



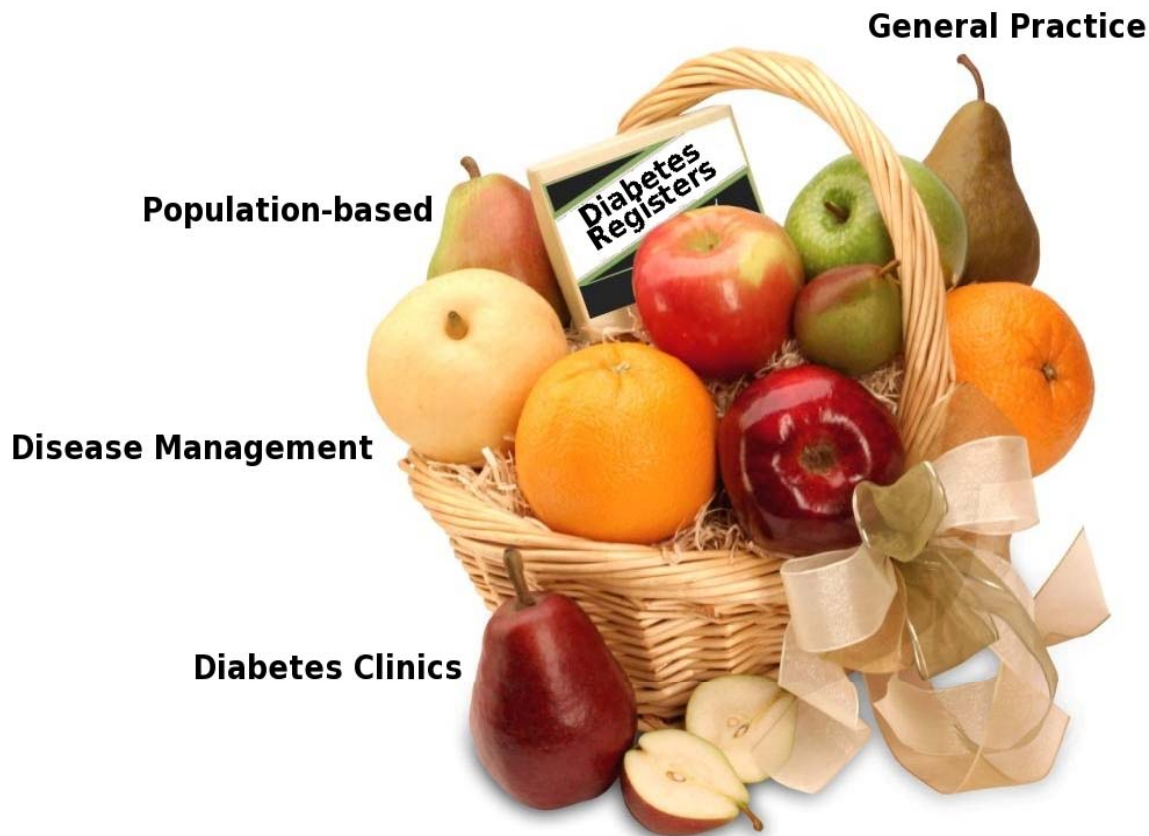
Measuring Quality and Efficiency in Large Health Care Systems

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

*Fabrizio Carinci, Concetta Tania Di Iorio (Serectrix),
Massimo Massi Benedetti (University of Perugia)
on behalf of the EUBIROD Project Consortium*

Academy Health Annual Research Meeting
Boston, 29th June 2010

Diabetes Registers: different fruits



Types of Registers



“Population-based”



“Disease Management”



“Specialistic”

Unified model: cathedral or bazaar?



*"The most important book about technology today,
with implications that go far beyond programming."
—Guy Kawasaki*

THE CATHEDRAL & THE BAZAAR

MUSINGS ON LINUX AND OPEN SOURCE
BY AN ACCIDENTAL REVOLUTIONARY



ERIC S. RAYMOND

WITH A FOREWORD BY BOB YOUNG, CHAIRMAN & CEO OF RED HAT, INC.

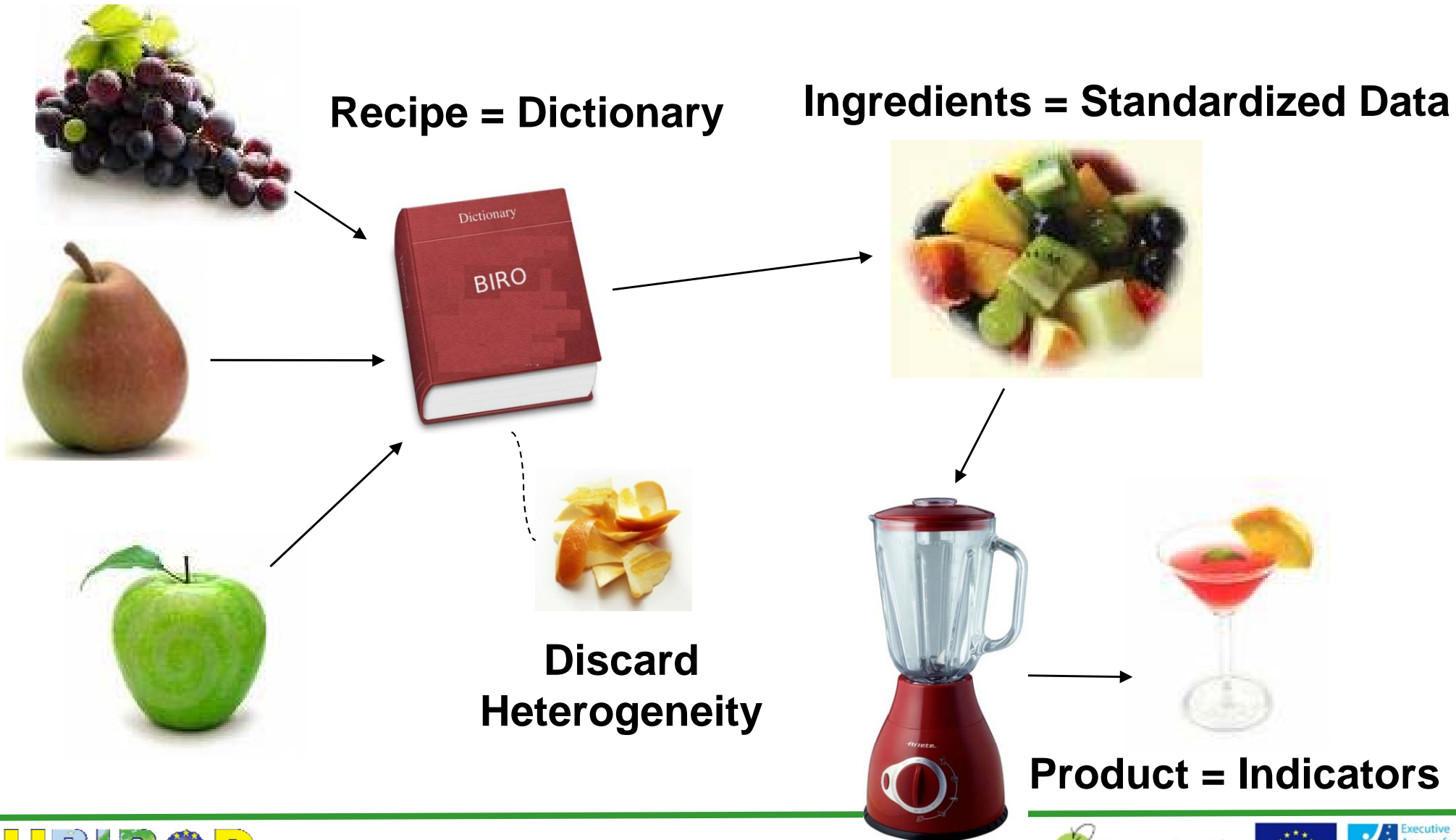


Best Information through Regional Outcomes (BIRO)



- 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



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.



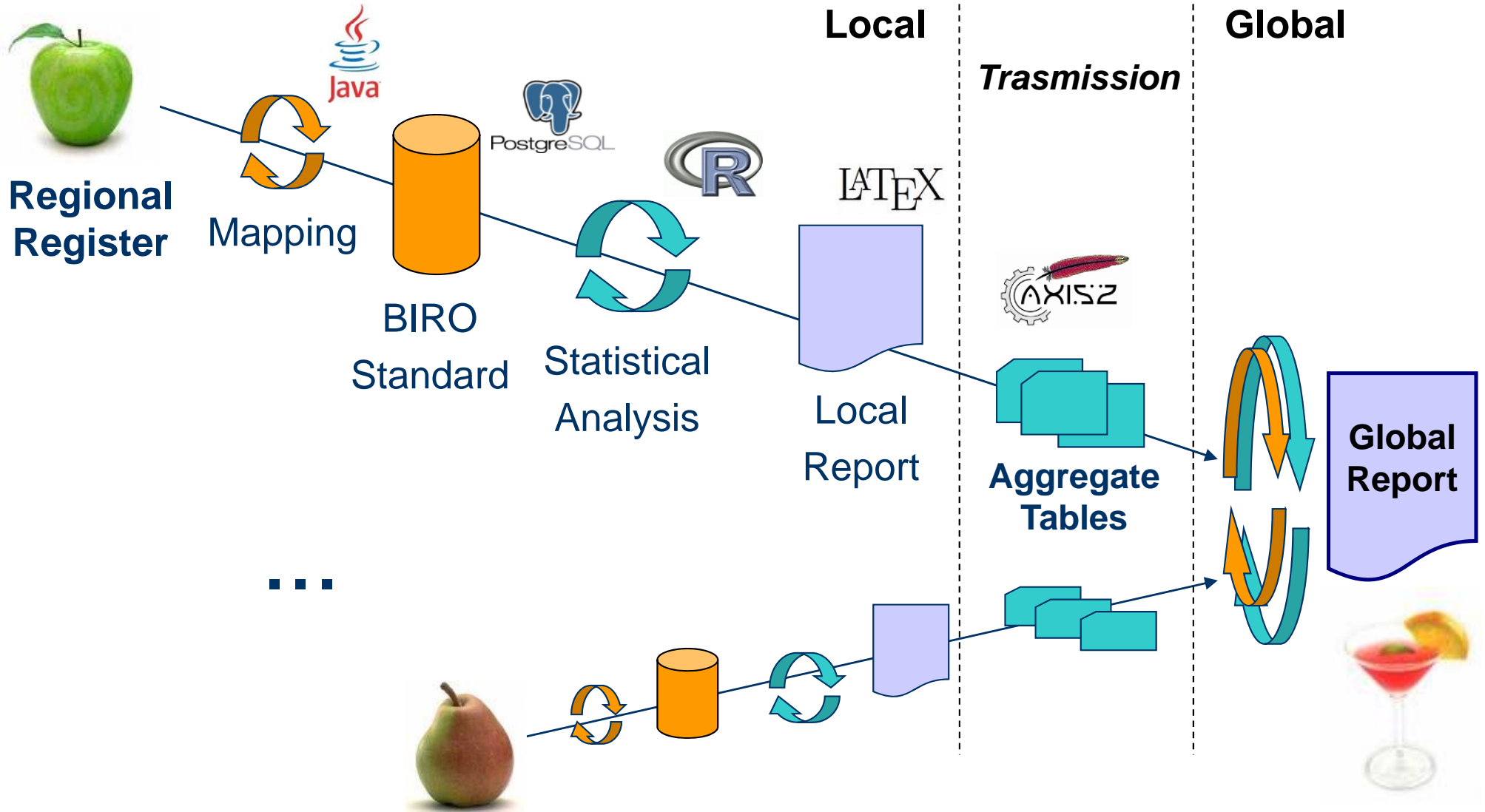
Law, ethics and medicine

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 Benedetti³

The complete BIRO model

www.biro-project.eu



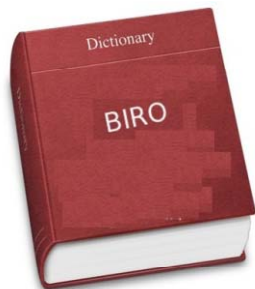
BIRO Ingredients: Required Data



- **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. **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 Dyalysis**
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”



BIROBox

Help



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	BIRO field name: TYPE_DM																
Date of Birth	BIRO field description: Type of Diabetes <input checked="" type="checkbox"/> Extract from local database Local field name: <input type="text" value="tipoDiabetelnt"/>																
Date of Diagnosis																	
Patient ID																	
Sex																	
Sub-Data Source ID																	
Type of Diabetes																	
Alcohol Intake																	
Alcohol status																	
Amputation																	
Anti Platelet Therapy																	
Average Injections	<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 15%;">BIRO category</th> <th style="width: 15%;">Expression</th> <th style="width: 15%;">Local value</th> <th style="width: 15%;">BIRO Value</th> </tr> </thead> <tbody> <tr> <td>Type 1</td> <td>if is custom text</td> <td>1</td> <td>1</td> </tr> <tr> <td>Type 2</td> <td>if is custom text</td> <td>2</td> <td>2</td> </tr> <tr> <td>Other Types</td> <td>if is custom text</td> <td>0</td> <td>3</td> </tr> </tbody> </table>	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
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														
Blindness																	
BMI																	
Cigarettes per day																	
Creatinine																	
Diabetes Specific Education																	
Diastolic blood-pressure																	
End Stage Renal Failure																	
Episode Date	<div style="text-align: center;"> <input type="button" value="Previous"/> <input type="button" value="Finish"/> </div>																
Eye Examination																	
Foot Examination																	
Foot Pulses																	
Foot Sensation																	
Foot Ulcer																	
HbA1c																	
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LDL																	
Lipid Therapy																	
Maculopathy																	
Microalbumin																	
Myocardial Infarction																	
Nasal Therapy																	
Oral Therapy																	

BIRO Indicators (N=72)

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



Demographic Characteristics (N=2)

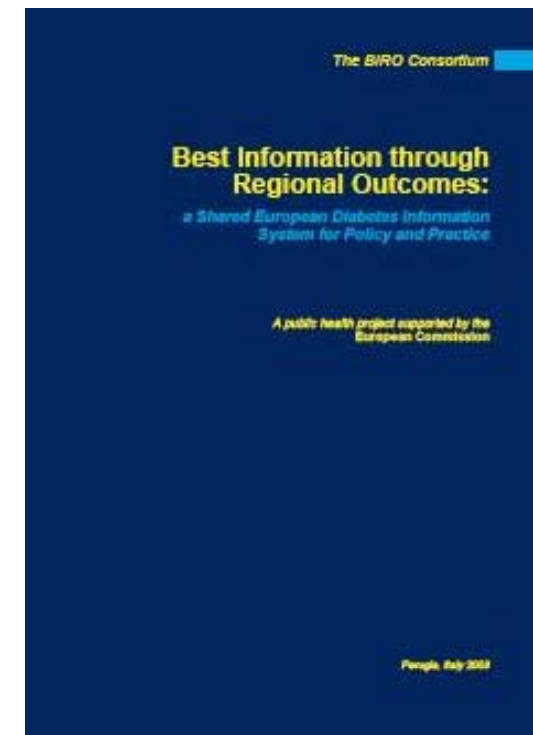
Clinical Characteristics (N=18)

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



BIROBox

Help

Statistical Engine Configuration

BIRO Database: **birope08**

Centre ID: **3=Healthgate Dataset, Austria**

Current year: **2010**

Start year: **2008**

Duration (years): **1**

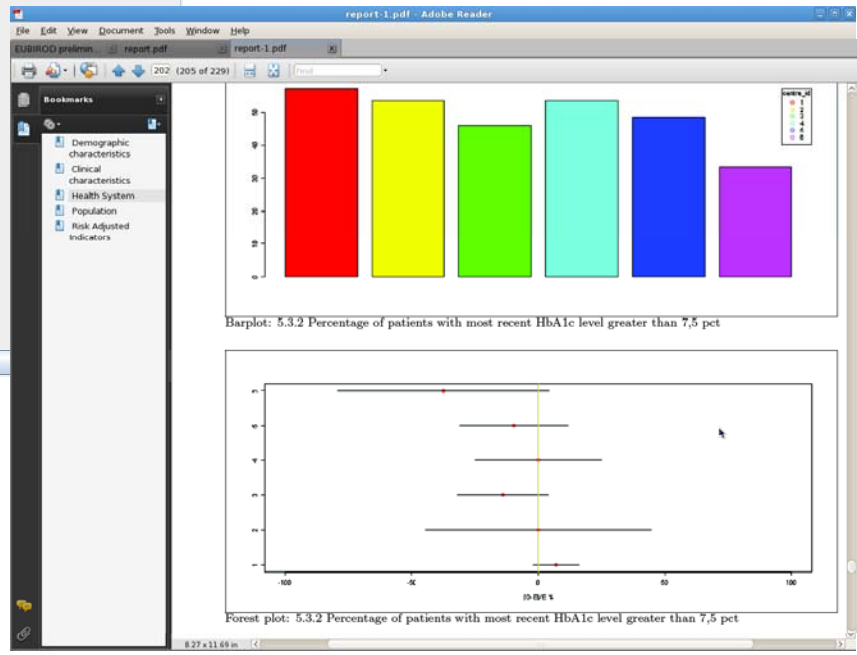
Reference date: **12-31**

Statistical Engine Status

```

Statistical Engine progress status:
processing file: biro_se_setup.r
biro_se_setup.r executed
calling BIRO_dircreate
BIRO_directories created
BIRO_dircreate executed
processing file: biro_se_datastep.r
biro_se_datastep.r executed
File .log created
Indicator Number: 69
calling BIRO_setenv
Loading required package: DBI
Loading required package: grid
Loading required package: foreign
Loading required package: sp
Loading required package: survival
Loading required package: splines
    
```

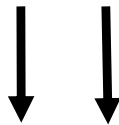
Run Statistical Engine | Browse Results



Standardization (AHRQ Quality Indicators)

Risk adjustment model (in each region/overall)

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



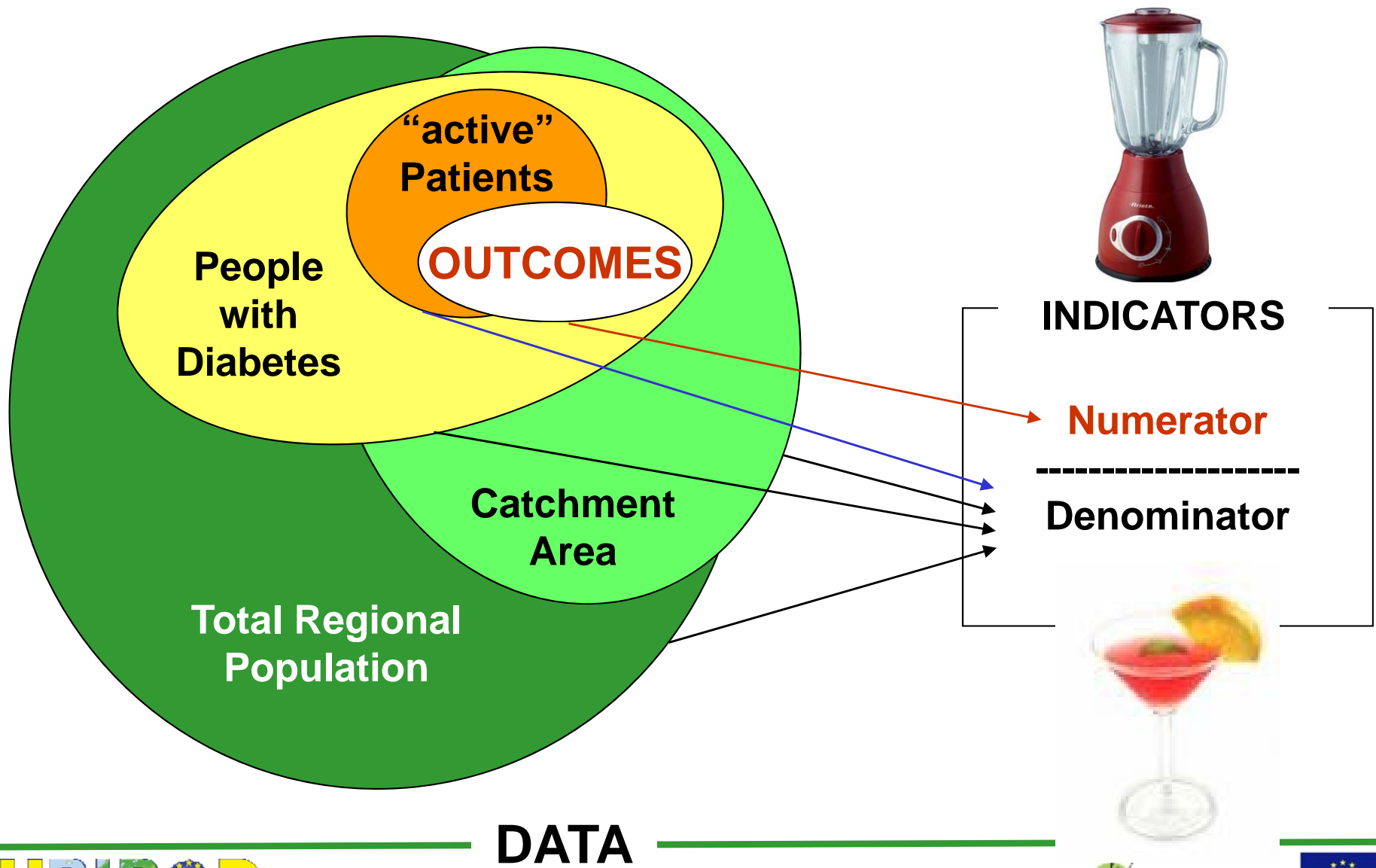
Source unit

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

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

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

Challenging Bias in Disease Registers





- 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)



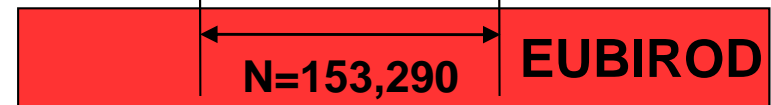
BIRO

11/2005

9/2008

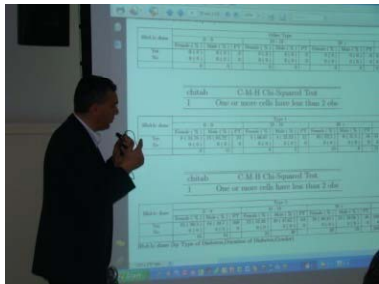
5/2009

8/2011



EUBIROD: complete, refine, measure, disseminate

<http://www.eubirod.eu/academy>







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- Software
- E-learning
- BIRO Monograph

[previous](#) [next](#) **News**

The Tayside Diabetes Register

R.Mc Alpine, U.Dundee, Scotland, UK

First BIRO Academy Residential Course, Kuwait City, Kuwait, 2nd May 2009

[Slides](#)



The Tayside area is located north of Edinburgh and is a good proxy for the population of Scotland, including a mix of agricultural and industrial lifestyles. The DARTS project conducted in 1996 was mainly an audit and research study aimed at monitoring quality of care for diabetic patients through electronic record linkage. In ten years, this study produced a wealth of knowledge on the topic and secured funds for the activity of a large team that is now managing not only the local network on a continuous basis, but the Scottish Diabetes Register.

In this presentation, **Ritchie McAlpine**, data facilitator for the Tayside Diabetes Network, briefs the results of such experience from a particular position in between the information technology group and the actual needs of real patients. Nowadays, the "SCI-DC" Collaboration includes data from about anything done on diabetic patients, from clinics to practices, biochemistry, demography, eye screening, etc., which is automatically transformed into audit tables.



Watch this space!



www.eubirod.eu