EUropean Best Information through Regional Outcomes in Diabetes

Measuring Quality and Efficiency in Large Health Care Systems

A novel international framework for privacy-enhanced data processing, exchange and pooled analysis of disease registers: the European BIRO/EUBIROD projects

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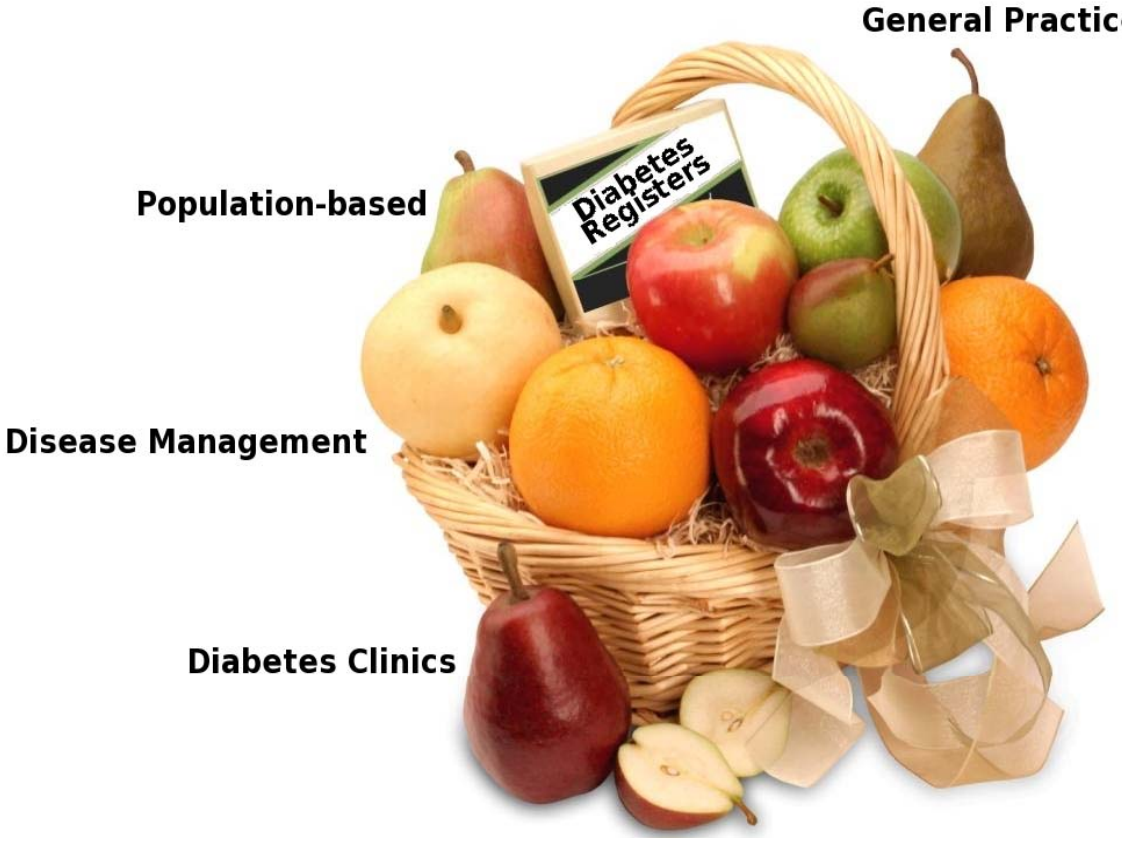
on behalf of the EUBIROD Project Consortium

Academy Health Annual Research Meeting
Boston, 29th June 2010

Directorate-General for Health & Consumers

Executive Agency for Health and Consumers

Diabetes Registers: different fruits



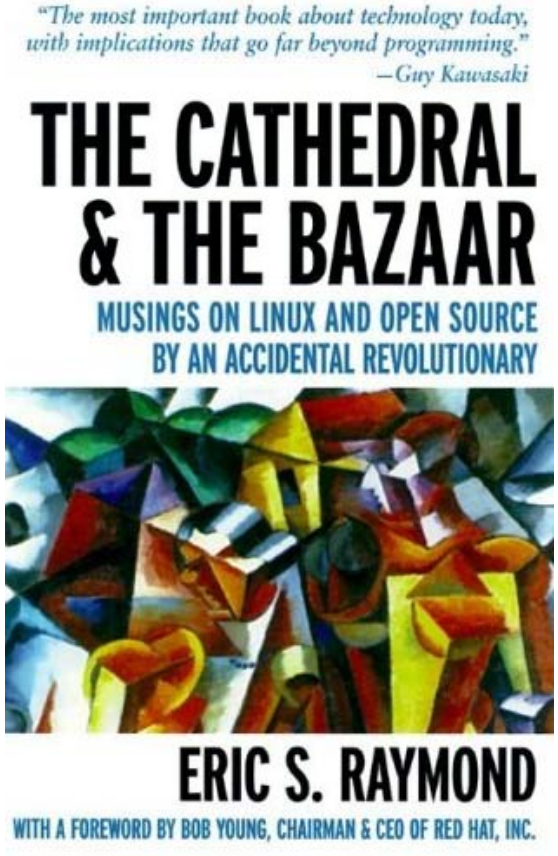
Types of Registers

“Population-based”

“Disease Management”

“Specialistic”

Unified model: cathedral or bazaar?

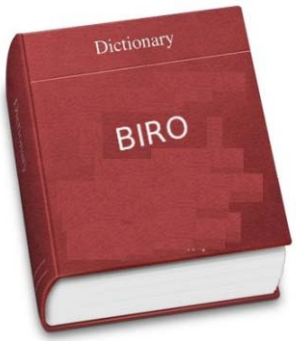


Best Information through Regional Outcomes (BIRO)

- Three year project in diabetes funded by the Health Information Strand, Public Health Program, DG-SANCO, European Commission
- Start: 1st December 2005
- Total cost: 1.2Mn€ - Total EU contribution: 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

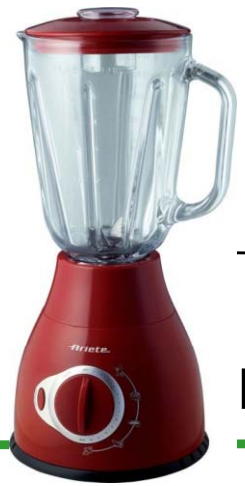
Coordination rather than unification: a pragmatic model

Recipe = Dictionary



Discard Heterogeneity

Ingredients = Standardized Data



Product = Indicators

Fundamental BIRO definitions

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

BIRO Infrastructure: “Privacy by Design”

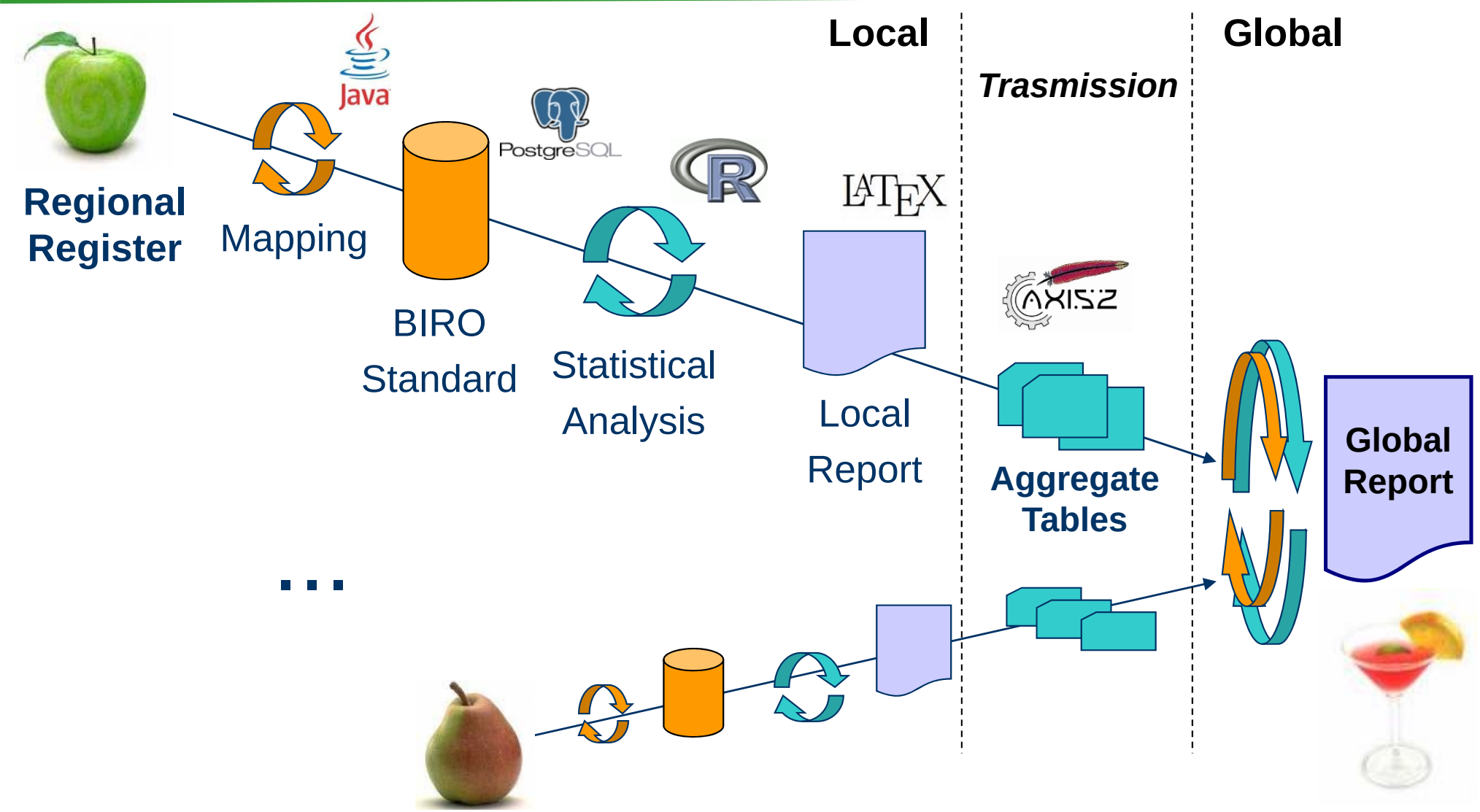
DI IORIO CT et al, J Med Ethics. 2009 Dec;35(12):753-61.

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 Federici,[3] S Pruna,[9] P Palladino,[10] S Skeie,[8] P Taverner,[8] V Traynor,[6] M Massi Benedetti[3]

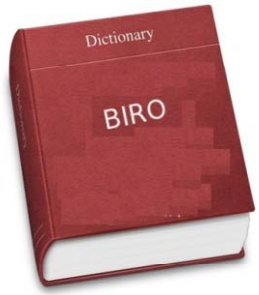
The complete BIRO model
www.biro-project.eu



BIRO Ingredients: Required Data

- **Core dataset (“Merge Table”)**
- **Activity Table** (transfer,death, residency change)
- **Structural profile** (n.physicians, nurses)
- **Population profile (catchment area)**

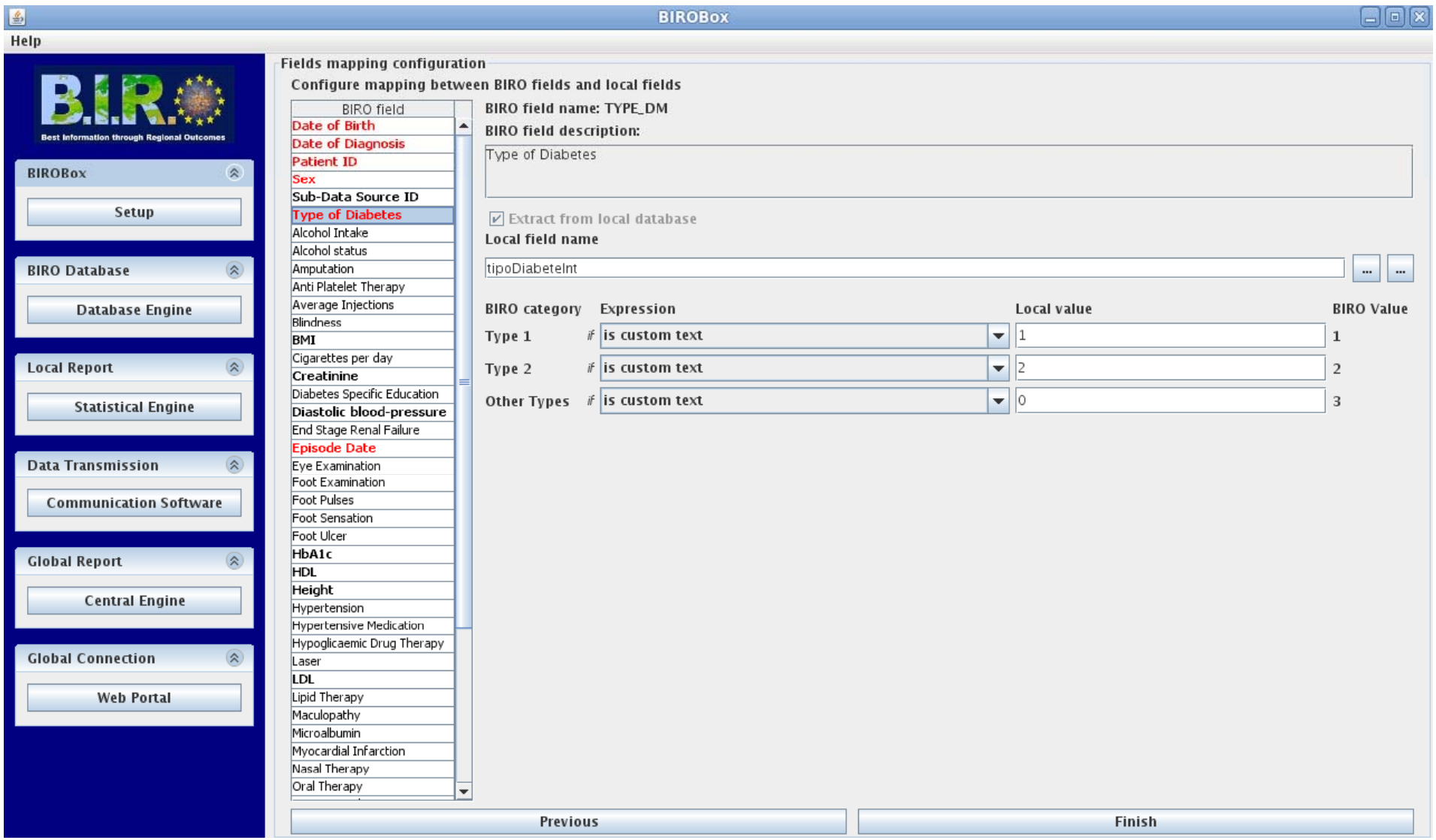
BIRO Core EU Dataset



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. Dyastolic Blood Pressure
16. HbA1c
17. Creatinine
18. Microalbumin
19. Total Cholesterol
20. HDL
21. Trygliceride
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

Common Interface: the “BIROBox”



BIRO Indicators (N=72)

http://www.biro-project.eu/documents/downloads/D14_4_BIRO_Monograph.pdf

Demographic Characteristics (N=2)

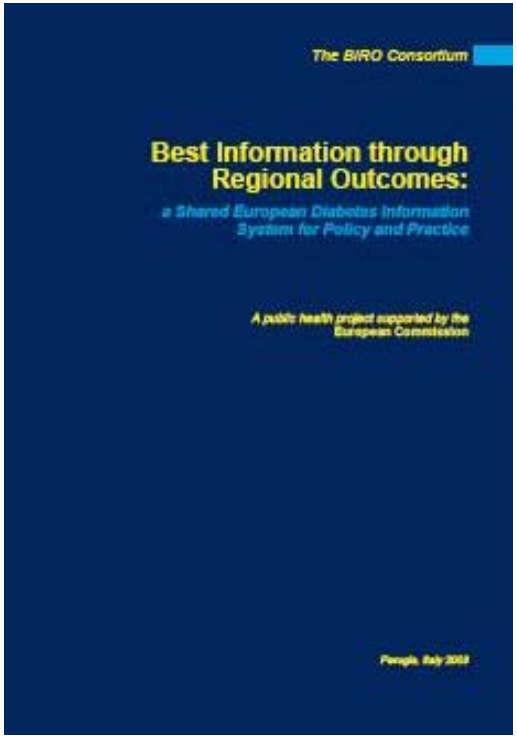
Clinical Characteristics (N=18)

Health System (N=21)

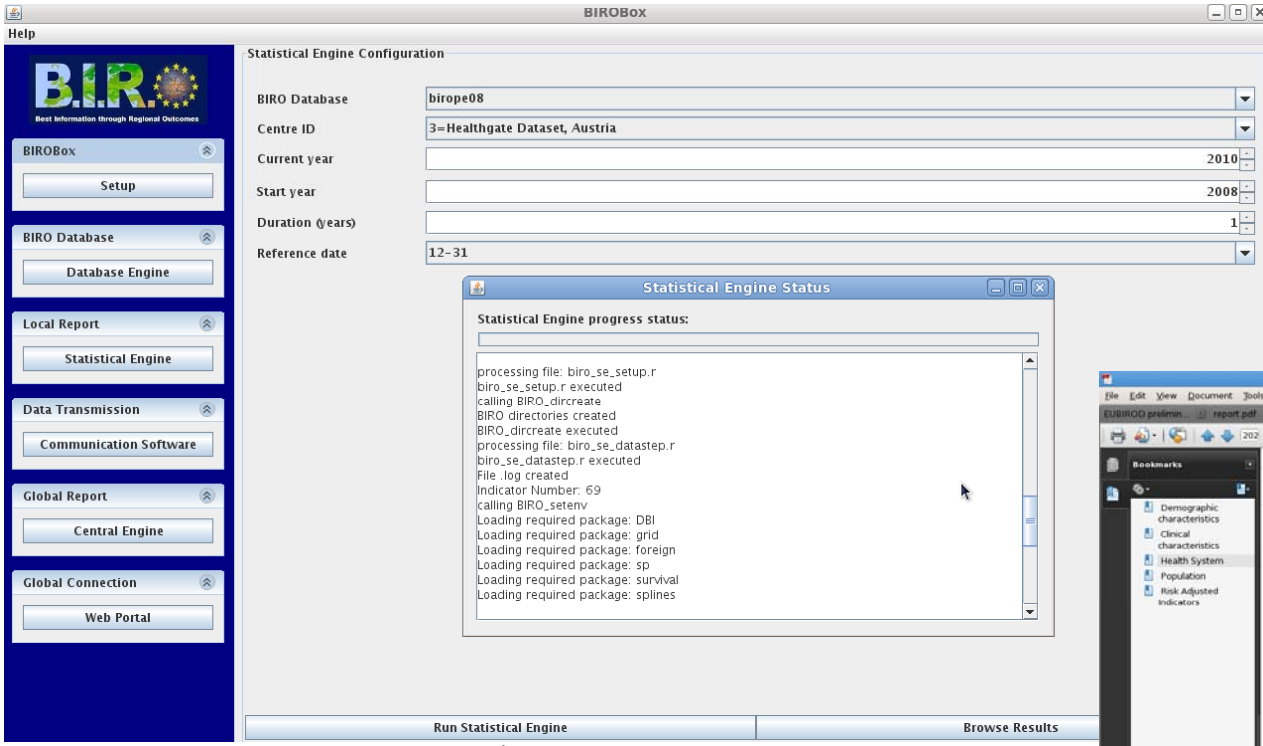
Population (N=3)

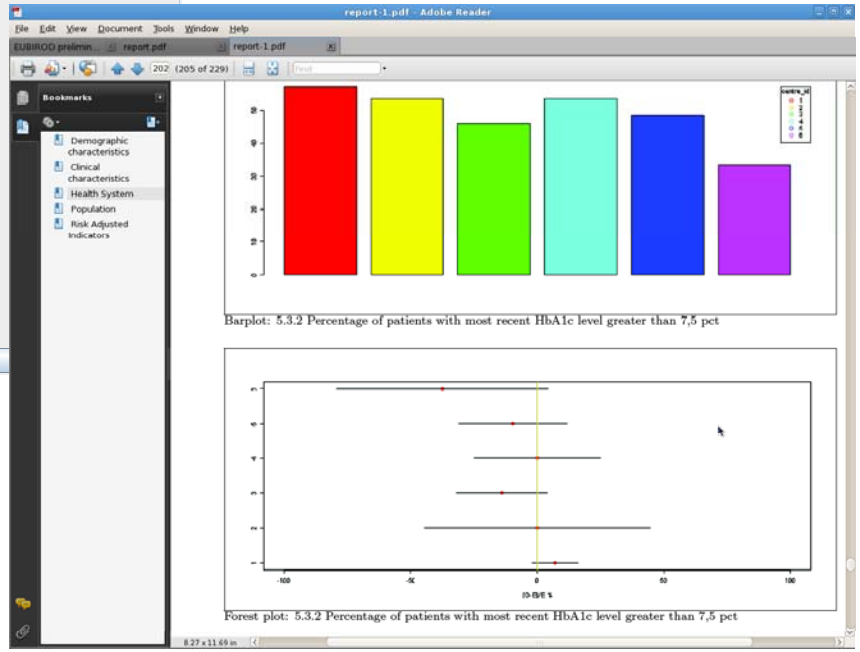
Standardized / Risk Adjusted (N=28)

- Epidemiological (N=2)
- Process (N=16)
- Intermediate Outcomes (N=7)
- Terminal Outcomes (N=3)



The BIRO Statistical Engine: Automated Local & Global Report Delivery





Standardization
(AHRQ Quality Indicators)

Risk adjustment model (in each region/overall)

$$Y(\%) = \beta_0+\beta_1(\text{females})+\beta_2(\text{age_class1})+\ldots\beta_k(\text{age_class4})$$

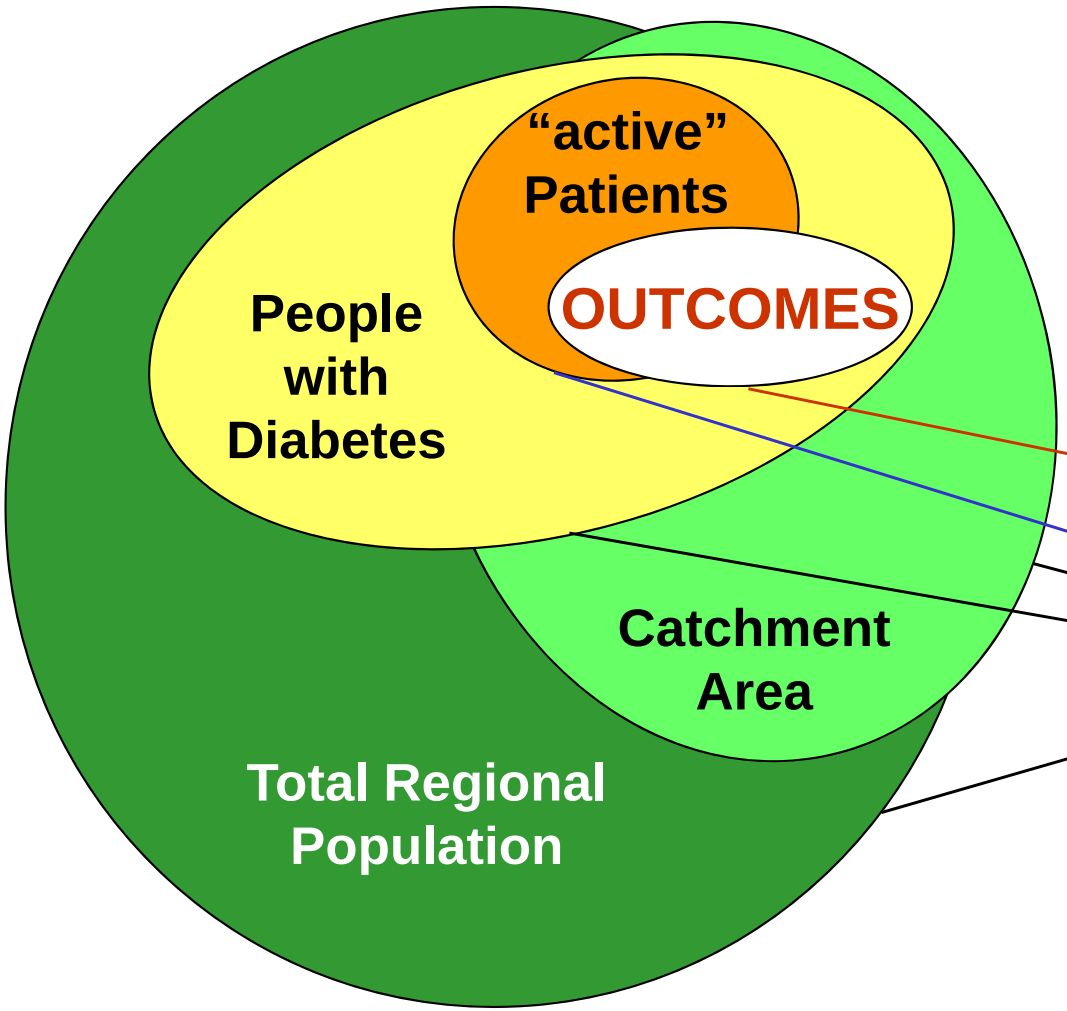
Source unit

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

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

Standardized Rate= (observed rate/expected rate)*population rate

Challenging Bias in Disease Registers



INDICATORS

Numerator

Denominator

DATA

www.eubirod.eu

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)

BIRO

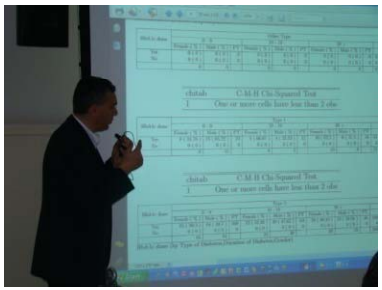
11/2005 **9/2008** 5/2009 **8/2011**

N=153,290

EUBIROD

EUBIROD: complete, refine, measure, disseminate

http://www.eubirod.eu/academy



Watch this space!

www.eubirod.eu