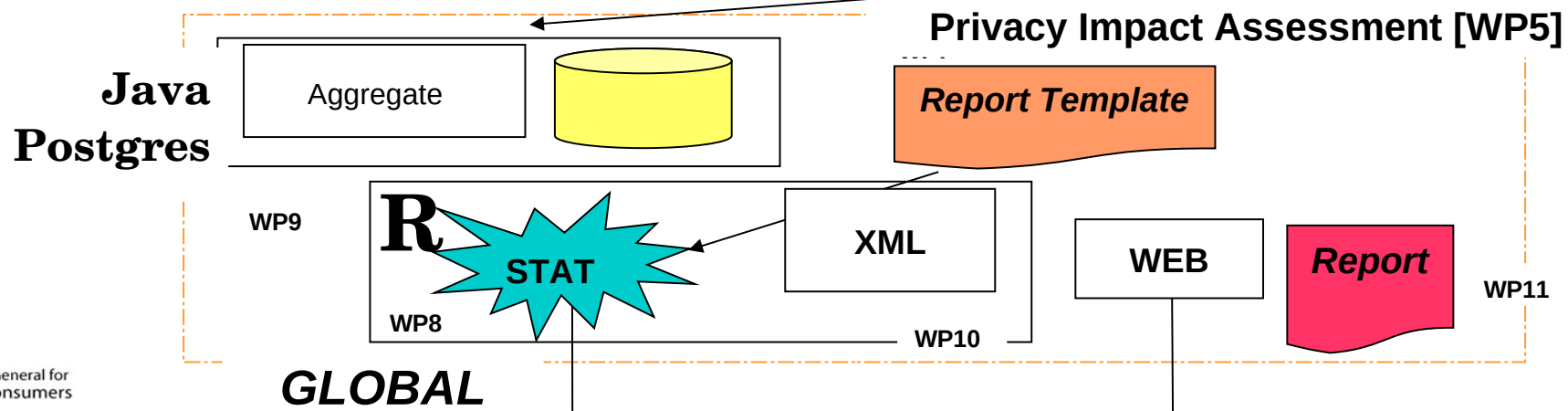
BIRO Technology

CLINICAL REVIEW + COMMON DATASET = DATA DICTIONARY (PARAMETERS, INDICATORS) [WP2,3,4]



“Statistical Objects”

LOCAL



GLOBAL

Clinical Review

- Indicator: “a measure used to determine, over time, performance of functions, processes and outcomes.”
- OECD defined selection:
 - Capture relevant aspect
 - Scientifically sound
 - Feasible
- 3 Dimensions per indicator
 - Impact on health
 - Policy importance
 - Susceptibility to be influenced by health care system

Common Dataset

- Dataset items recorded as a “Parameter”
- Parameters have a unique reference
- Clear definition
- Associated data type
- Unit of measurement (e.g.kg/m²)
- May have an upper or lower range

Core Dataset Components

- Basic Patient Information
 - e.g. Type of Diabetes, Date of Birth, Year of Diagnosis
- Risk Factors
 - e.g. Cigarettes / Day
- Clinical Measurements
 - e.g. Weight, Height, SBP, DBP, HbA1c, Creatinine
- Examinations
 - e.g. Eye Examinations
- Outcomes
 - e.g. End Stage Renal Failure

Core Dataset Specifications

Reference	Field Name	Parameter	Data Type	Enumerated Codes
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 Types of Diabetes
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	
BRIO047	ALC_STAT	Alcohol Status	Enumerated	1 = Current Drinker 2 = Non-Drinker 3 = Ex-Drinker
BIRO010	ALCOHOL	Alcohol Intake	Integer	
BIRO011	WEIGHT	Weight	Real	
BIRO012	HEIGHT	Height	Real	
BIRO013	BMI	Body Mass Index	Real	
BIRO014	SBP	Systolic Blood Pressure	Integer	
BIRO015	DBP	Diastolic Blood Pressure	Integer	
BIRO016	HBA1C	HbA1c	Real	
BIRO017	CREAT	<u>Creatinine</u>	Integer	
BIRO018	MA_TEST	<u>Microalbumin</u>	Enumerated	1 = MA Test Normal 2 = MA Test Abnormal 0 = No MA Test Recorded
BIRO019	CHOL	Total Cholesterol	Integer	

Data Dictionary

- Data Standardisation
- Metadata
 - Consistency
 - Completeness
 - Quality
 - Additional comments
- Can be displayed alongside outputs
 - Explain discrepancies
 - Provide commentary on data comparisons
- XML Schema

Reports Template

Indicators and statistical output for each BIRO-user

Governance

Indicator	Planned statistical outputs
1. Demographic characteristics	
1.1 Age (Classes)	Table, <u>histogram</u>
1.2 Gender	Table, <u>histogram</u>
2. Clinical characteristics	
2.1 Diabetes status	
2.1.1 Type of diabetes	Table, <u>histogram</u>
2.1.2 Duration of diabetes	<u>Table</u> , <u>histogram</u>
2.2 Risk factors for diab. complications	
2.2.1 Obesity	
2.2.1.1 Weight	Table, <u>lines</u>
2.2.1.2 BMI	Table, <u>lines</u>

Underlined
preferred
output

Different
output
according
to target
audience

Health care and research

Indicator	Planned statistical outputs
1. Demographic characteristics	
1.1 Age (Classes)	Table, <u>histogram</u>
1.2 Gender	Table, <u>histogram</u>
2. Clinical characteristics	
2.1 Diabetes status	
2.1.1 Type of diabetes	Table, <u>histogram</u>
2.1.2 Duration of diabetes	<u>Table</u> , <u>histogram</u>
2.2 Risk factors for diab. complications	
2.2.1 Obesity	
2.2.1.1 Weight	Table, lines, starplot, <u>boxplot</u>
2.2.1.2 BMI	Table, lines, starplot, <u>boxplot</u>

Final BIRO Report Indicators

- Demographic Characteristics (N=2)
- Clinical Characteristics (N=18)
- Health System (N=21)
- Population (N=3)
- Risk Adjusted (N=28)
 - Epidemiology (N=2)
 - Process Quality (N=16)
 - Intermediate Outcomes (N=7)
 - Terminal Outcomes (N=3)



Best Information through Regional Outcomes

Privacy Impact Assessment of the B.I.R.O. Information System

Introduction:

Privacy impact assessment is a systematic and flexible process for evaluating a proposal/project in terms of its impact upon privacy, which has been specifically adapted to the BIRO context

Objectives:

To provide a definitive description of privacy risks, applicable privacy legislation and mitigation strategies adopted in the implementation and management of the BIRO Information System

Procedure

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

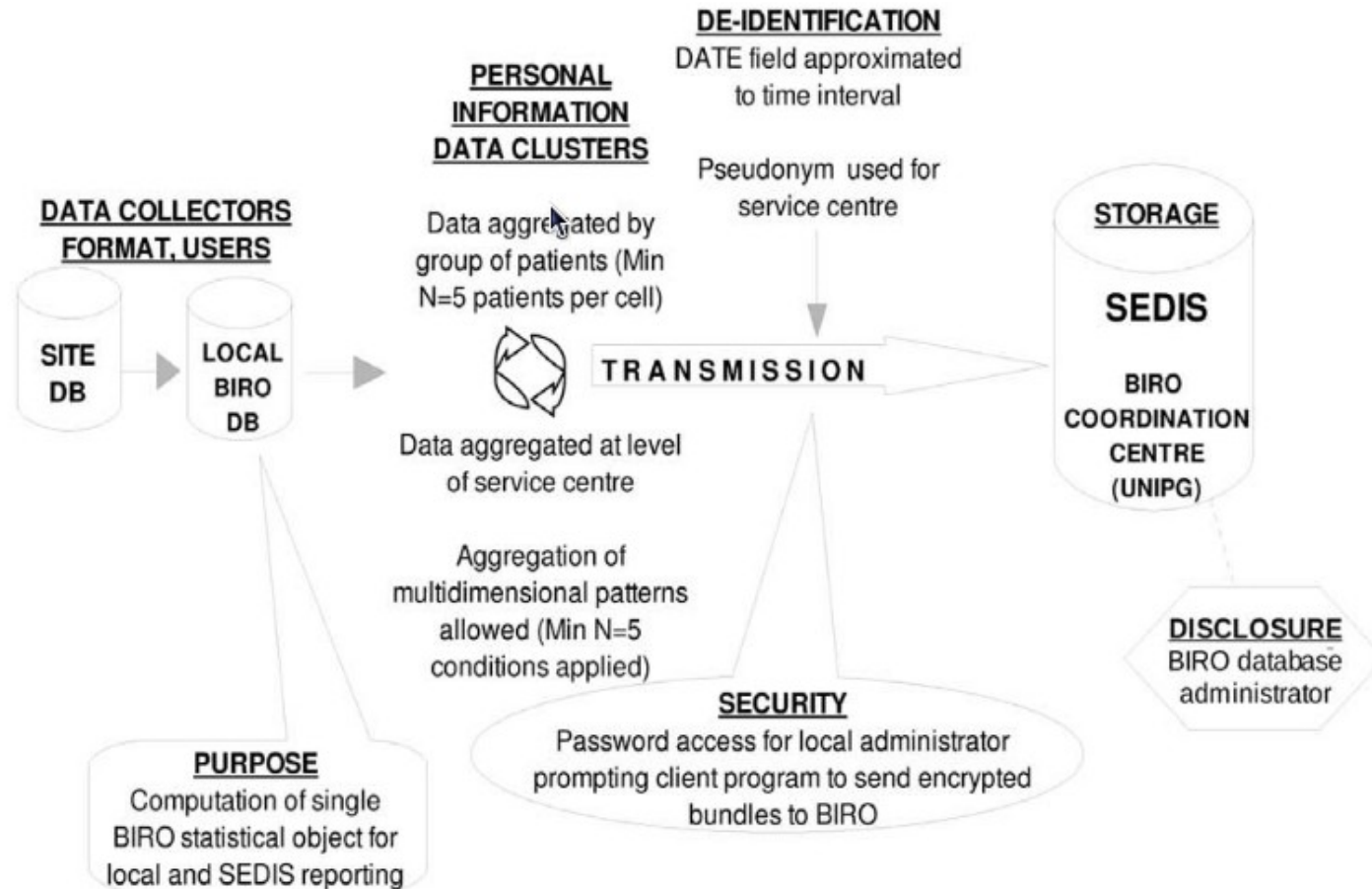
SCENARIO 1:
Question 1. PERSONAL INFORMATION/DATA CLUSTER: DECISION 1

Option	Privacy				Information Content Overall	Technical Complexity Overall
	Identifiability	Linkability	Observability	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	5	5	4	3
B	Decision 1	Min Aggregation N=5 patients per cell	2	3	3	3
C	Personal Data	Min aggregation N=5 patients per cell, only applicable for high critical privacy variables e.g. service centre, geographical site etc	3	4	3	3
D	Decision 2	Aggregation across service centres	3	3	3	3
E	Personal Data	Data aggregated at the level of service centre	2	3	3	3
F	Decision 3	Aggregation of multidimensional patterns (e.g. risk adjustment NOT allowed)	2	3	3	3
G	Personal Data	Aggregation of multidimensional patterns (e.g. risk adjustment allowed)	3	3	3	3
H	Decision 1	Aggregation of multidimensional patterns (e.g. risk adjustment) allowed, Min N=5 condition applied	2	4	3	3
I	Transmission	All DATE fields transmitted as in original	3	4	3	3
J	Decision 1	DATE fields approximated to time interval (e.g. months)	2	4	3	3
K	Transmission	Client program automatically sending encrypted data (agent)	3	4	3	3

Best architecture

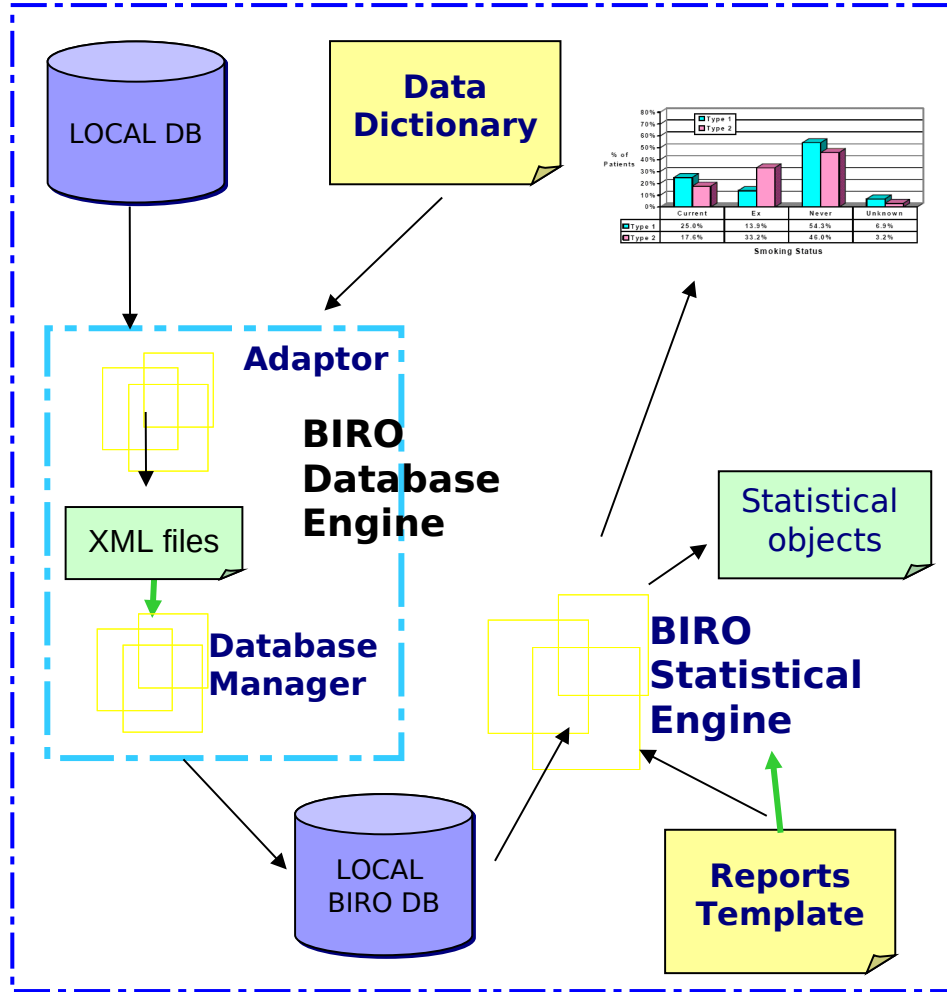


Privacy Analysis

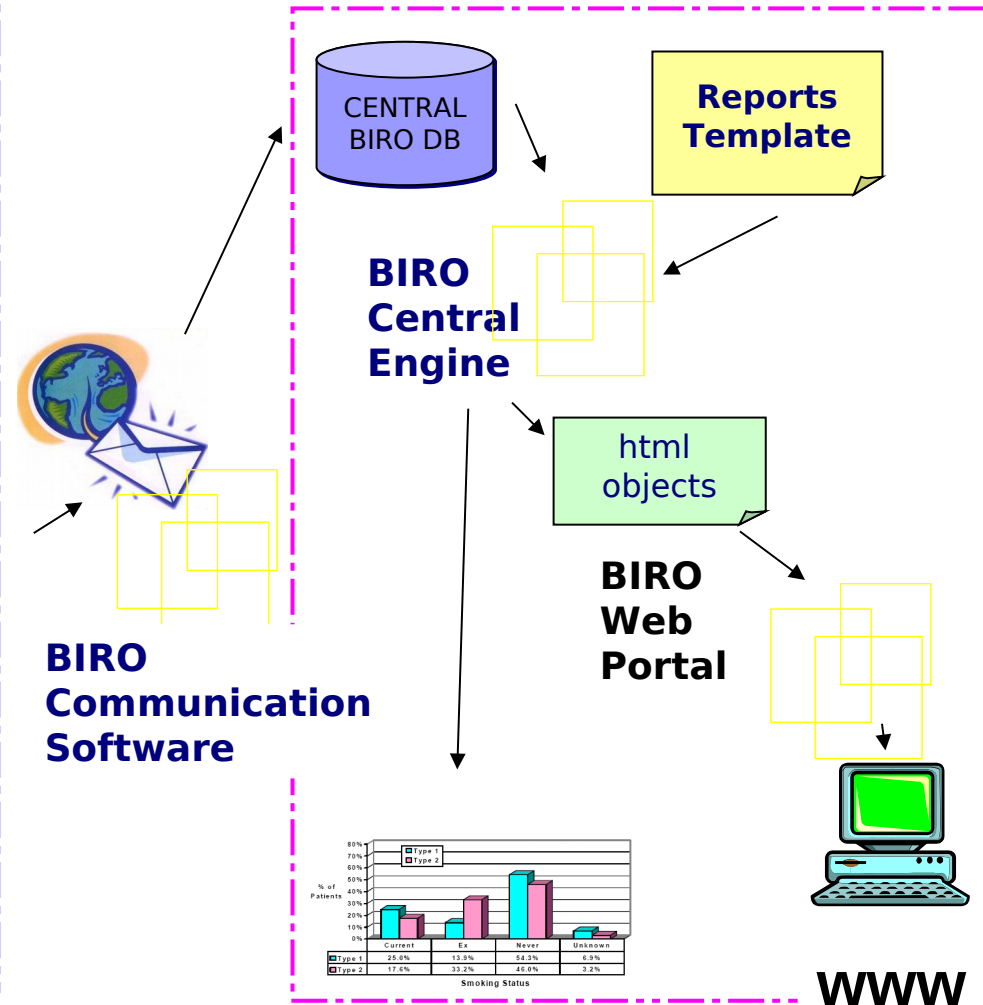
- Privacy impact assessment shows that the selected BIRO architecture **fulfills privacy protection requirements** by addressing and resolving broad privacy concerns from different angles
- The architecture of the system flexibly affords the **best privacy protection** in the construction of an efficient model for the continuous production of European diabetes reports.
- Trans-border data flow envisaged in BIRO is **legally viable according to the EU legislation.**
- The privacy impact assessment method developed and applied in B.I.R.O. may represent a **general tool that can be used to design trans-border health information systems.**

The BIRO System

Local BIRO System



Central BIRO System



Fragmented Analysis

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

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
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CL_AGE4	1	-0.2491	0.1086	5.2637	0.0218

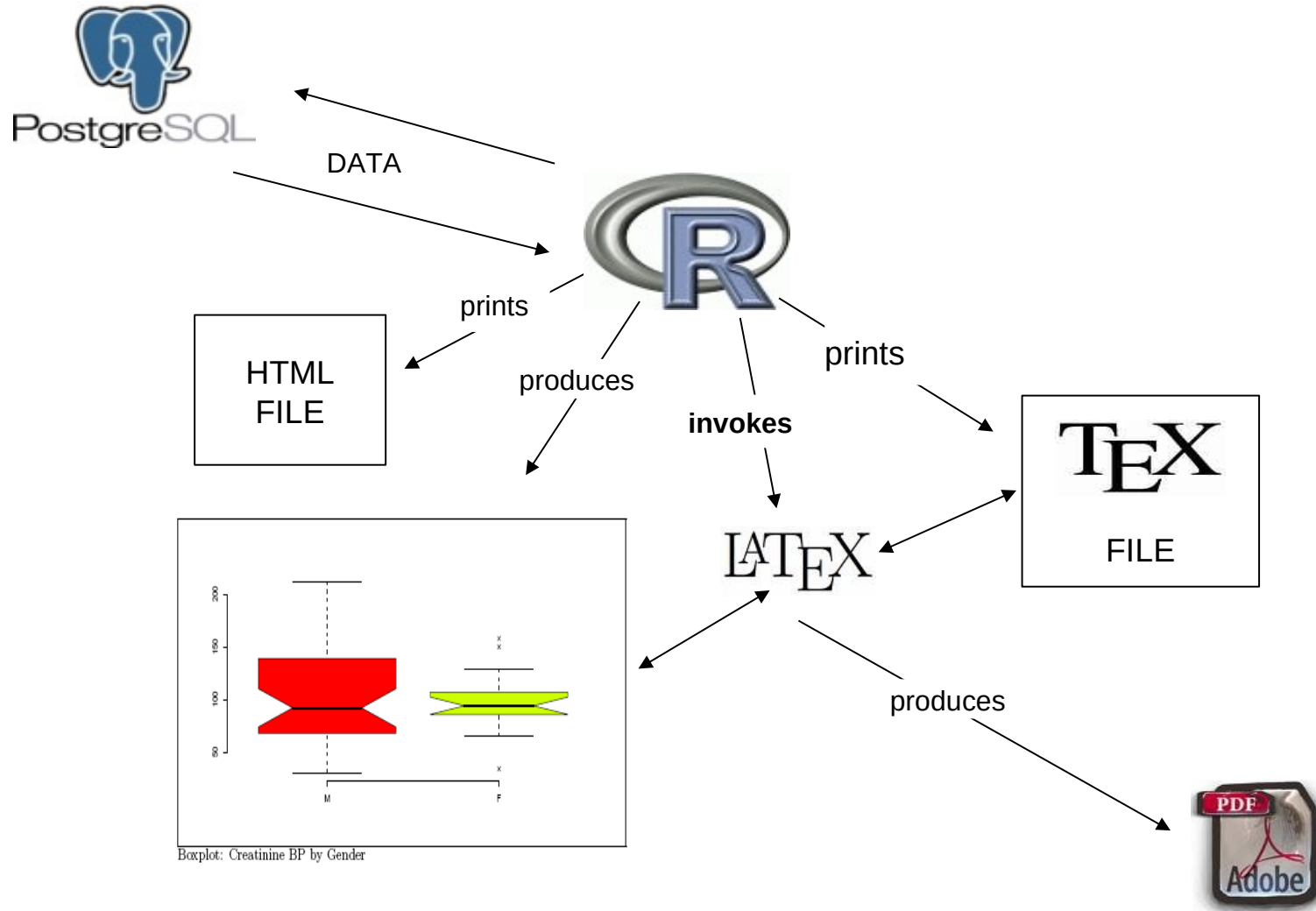
Box 3.4.4. Observed/expected rates by centre using logistic regression

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

Statistical Object

An element of a distributed information system that carries 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

BIRO Statistical Engine Design



Performance

LOCAL

Centre	N Patients	N episodes	Elapsed Time
1	17,552	92,237	24' 25"
2	5,315	19,434	7' 01"
3	7,846	60,274	12' 20"
4	7,827	45,345	10' 51"
5	5,008	10,994	5' 22"

GLOBAL

Centre	N Patients	N episodes	Elapsed Time
1	17,552	92,237	20' 12"
1+2	22,867	111,671	20' 54"
1+2+3	30,713	217,290	21' 33"
1+2+3+4	38,540	262,635	21' 56"
1+2+3+4+5	43,548	273,629	22' 27"



Best Information through Regional Outcomes

Web Portal



Biro Indicators

- o Home
- o Why BIRO
- o BIRO model
- o Diabetes info
- Diabetes Indicators
- o Data dictionary
- Work packages
- o Project partners
- o E-learning
- o How to participate

User login

Username: *

Content

BIRO - Best Information through Regional Outcomes

We live in an information age, but good information is still scarce and hard to find.

Chronic conditions in general and diabetes in particular represent a challenge for good health in Europe that is already significant, and which we can expect to become greater in the years to come.

Action must be taken to significantly reduce this burden.

Good indicators to benchmark the problems we face and the steps being taken may represent a powerful mechanism to help bring about improvements and support the identification, dissemination and application of best practice.

The BIRO web portal provides access to the results produced by a sustained effort across countries, organisational and professional boundaries, involving citizens and the wider community through the support of the European Commission.

Nick Fahy

Head of the Health Information Unit

Health and Consumers Directorate-General European Commission



BIRO Report

Biro Indicators

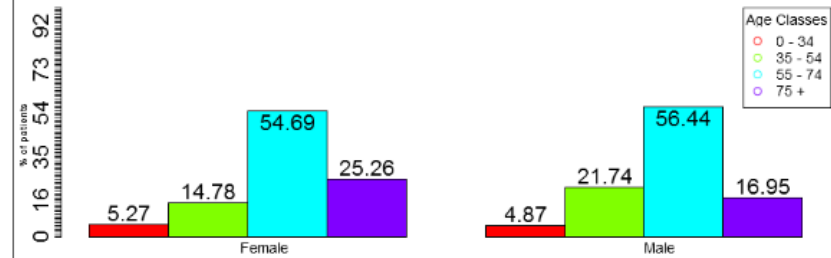
- o Home
- o Why BIRO
- o BIRO model
- o Diabetes info
- ▼ Diabetes Indicators
 - ▼ 1. Demographic characteristics
 - o 1.1. Age (Classes)
 - o 1.2. Gender
 - ▶ 2. Clinical characteristics
 - ▶ 3. Health system
 - ▶ 4. Population (Area level)
 - ▶ 5. Risk adjusted indicators
- o Data dictionary
- ▶ Work packages
- o Project partners
- o E-learning
- o How to participate

Home » Diabetes Indicators » 1. Demographic characteristics » 1.1. Age (Classes)

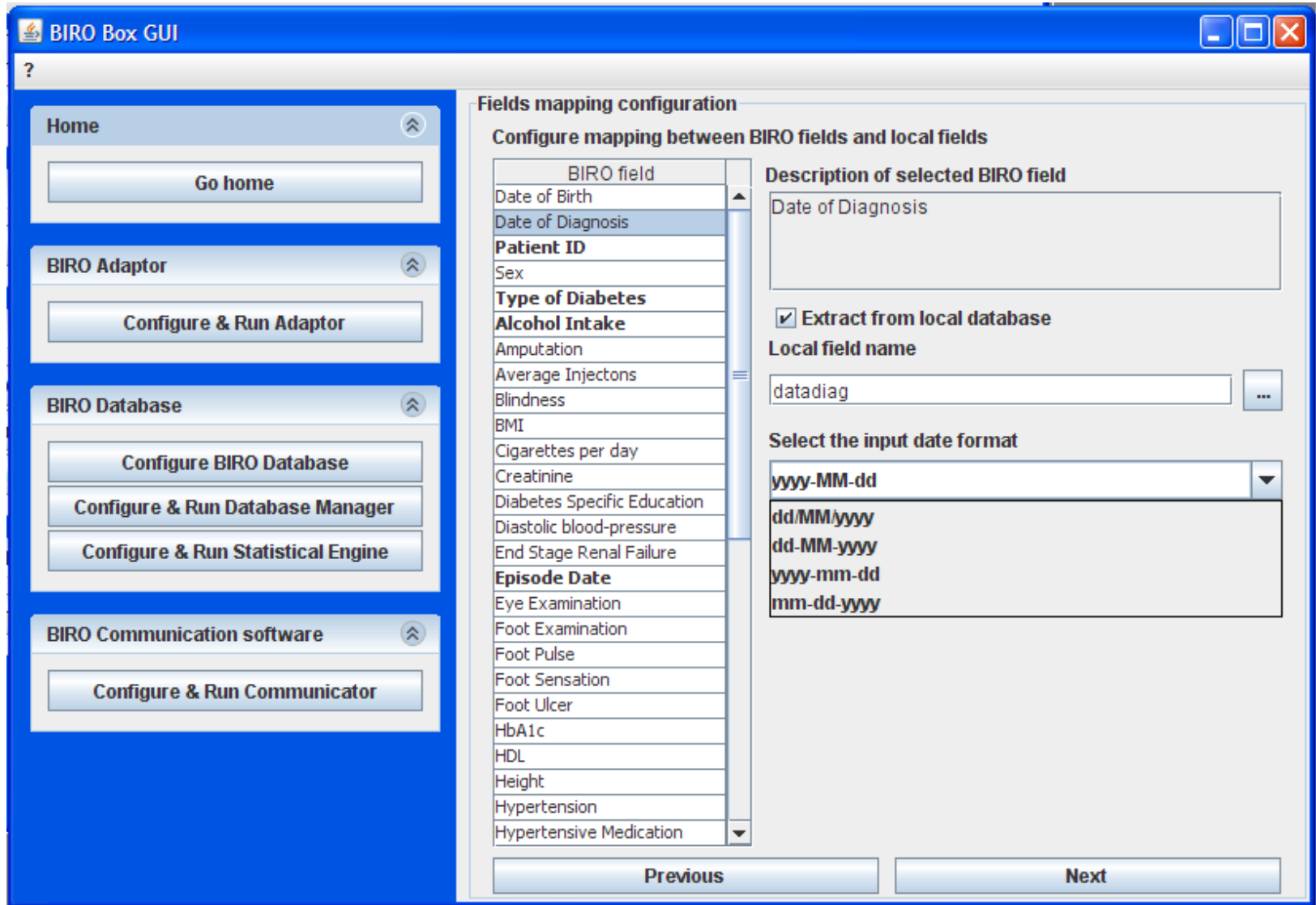
1.1. Age (Classes)

Indicator Definition

Age Classes	Female	Male	
0 - 34	775 (49.81 %)	781 (50.19 %)	1556 (5.06 %)
35 - 54	2175 (38.40 %)	3489 (61.60 %)	5664 (18.41 %)
55 - 74	8046 (47.04 %)	9058 (52.96 %)	17104 (55.6 %)
75 +	3716 (57.74 %)	2720 (42.26 %)	6436 (20.92 %)
	14712 (47.83 %)	16048 (52.17 %)	30760



The BIRO Box



The screenshot shows the BIRO Box GUI with a sidebar on the left and a main configuration area on the right. The sidebar contains four sections: Home (Go home), BIRO Adaptor (Configure & Run Adaptor), BIRO Database (Configure BIRO Database, Configure & Run Database Manager, Configure & Run Statistical Engine), and BIRO Communication software (Configure & Run Communicator). The main area is titled 'Fields mapping configuration' and contains a table of BIRO fields, a description of the selected field, and options for extraction and date format.

Fields mapping configuration

Configure mapping between BIRO fields and local fields

BIRO field	Description of selected BIRO field
Date of Birth	Date of Diagnosis
Date of Diagnosis	
Patient ID	
Sex	
Type of Diabetes	
Alcohol Intake	
Amputation	
Average Injectons	
Blindness	
BMI	
Cigarettes per day	
Creatinine	
Diabetes Specific Education	
Diastolic blood-pressure	
End Stage Renal Failure	
Episode Date	
Eye Examination	
Foot Examination	
Foot Pulse	
Foot Sensation	
Foot Ulcer	
HbA1c	
HDL	
Height	
Hypertension	
Hypertensive Medication	

Extract from local database

Local field name: ...

Select the input date format

yyy-MM-dd (selected)

dd/MM/yyyy

dd-MM-yyyy

yyyy-mm-dd

mm-dd-yyyy

Previous Next

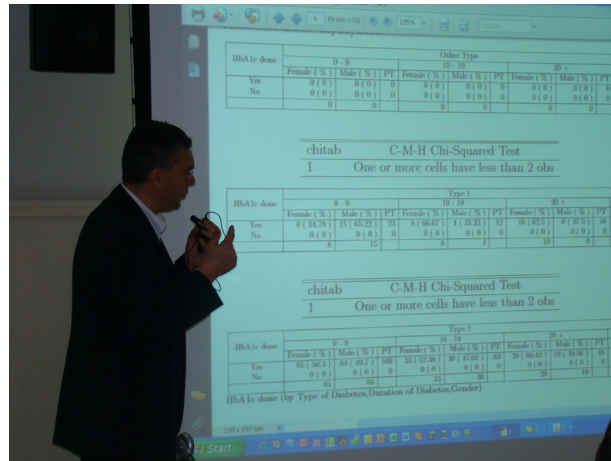
Learning from data



Continuous development....



Success stories....



Statistical explanations....



Doctors objections...



Best Information through Regional Outcomes

www.biro-project.eu

The image shows a navigation menu for the B.I.R. website. It features the B.I.R. logo on the left and a central graphic of a globe with yellow stars. Surrounding the globe are several menu items: About, Partners, Objectives, Activities, Documents, Restricted Area, Results, Forum, and Links. Below the navigation menu, there is a dark blue banner with the text "Best Information through Regional Outcomes Building a Shared European Diabetes Information System". Underneath this banner, it states "A Public Health Project funded by the European Commission Health Information Strand, DG-SANCO 2005". At the bottom of the menu area, there is a "Latest Updates" section with a list of recent events and document additions.

Website

The image is a screenshot of the B.I.R. Forum website. The browser window title is "B.I.R.O. Forum - The European Diabetes Project's Forum". The page header includes the B.I.R. logo and the text "Best Information through Regional Outcomes". Below the header, there is a navigation menu with links for Search, Recent Topics, Member Listing, Back to home page, My Profile, My Bookmarks, Private Messages, and Logout (Fabrizio). The main content area features a "Forum Index" table with columns for Forums, Topics, Messages, and Last Message. The table lists three forums: "Restricted Forum", "The B.I.R.O. Blog", and "Bugs and Problems". Below the table, there is a "Who is online" section with statistics on registered users and online users. The browser's status bar at the bottom shows "Done".

Forums	Topics	Messages	Last Message
B.I.R.O.			
Restricted Forum B.I.R.O. Consortium restricted forum	21	62	13/12/2006 09:05:00 Fabrizio
The B.I.R.O. Blog In this forum you can write all you think about B.I.R.O. and all related things Moderators: B.I.R.O. Consortium	3	8	06/04/2006 10:57:39 Pietro
Bugs and Problems If you find any bugs or problems write a message in this forum	1	3	14/07/2006 13:30:59 pback

Forum