Best Information through Regional Outcomes

The B.I.R.O. Project

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"A Shared Information System for Diabetes in Europe: final results of the B.I.R.O. Project"
Dessau Conference Room
Perugia, 25th May 2009

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EU Health Council 2004

- There is merit in addressing diabetes in a coordinated, strategic & comprehensive way
- A European strategy for diabetes could make important contributions to reducing public health expenditure in member states

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

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"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

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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	

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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

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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

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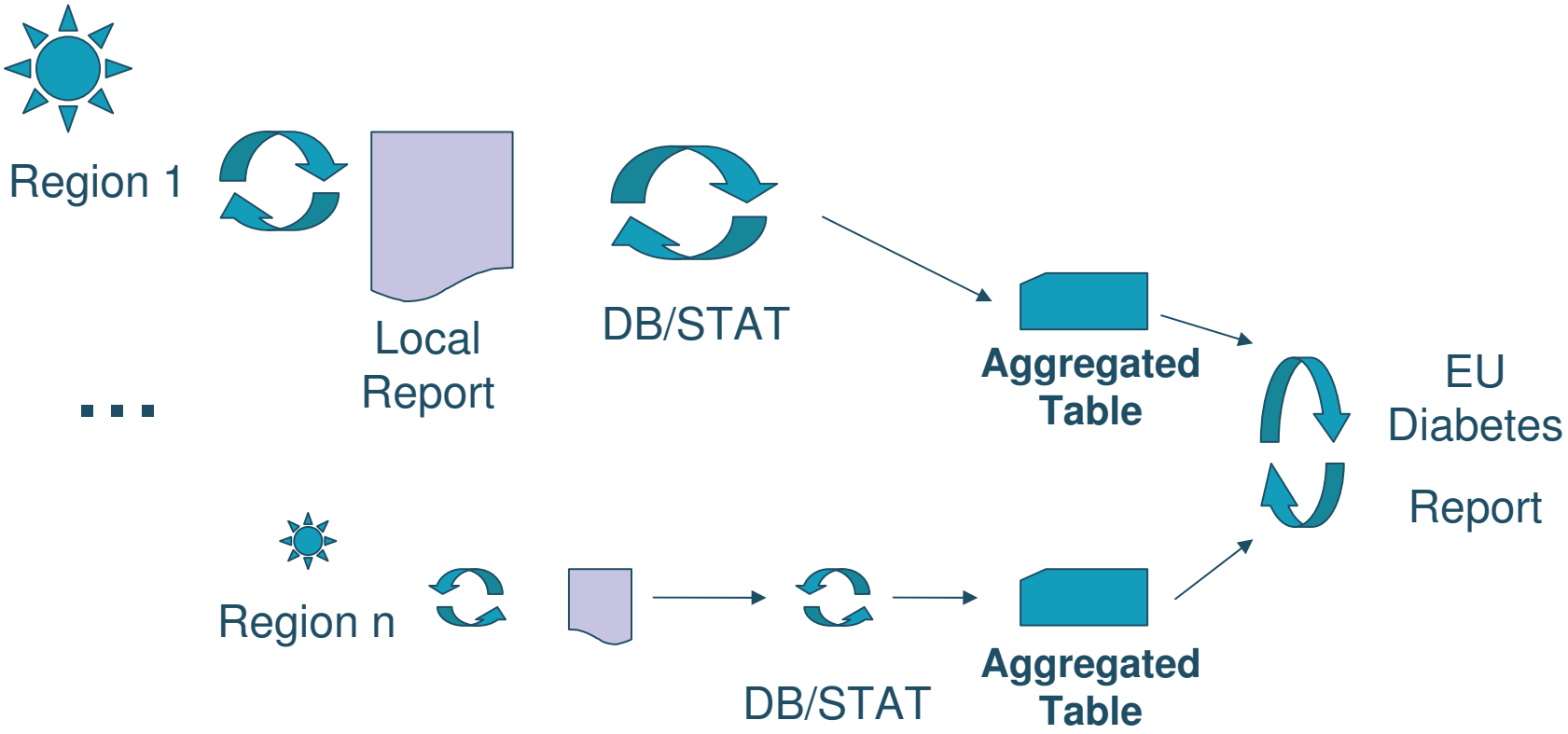
BIRO model



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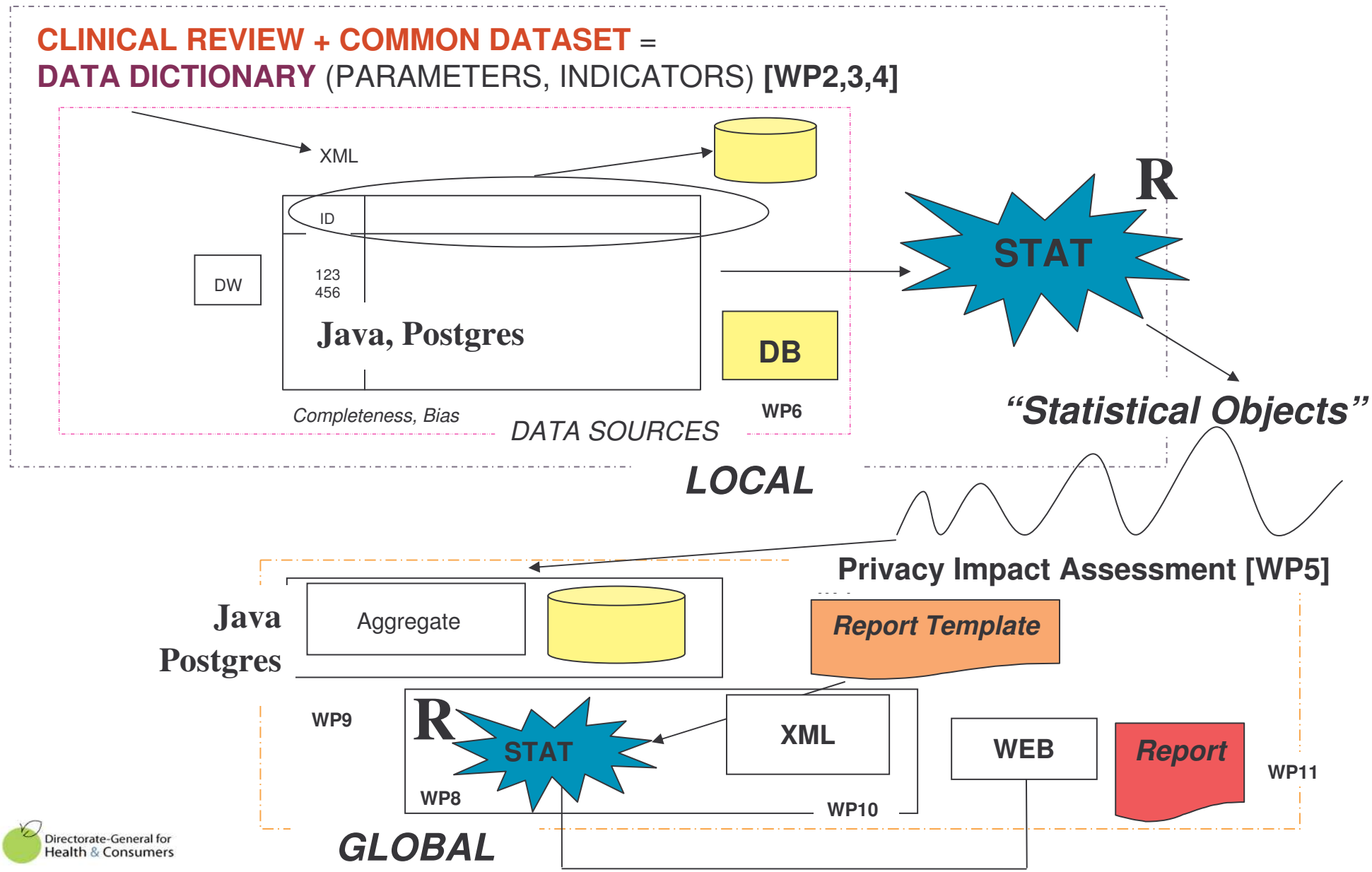
BIRO Technology



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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

Specification of Data items needed

- Indicator needs data
- Data clearly defined
- Information gathering by BIRO system

- New indicators can be defined by partners

Common Dataset

- Dataset items recorded as a “Parameter”
- Parameters have a unique reference
- Clear definition
- Associated data type
- Unit of measurement (e.g.kg/m^2)
- 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

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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	Creatinine	Integer	
BIRO018	MA_TEST	Microalbumin	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

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Reports Template
Indicators and statistical output for each BIRO-user

Governance

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

Underlined preferred output

Health care and research

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

Different output according to target audience

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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)
  - Intemediate Outcomes (N=7)
  - Terminal Outcomes (N=3)

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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	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)
Aggregation across service centres									

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

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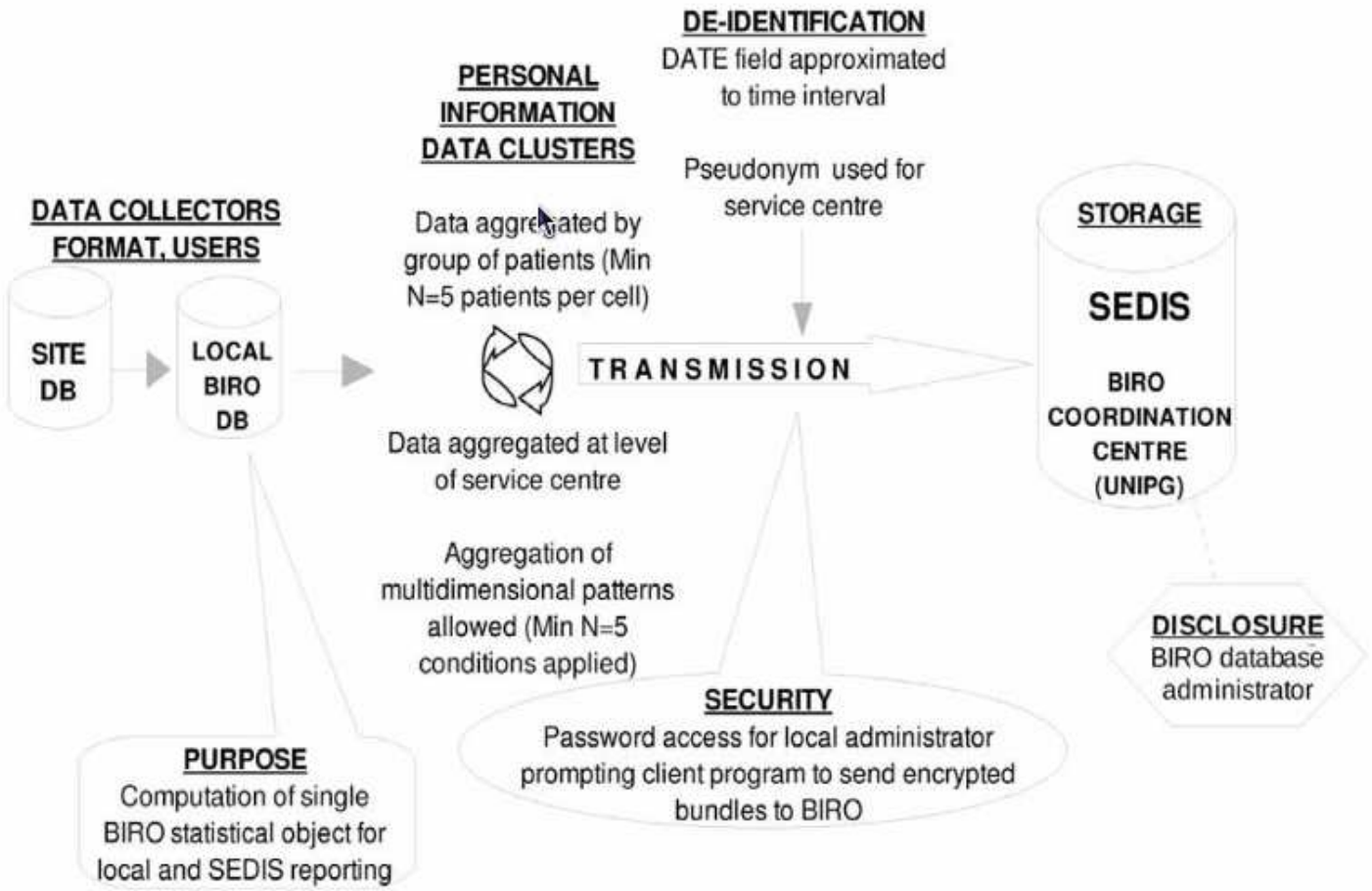
Best architecture



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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.

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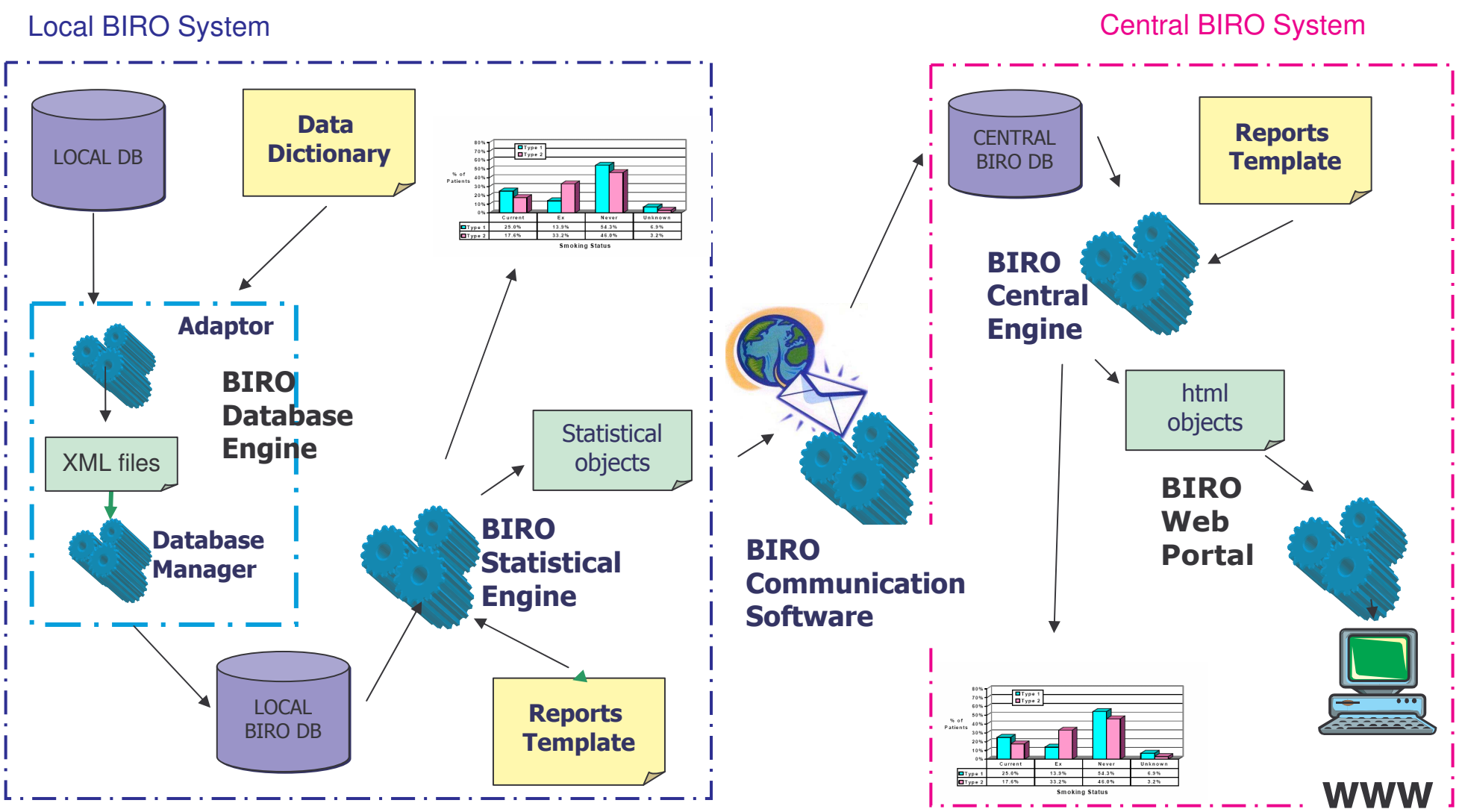
The BIRO System



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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

Parameter	Standard DF	Wald 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

Parameter	Standard DF	Wald Estimate	Error	Chi-Square	Pr > ChiSq
Intercept	1	-0.6862	0.1028	44.5243	<.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

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

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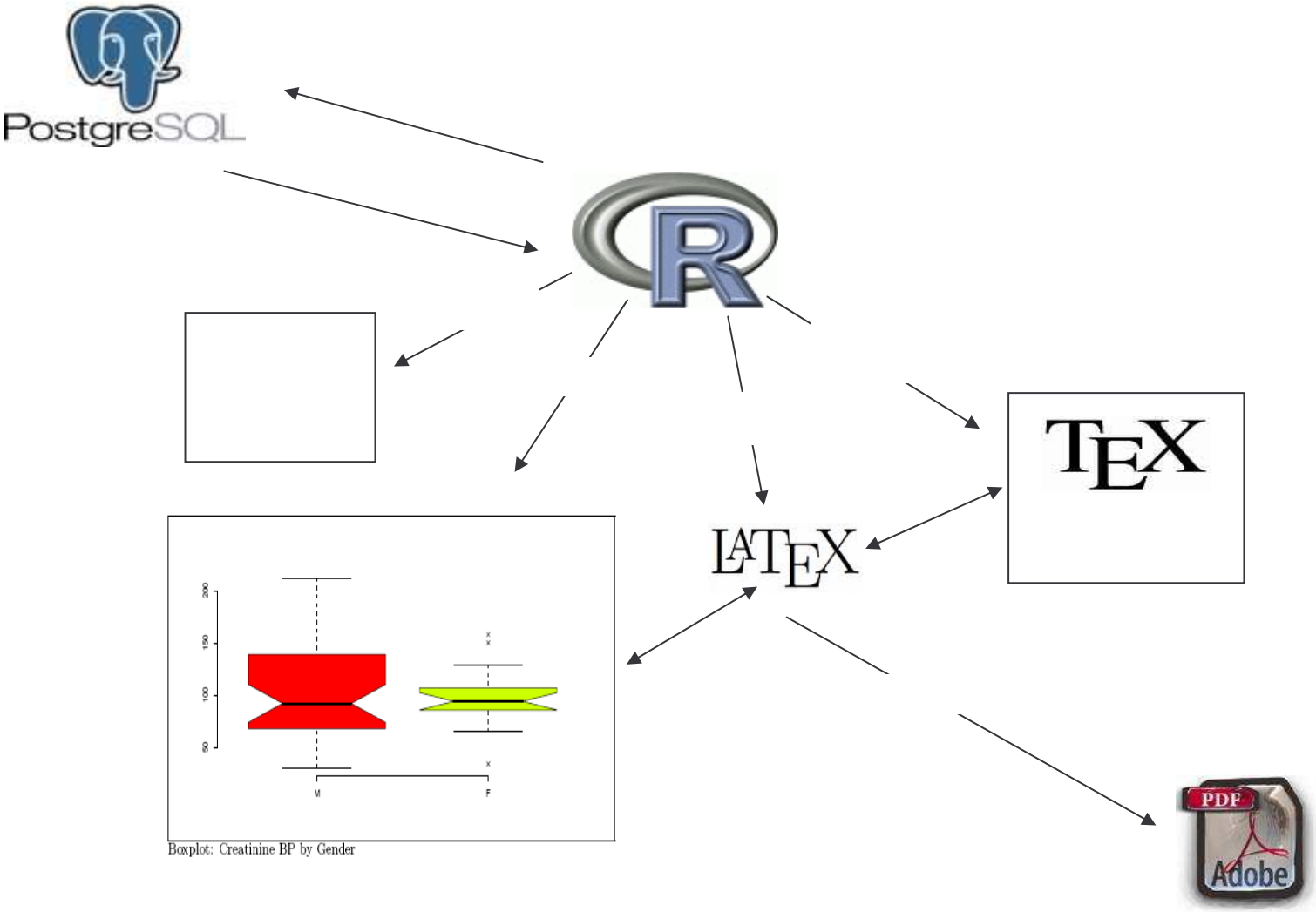
Statistical Object

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

Arithmetic Mean

Code	2.1
Statistical Object	Arithmetic Mean
Description	Weighted average of a single characteristic, with weights equal to the number of observations for each specific value of the target variable
Variables	CONTINUOUS
Properties	The mean of the overall sample is equal to the weighted mean of the arithmetic means from all local repositories
Local Component	Data vector composed of two quantities: sum of the values of the target variable; total number of observations DATA: **<2.1.a>id, date, stratum, sum_x, n**
Cumulative Component	Sum of the sum of values from each local object DATA: **<2.1.a> id, date, stratum, sum_x, n**
Output	Single value of the overall arithmetic mean: cumulative object, divided by the sum of the total number of observations from each local object DATA: **<2.1.a>mean** Single value of the arithmetic mean by centre: cumulative object, divided by the sum of the total number of observations from each local object, for each centre, for each stratum DATA: **<2.1.b>id, date, stratum, mean**

BIRO Statistical Engine Design



Boxplot: Creatinine BP by Gender

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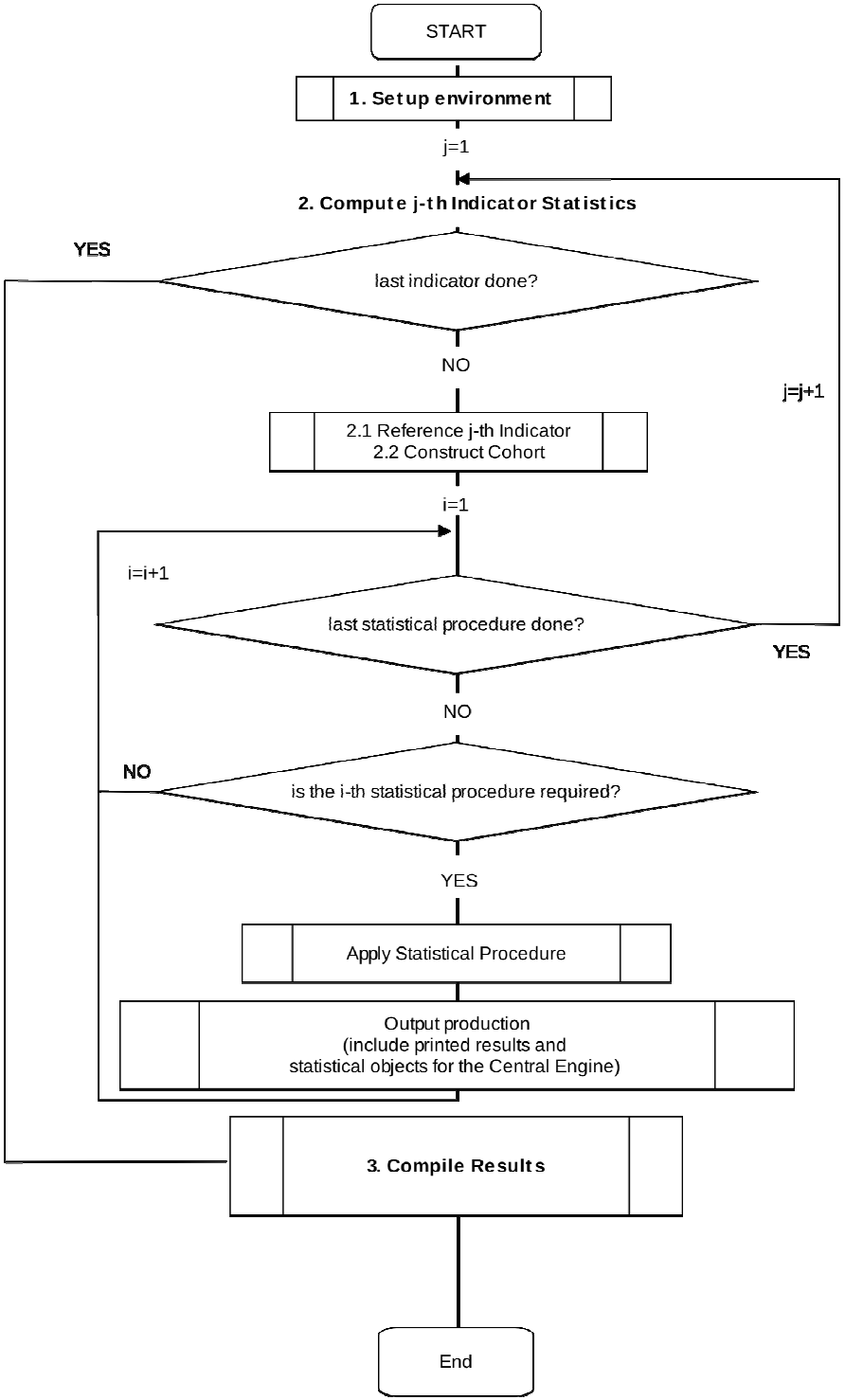

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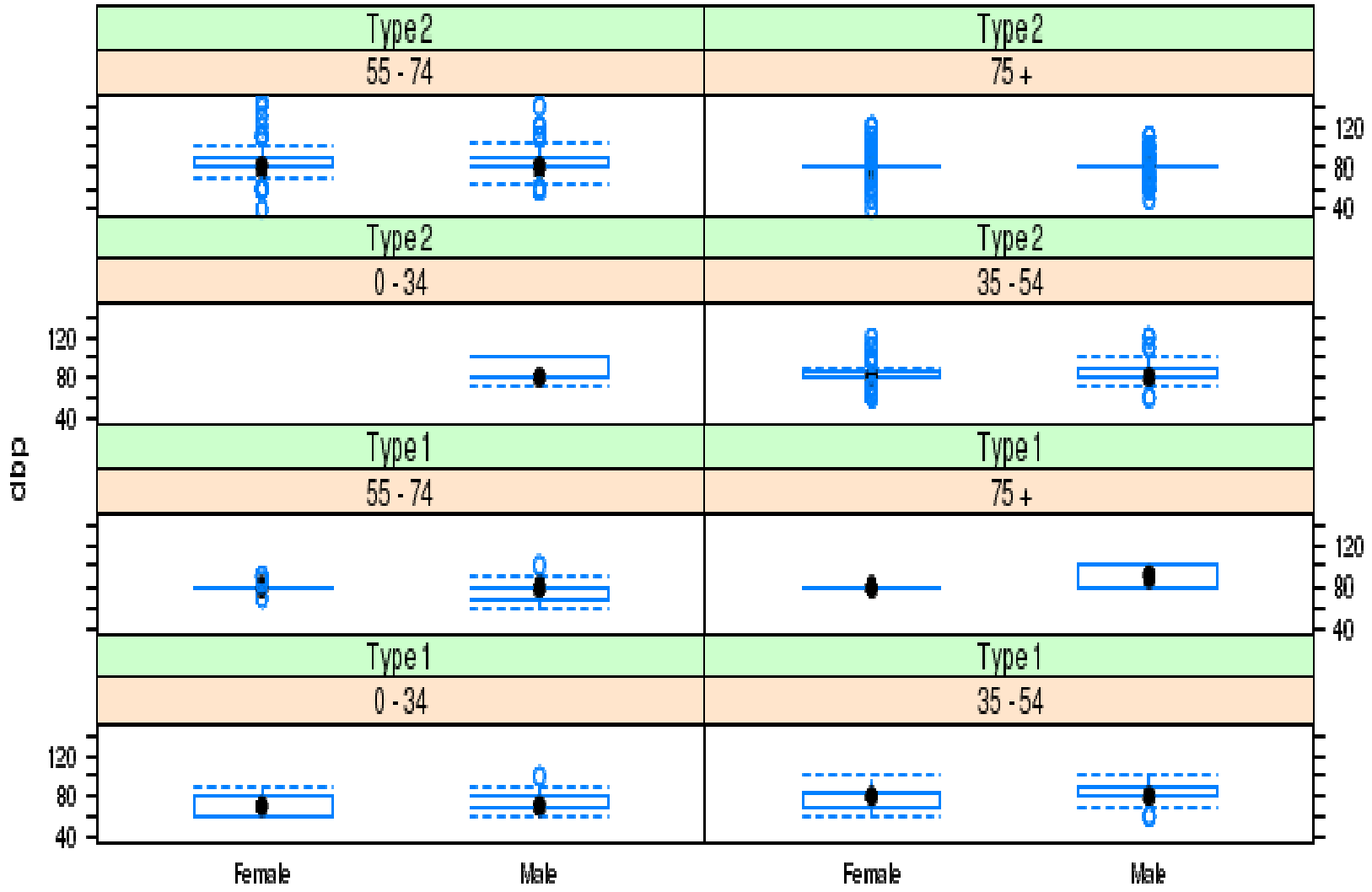
Graphics


Type 2
55 - 74
Type 2
75 +
Type 2
0 - 34
Type 2
35 - 54
Type 1
55 - 74
Type 1
75 +
Type 1
0 - 34
Type 1
35 - 54
dbp
120
80
40
Female
Male

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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"

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Web Portal

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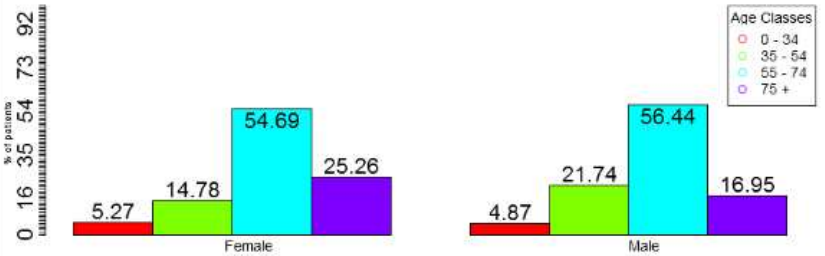
BIRO Report

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



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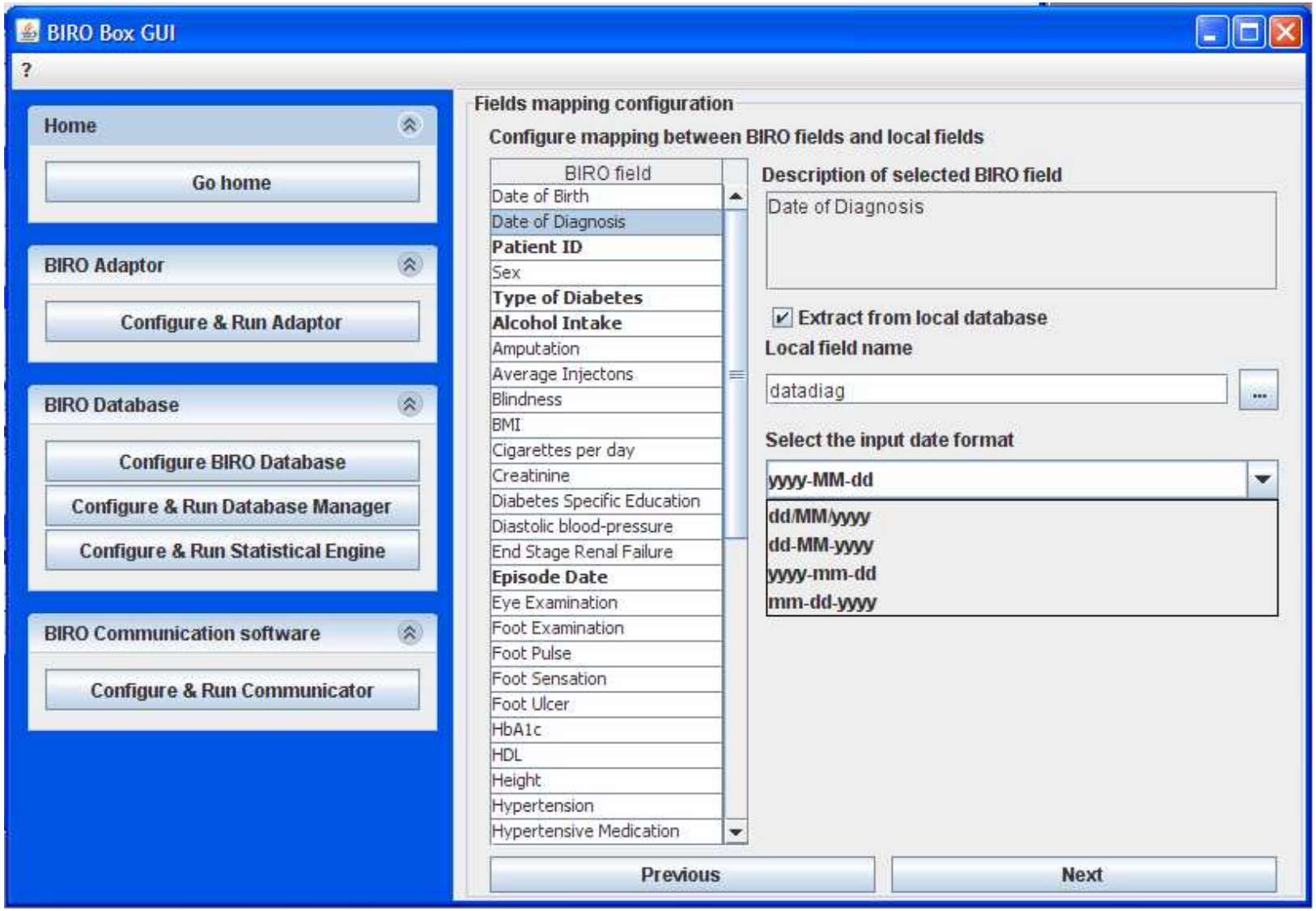
The BIRO Box



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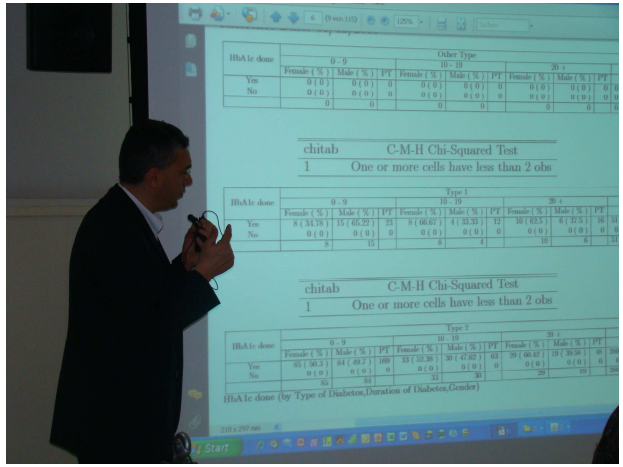
Learning from data

Continuous development....

Success stories....



Statistical explanations....

Doctors objections...

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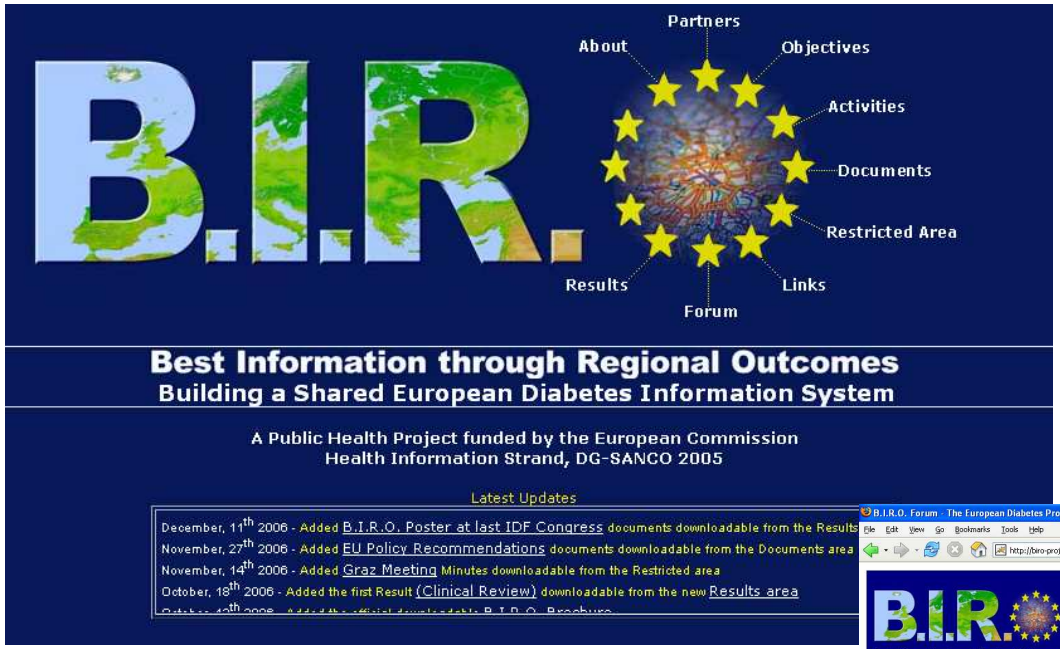
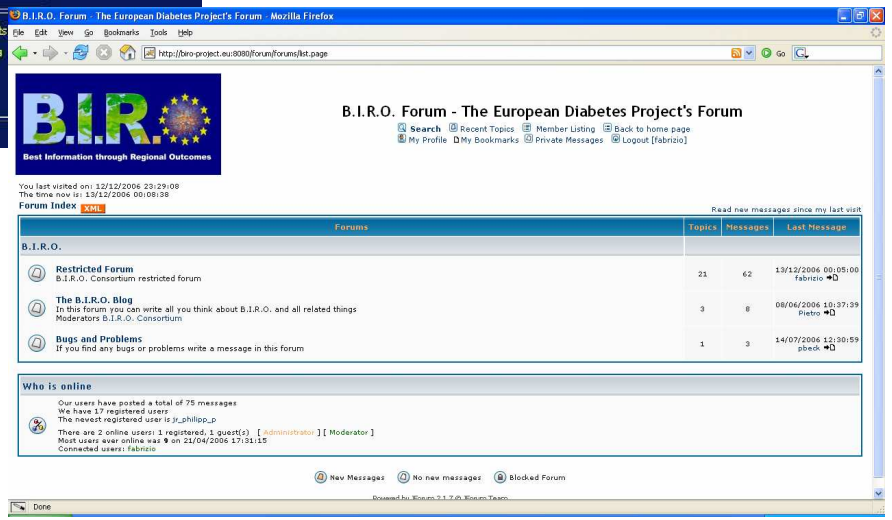
www.biro-project.eu



Website

Forum



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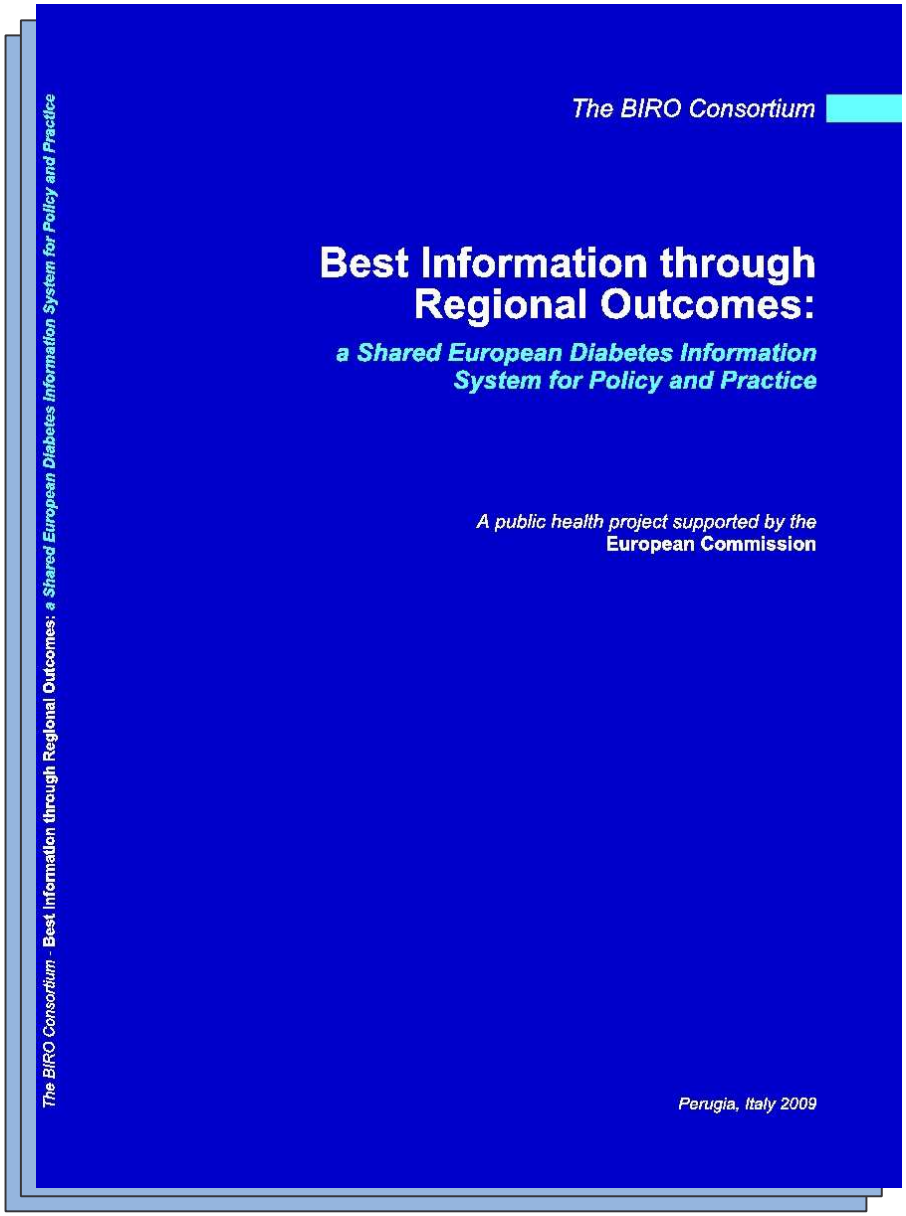
The BIRO Book
May 2009



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BIRO Brother?

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Just keep going..

BIRO Academy

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