



B.I.R.O.

Best Information through Regional Outcomes

A Public Health Project funded by the European Commission, DG-SANCO 2005

WORK PACKAGE 14: DISSEMINATION

DELIVERABLE D14.3

PLENARY SESSION

VERS. 1.1

WP LEADER: UNIVERSITY OF PERUGIA



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Project Website

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Index

| | |
|--|-----------|
| 1. DISSEMINATION OF BIRO PROJECT | 4 |
| 2. PLENARY SESSION IN BRUSSELS..... | 5 |
| 2.1. AGENDA | 5 |
| 2.2. SUMMARY REPORT..... | 5 |
| 2.3. PRESENTATIONS..... | 7 |
| 2.3.1 <i>Diabetes information for Policy in Europe</i> | 7 |
| 2.3.2 <i>BIRO Results</i> | 16 |
| 2.3.3 <i>Using BIRO: the Cyprus experience</i> | 34 |
| 2.3.4 <i>Using BIRO: the Malta Experience</i> | 39 |
| 2.4. PICTURES..... | 51 |
| 2.5. PRESS CLIPPINGS..... | 54 |
| 3. PLENARY SESSION IN PERUGIA | 55 |
| 3.1. AGENDA..... | 55 |
| 3.2. SUMMARY REPORT..... | 55 |
| 3.3. PRESENTATIONS..... | 56 |
| 3.3.1 <i>Population Based Diabetes Registers</i> | 56 |
| 3.3.2 <i>The BIRO Project</i> | 69 |
| 3.3.3 <i>Using BIRO: the Malta experience</i> | 69 |
| 3.3.4 <i>Using BIRO: the Cyprus experience</i> | 69 |
| 3.3.5 <i>BIRO Technology Transfer in New Member States</i> | 70 |
| 3.3.6 <i>The BIRO System</i> | 76 |
| 3.4. PICTURES | 81 |
| 3.5. PRESS CLIPPINGS..... | 85 |

1. Dissemination of BIRO Project

The BIRO approach and its outcomes have received maximum visibility across relevant stakeholder and the major prospective users of the information system. Several strategies have been put in place to disseminate the project.

The BIRO web site (www.biro-project.eu) was designed with the purpose of neatly explaining the project mission and its specific objectives, readily reporting activities, events, achieved results and easily sharing documents and meeting materials between the Partners.

Two brochures and two newsletters per year have been issued. The BIRO monograph, a book summarizing all BIRO achievements within each work package, has been printed in more than 100 copies.

Finally, at the end of the project, two conference events have been organized to disseminate the Project results. The first one, in Brussels, had an international visibility and was specially aimed at explaining the achievements to the Project sponsors of the European Commission while the second one, in Perugia, had a limited scope since it was aimed at presenting BIRO to the local Authorities, Institutions and stakeholders of Umbria region. During both conference events, copies of BIRO Monograph were distributed to Participants.

The aim of the present deliverable is to make a summary report of Brussels and Perugia plenary sessions, by collecting slides, pictures and press clippings.

2. Plenary session in Brussels

The official presentation of BIRO Project results in Brussels took place at the Umbria Region Brussels Office - 14, Round-Point Schuman on 7th May 2009.

2.1. Agenda

| | |
|---------------|--|
| 10:30 – 11:00 | Welcome cocktail |
| 11:00 – 11:15 | The BIRO Project (<i>Prof. Massimo Massi Benedetti</i>) |
| 11:15 – 11:30 | Diabetes Information for Policy in Europe (<i>Fred Storms</i>) |
| 11:30 – 12:00 | BIRO results (<i>Fabrizio Carinci</i>) |
| 12:00 – 12:15 | Using BIRO: the Cyprus experience (<i>George Olympios</i>) |
| 12:15 – 12:30 | Using BIRO: the Malta experience (<i>Prof. Joseph Azzopardi</i>) |
| 12:30 – 13:00 | Discussions / Questions |

2.2. Summary report

A selected audience of relevant stakeholders in the field of European projects gathered in Brussels on 7th May 2009 for the official presentation of BIRO results. The meeting was held at the Umbria Region Brussels Office in Round-Point Schuman, thanks to the hospitality of the regional government and the continued assistance of the local office staff. Speakers on behalf of the Consortium included coordinators Prof. Massi Benedetti and Dr.Carinci (Italy), Prof. Azzopardi (Malta), Dr.Olympios (Cyprus) and Dr.Storms (Netherlands).

Participants included representatives of the European Commission (DG-SANCO, DG-RESEARCH, DG-INFOS), NGOs (Eurohealthnet, Health Consumer Powerhouse, European Heart Network, HOPE, Eucomed, PGEU), Research Institutes (Belgium Scientific Institute of Public Health, Denmark FOU).

Presentations included an overview of the whole project including scope and achievements, its relevance for clinical practice, and how to translate it into action for public health in Member States. The audience reacted very positively and looked at results particularly from the point of view of prospective implementation. Distinguished remarks deserve to be mentioned in this short summary.

According to G.Dargent (EC, EAHC, Luxembourg), BIRO represents an important project in the field of public health, as witnessed by the continued support offered by

the EUBIROD project. The successful delivery of this project can be important for the Agency. It can demonstrate the validity of connecting existing data sources as a sustainable strategy to public EU health information system

K.McCarthy (Public Health Sector, DG-RESEARCH, Brussels) commented that the project is interesting since it may have interesting features also for research, particularly in the field of dissemination. The possibility that results can be shared across Europe in a timely and relatively inexpensive way may constitute an innovative solution filling the gap between policy and practice. However, there must be clear evidence that the system can work in real life conditions. Publication of results of its usage in a high impact scientific journal may constitute a necessary step to raise the attention of the scientific community.


L.Montanari (EC DG-RESEARCH, UNIT D3) added that results obtained are also interesting for their general value beyond diabetes. The system seems to be customizable to solve the needs of different areas, particularly chronic diseases in general. Such results need also to be highlighted for future research applications.

In a later communication, Roberto Giampieretti (European Commission, DG INFSO, Unit H1, "ICT for Health") made his congratulations to the project team for the results achieved. In particular, he reported that he found the overview of the project made by F.Carinci very interesting, with strong relevance to the activities carried out at the Directorate.

The meeting was preceded and followed by a cocktail reception, celebrating the successful end of the project. All participants received a printed hardcopy the BIRO Monograph, a complete, original publication of over 200 pages packaging all major results and including details on all the features of the BIRO system.

2.3. Presentations

2.3.1 Diabetes information for Policy in Europe






Information through Regional Outcomes

Diabetes information for Policy in Europe

Fred Storms
CBO
The Netherlands



*“A Shared Information System for Diabetes in Europe:
final results of the B.I.R.O. Project”
Brussels, 7th May 2009*





Information through Regional Outcomes




From data gathering to comparability

- EUDIP
- EUCID
- Data Dictionary of Diabetes Indicators
- EUPHIX






- Establishment of indicators monitoring diabetes mellitus and its morbidity
 - I. Risk factors for diabetes mellitus
 - II. Epidemiology of diabetes mellitus
 - III. Risk factors for diabetes complications
 - IV. Epidemiology of diabetes complications
- Final report 2002

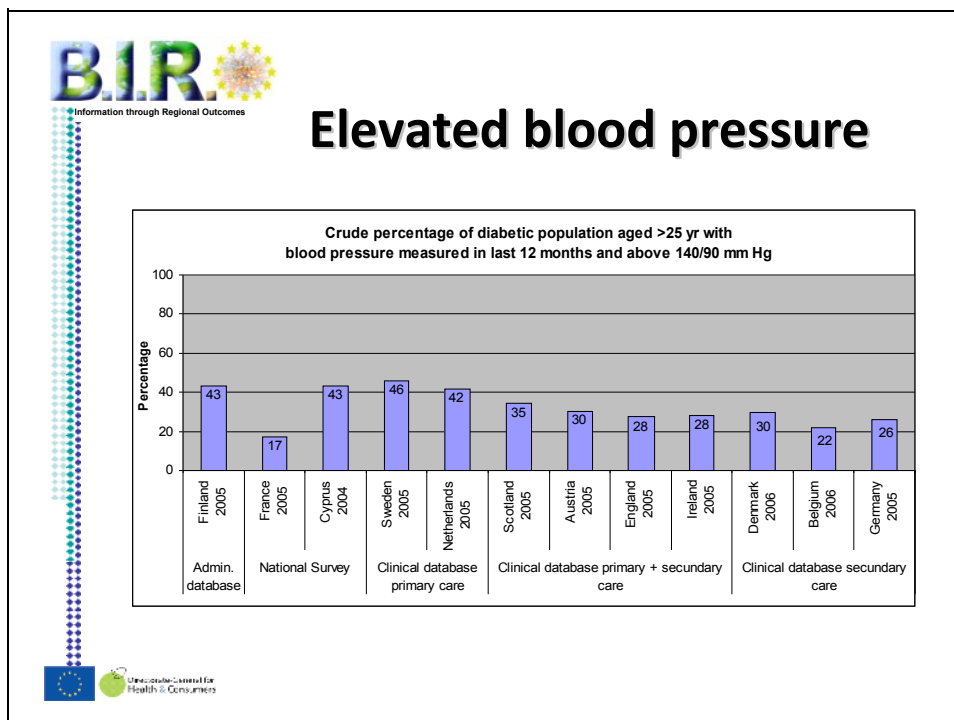
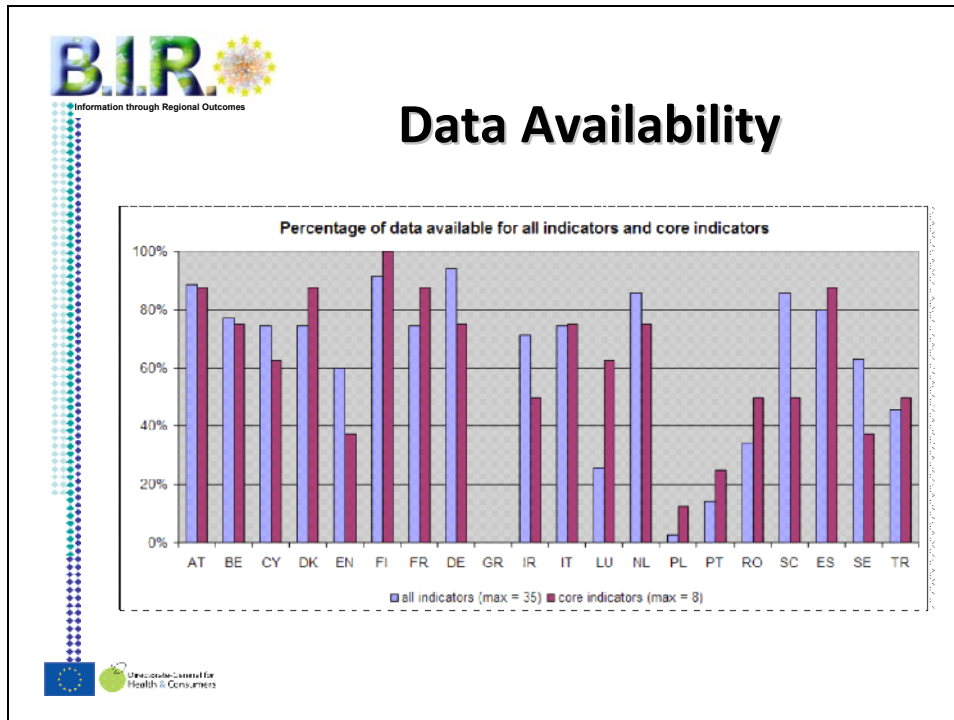




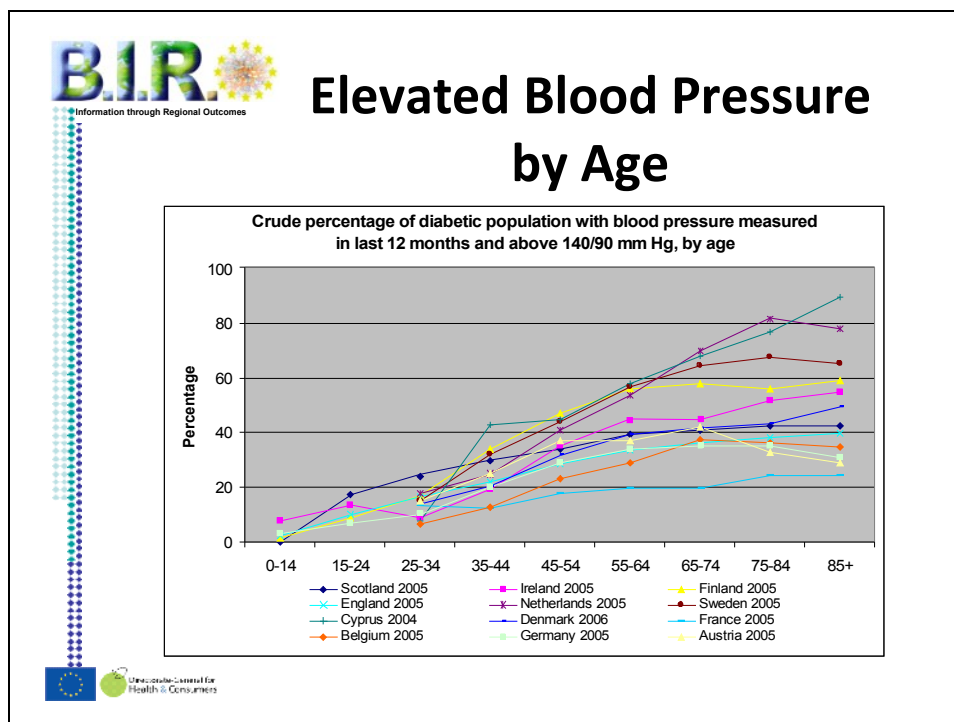
Indicators on Diabetes and risk factors for diabetes



- 35 indicators
 - General population
 - Diabetes population
 - Biochemical
 - Physical
 - Complications
- Represented as
 - Bargraphs
 - Age bands
 - Maps
 - Spiderwebs






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Conclusions EUCID



- It is a joy to work with other professionals
- Data availability on diabetes and diabetes risk factors in Europe is suboptimal
- Data comparability is low
- Available estimations from IDF are at least suboptimal
- Clinical data originate almost all from regional databases
- EUBIROD is the way to go forward

European Union logo and text: Directorate-General for Health & Consumers




BIRO Data Dictionary


- Health indicators: EUDIP, ECHI, OECD
- Guidelines: IDF, SIGN, Consensus on diabetic foot, New Zealand, ADA, Canada, German Diabetes Association
- Systematic literature search in: Cochrane database, Medline



BIRO Thematic Areas



- Risk profile for Diabetes
- Diagnosis and classification
- Risk profile for complications and intermediate outcomes
- Management and care of diabetes and its comorbidities
- Self management and lifestyle management
- Complications
- Individual characteristics
- Health status
- Demographic and socio-economic factors
- Health system & health care delivery






BIRO Selection Process


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

BIRO Indicators selected: epidemiology and structure



- Epidemiology:
 - Annual incidence in children of type 1 diabetes
 - Prevalence of diabetes mellitus
 - Age at diagnosis with 10 year age bands
- Structural indicators (regional):
 - Hospital beds per 100.000 population
 - Physicians employed per 100.000 population
 - Number of Diabetologists per 100.000 population
 - Number of doctors taking care of diabetes per 100.000
 - Number of diabetes nurses per 100.000 population
 - Number of physicians in DMP per 1000 diabetes
 - Portion of diabetes patients in DMP






BIRO Indicators: process


- Examined during last 12 months:
 - HbA1c
 - Total/HDL cholesterol
 - Micro-albuminurea
 - Eye examination
 - Foot examination
 - Smoking status
 - Serum creatinine
 - Blood pressure
- Elevated RR and med.
- Portion with RR med.
- Number anti RR med. Used
- Number lipid med.
- At least once education
- Number on self monit.
- Oral medication
- Portion Oral/insulin
- Pump therapy %
- Number insulin injections
- Number diet only
- Diagnosed CVD and antiplatelet

BIRO Indicators: intermediate outcomes



- % HbA1c most recent > 9.0
- % HbA1c most recent < 7.5
- % Total/HDL Cholesterol < 4.5
- % RR < 140/90
- % BMI > 30
- % with fundus inspection with prol.ret. or maculop.
- % laser treatment ever
- % of tested with micro-albuminurea
- % of current smokers
- % with current alcohol abuse/dependence
- % former or current foot ulceration






BIRO Indicators: final outcome

- Annual incidence of blindness
- Annual incidence of dialysis/transplantation
- ESRD prevalence
- Annual incidence of amputations above ankle
- Annual incidence of stroke
- Annual incidence of MI
- Annual death rate in diabetes adjusted for standard European population












BIRO data items needed




- Indicator needs data
- Data clearly defined in Data-Dictionary
- Information gathering by BIRO system
- New indicators (and consequently data) can be defined by partners in EUBIROD project

| | |
|---|--|
| <ul style="list-style-type: none"> • Public size • Date of birth • Sex • Ethnic origin • Marital status • Number of children • Total number of children below 14 yrs • Number of children aged 0-4 yrs • Number of children aged 5-14 yrs • Number of children aged 15-17 yrs • Number of children aged 18-24 yrs • Number of children aged 25-34 yrs • Number of children aged 35-44 yrs • Number of children aged 45-54 yrs • Number of children aged 55-64 yrs • Number of children aged 65-74 yrs • Number of children aged 75-84 yrs • Number of children aged 85+ yrs • Number of children aged 0-4 yrs with disability • Number of children aged 5-14 yrs with disability • Number of children aged 15-17 yrs with disability • Number of children aged 18-24 yrs with disability • Number of children aged 25-34 yrs with disability • Number of children aged 35-44 yrs with disability • Number of children aged 45-54 yrs with disability • Number of children aged 55-64 yrs with disability • Number of children aged 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disease • Total number of children aged 55-64 yrs with chronic disease • Total number of children aged 65-74 yrs with chronic disease • Total number of children aged 75-84 yrs with chronic disease • Total number of children aged 85+ yrs with chronic disease • Total number of children aged 0-4 yrs with mental health problem • Total number of children aged 5-14 yrs with mental health problem • Total number of children aged 15-17 yrs with mental health problem • Total number of children aged 18-24 yrs with mental health problem • Total number of children aged 25-34 yrs with mental health problem • Total number of children aged 35-44 yrs with mental health problem • Total number of children aged 45-54 yrs with mental health problem • Total number of children aged 55-64 yrs with mental health problem • Total number of children aged 65-74 yrs with mental health problem • Total number of children aged 75-84 yrs with mental health problem • Total number of children aged 85+ yrs with mental health problem |
|---|--|





- EUPHIX is a web-based knowledge system for health professionals, policy makers and others. It presents structured European public health information, giving a special insight into similarities and differences between EU Member States.
- No data production but data gathering
- Hosted by:  







EUPHIX Diabetes Data


EUPHIX
European Union Public Health Information System

[Home](#) » [EUphact](#) » [Health Status](#) » [Diseases, disorders, injuries](#) » [Other non-communicable diseases](#) » [Diabetes](#)

| | |
|--|---|
| <p>Health Status</p> <ul style="list-style-type: none"> Summary measures Diagnosed and functional health Mortality Diseases, disorders, injuries <ul style="list-style-type: none"> Infectious diseases Cancer Mental behavioural disorders Cardiovascular diseases Other non-communicable diseases <ul style="list-style-type: none"> Diabetes Asthma COPD Pregnancy-related conditions Injuries Determinants of health Health interventions & systems Health policies Demography | <p>Diabetes</p> <p>Status</p> <p>This LUphact has been peer reviewed by one reviewer.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Summary <input type="checkbox"/> Definition and scope <input type="checkbox"/> Occurrence <input type="checkbox"/> Mortality <input type="checkbox"/> Consequences for individual and society <input type="checkbox"/> Causes and risk factors <input type="checkbox"/> Interventions <p>Links</p> <ul style="list-style-type: none"> <input type="checkbox"/> Related EUphacts and EUphact <input type="checkbox"/> Relevant databases, organisations and projects <p>Data presentation</p> <ul style="list-style-type: none"> <input type="checkbox"/> Figures, underlying data and maps <p>Authors, editors and reviewers</p> <ul style="list-style-type: none"> <input type="checkbox"/> Authors, editors and reviewers Diabetes EUphact <p><input type="checkbox"/> Literature and data sources</p> |
|--|---|

2.3.2 BIRO Results



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**BIRO Project:
Activities and Results**

Fabrizio Carinci
Technical Coordinator
University of Perugia, Italy

*"A Shared Information System for Diabetes in Europe:
final results of the B.I.R.O. Project"
Brussels, 7th May 2009*




Perugia, 25th May 2009




Best Information through Regional Outcomes

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




Perugia, 25th May 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




Perugia, 25th May 2009



“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

| | | |
|---|--|--|
|  | <p>Department of Internal Medicine University of Perugia, Italy</p> | <p>COORDINATION, MANAGEMENT, DISSEMINATION PRIVACY IMPACT ASSESSMENT DATABASE/STATISTICAL/CENTRAL ENGINES</p> |
|  | <p>Division of Medicine and Therapeutics University of Dundee, Scotland, UK</p> | <p>COMMON DATASET DATA DICTIONARY</p> |
|  | <p>Joanneum Research, Graz, Austria</p> | <p>CLINICALREVIEW COMMUNICATION SOFTWARE</p> |
|  | <p>Department of Medicine, University of Bergen, Norway</p> | <p>REPORTS TEMPLATE WEB PORTAL</p> |
|  | <p>Institute of Diabetes "Paulescu", Bucharest, Romania</p> | <p>TECHNOLOGY TRANSFER</p> |
|  | <p>Department of Medicine, University of Malta, Malta</p> | <p>EVALUATION</p> |
|  | <p>Department of Health Promotion, Ministry of Health, Republic of Cyprus</p> | |




Perugia, 25th May 2009

Directorate General for
Health & Consumers





Best Information through Regional Outcomes

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.


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Health & Consumers




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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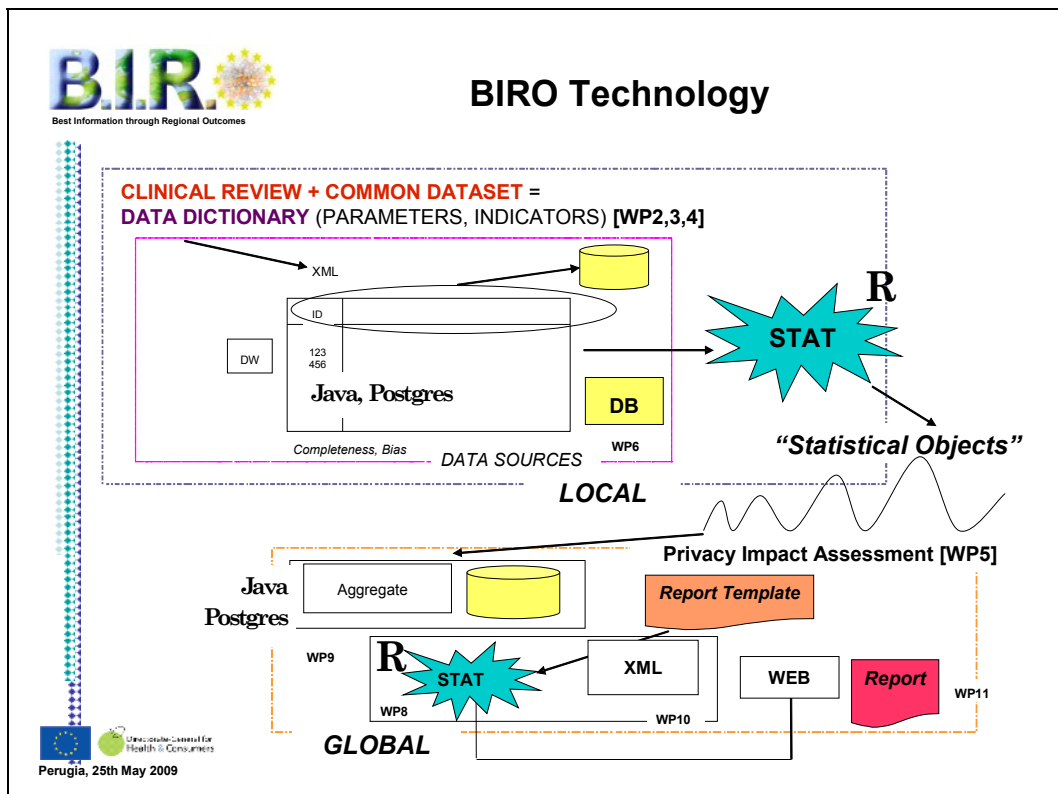
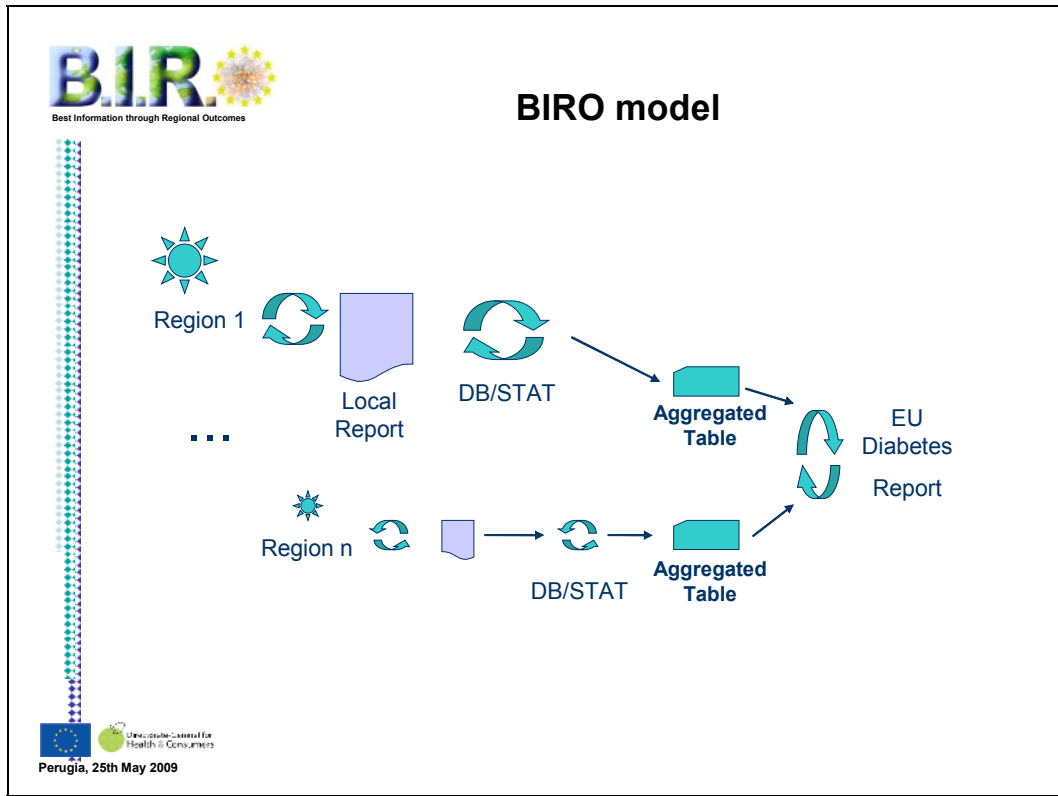



Who are the BIRO Users?

| | |
|--|---|
| <p>Governance</p> <ul style="list-style-type: none"> • 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 <p>Research</p> <ul style="list-style-type: none"> • EU Directorates Research and Public Health • Scientific Organizations | <ul style="list-style-type: none"> • National and international scientific organizations • Research institutions • Universities, Foundations • Statistical Departments of Local Governments • Research areas • Epidemiology, health policy, clinical medicine <p>Health Care</p> <ul style="list-style-type: none"> • Primary Care Societies • Diabetes Care Units • Health Care Professional Associations • Quality Management Associations <p>Citizens</p> <ul style="list-style-type: none"> • Consumer organizations • Patients organizations |
|--|---|




Perugia, 25th May 2009






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




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Specification of Data items needed

- Indicator needs data
- Data clearly defined
- Information gathering by BIRO system
- New indicators can be defined by partners





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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





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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 |
|-----------|------------|--------------------------|------------|---|
| BIR001 | PAI_ID | Pat ID | String(1) | |
| BIR002 | DS_ID | Data Source ID | String(1) | |
| BIR003 | TYPE_ID | Type of Diabetes | Enumerated | 1 = Type 1 2 = Type 2 3 = Other types of diabetes |
| BIR004 | SEX | Sex | Enumerated | 1 = Male 2 = Female |
| BIR005 | DOB | Date of Birth | DateTime | |
| BIR006 | DT_DIAG | Date of Diagnosis | DateTime | |
| BIR007 | EPI_DATE | Survey Date | DateTime | |
| BIR008 | SMOK_STAT | Smoking Status | Enumerated | 1 = Current Smoker 2 = Non-Smoker 3 = Ex-Smoker |
| BIR009 | CIGETS_DAY | Cigarettes per day | Integer | |
| BIR0047 | ALCO_STAT | Alcolic Status | Enumerated | 1 = Current Drinker 2 = Non-Drinker 3 = Ex-Drinker |
| BIR010 | ALCOHOL | Alcolic Intake | Integer | |
| BIR011 | WEIGHT | Weight | Real | |
| BIR012 | HEIGHT | Height | Real | |
| BIR013 | BMI | Body Mass Index | Real | |
| BIR014 | SBP | Systolic Blood Pressure | Integer | |
| BIR015 | DBP | Diastolic Blood Pressure | Integer | |
| BIR016 | HBA1C | HbA1c | Real | |
| BIR017 | CREAT | Creatinine | Integer | |
| BIR018 | MA_TEST | Microalbumin | Enumerated | 1 = MA Test Normal 2 = MA Test Abnormal 3 = No MA Test Recorded |
| BIR019 | CHOL | Total Cholesterol | Integer | |




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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, <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 | Table, <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> |

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 | Table, <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> |

Underlined preferred output

Different output according to target audience






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Perugia, 25th May 2009




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)

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Perugia, 25th May 2009



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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



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Perugia, 25th May 2009



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Procedure

Data Flow Table

SCENARIO: 1- GROUPING CONDITION DIRECTLY BY STATISTICAL OBJECT (e.g. extended frequency distribution of LOS by CENTRE) vs. compute variability of patients

| Concepts of data or data collection | Collected by | Type of format | Used by | Purposes of collection | Transmission to third parties | Security measures for data | Format of data | Disposal of data | Storage of records or data |
|--|--------------------|------------------|--------------------|------------------------|-------------------------------|----------------------------|------------------|--------------------|----------------------------|
| Aggregation of data for statistical analysis | Information system | Data aggregation | Information system | Statistical analysis | Information system | Information system | Data aggregation | Information system | Information system |


Data Flow Questionnaire

SCENARIO: 1- PERSONAL IDENTIFICATION, EXCEPT: BIDDING

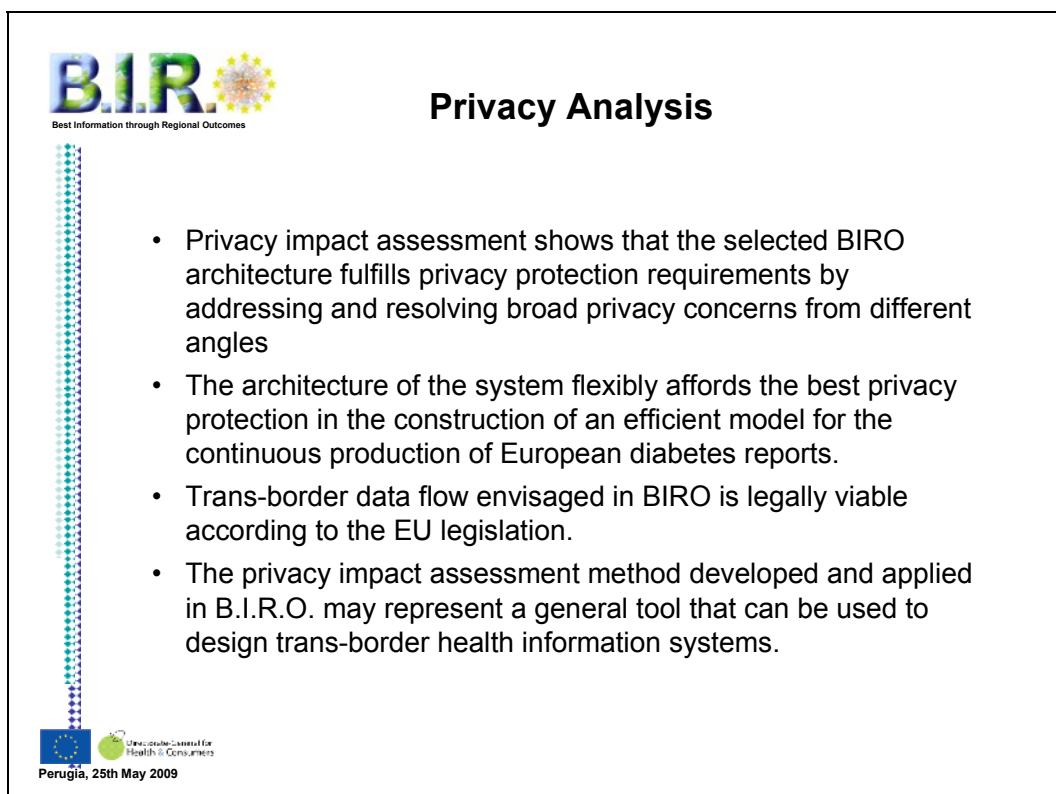
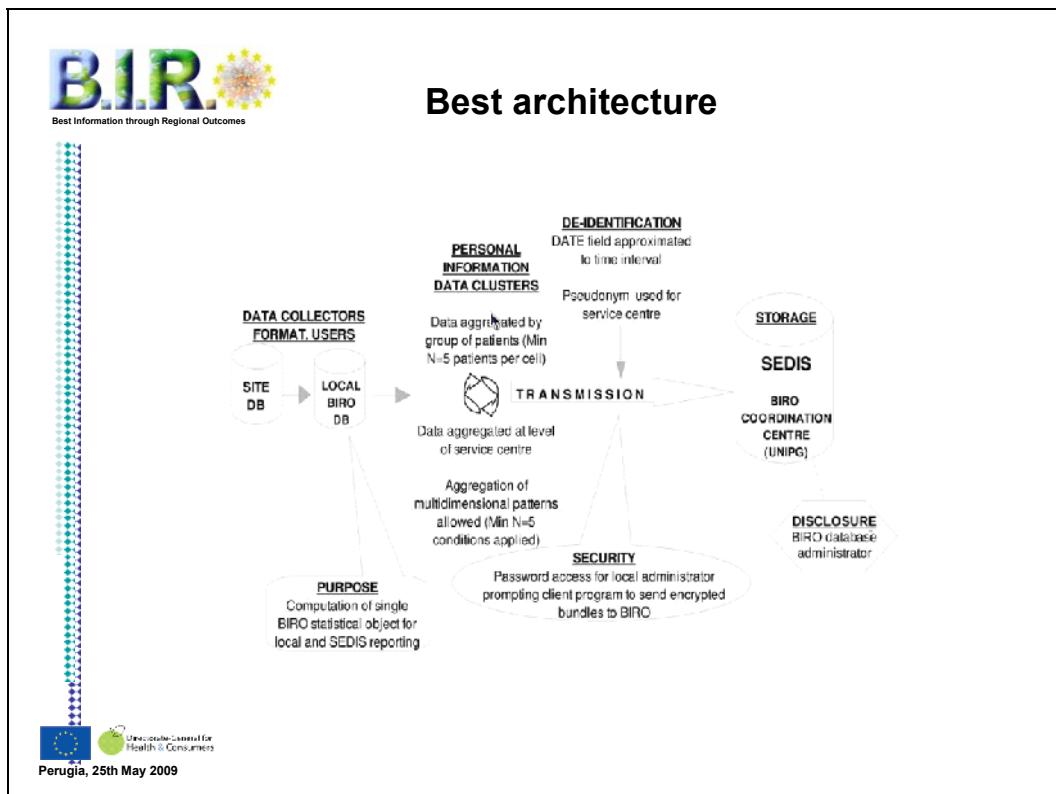
| System | Identify | Priority | Information | Subtotal |
|--|----------|----------|-------------|----------|
| | Identify | Priority | Identify | Identify |
| Aggregation of data for statistical analysis | | | | |

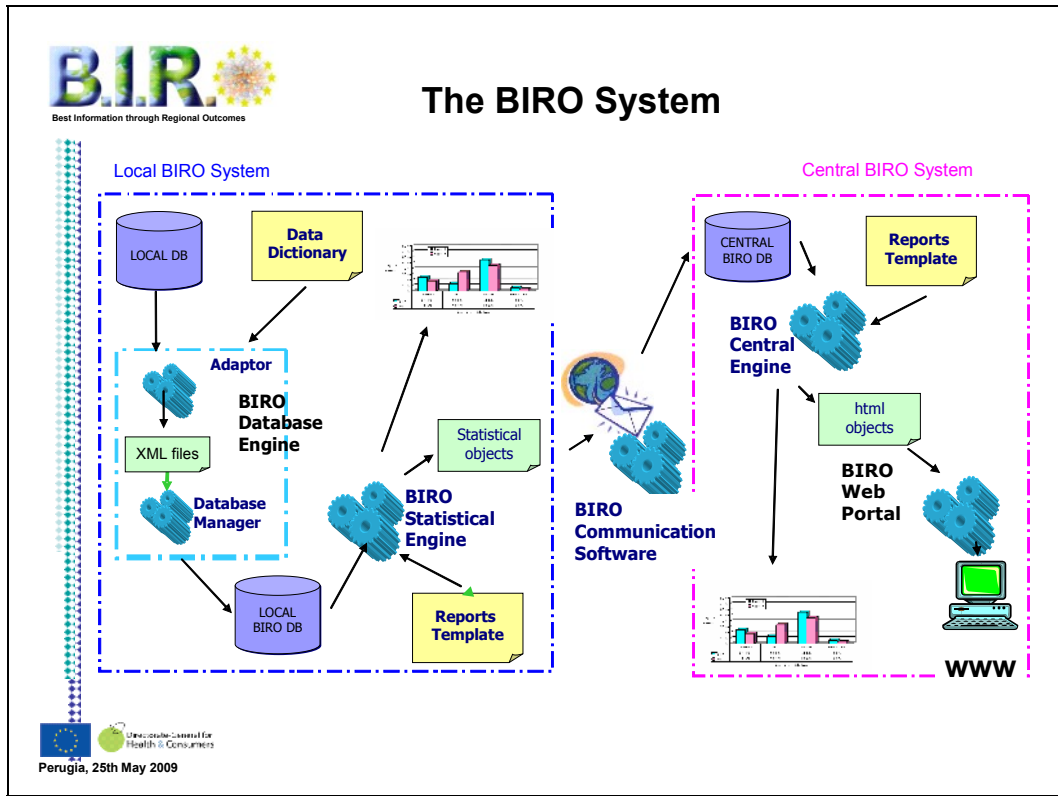
Overall Consensus Table

| System | Identify | Priority | Information | Subtotal |
|--|----------|----------|-------------|----------|
| Aggregation of data for statistical analysis | | | | |



Univ. Centre for Health & Consumers
Perugia, 25th May 2009





Best Information through Regional Outcomes

Fragmented Analysis

Box 3.4.2. Output Logistic Model on all observations

The LOGISTIC Procedure
Model Information

| | |
|---------------------------|------------------|
| Data Set | WORK_MODEL_ |
| Response Variable | ILI_ILDA |
| Number of Response Levels | 2 |
| Number of Observations | 17102 |
| Model | Binary Logistic |
| Optimization Technique | Fisher's scoring |

Response Profile

| | | |
|---------------|----------|-----------------|
| Ordered Value | ILI_ILDA | Total Frequency |
| 1 | 1 | 4858 |
| 2 | 0 | 12240 |

Probability modeled is P(ILI_ILDA=1).

Analysis of Maximum Likelihood Estimates

| Standard Parameter | Wald DF | Estimate | Error | Chi-Square | Pr > ChiSq |
|--------------------|---------|----------|--------|------------|------------|
| Intercept | 1 | -0.6662 | 0.1028 | 44.5245 | <.0001 |
| GENDER | 1 | 0.2297 | 0.0318 | 41.7555 | <.0001 |
| CL_AGE1 | 1 | 0.0976 | 0.1054 | 0.027 | 0.4019 |
| CL_AGE2 | 1 | -0.1465 | 0.1040 | 1.9642 | 0.1609 |
| CL_AGE3 | 1 | 0.2497 | 0.1068 | 5.2657 | 0.0218 |

Box 3.4.3. Output Logistic Model on aggregate data

The LOGISTIC Procedure
Model Information

| | |
|---------------------------|------------------|
| Data Set | WORK_ILDA_015 |
| Response Variable | ILI_ILDA |
| Number of Response Levels | 2 |
| Number of Observations | 76 |
| Weight Variable | COLN |
| Sum of Weights | 7102 |
| Model | Binary Logistic |
| Optimization Technique | Fisher's scoring |

Response Profile

| | | | |
|---------------|----------|--------------|-----------------|
| Ordered Value | ILI_ILDA | Total Weight | Total Frequency |
| 1 | 1 | 8 | 1658.000 |
| 2 | 0 | 6 | 12246.000 |

Probability modeled is P(ILI_ILDA=1).


Analysis of Maximum Likelihood Estimates

| Standard Parameter | Wald DF | Estimate | Error | Chi-Square | Pr > ChiSq |
|--------------------|---------|----------|--------|------------|------------|
| Intercept | 1 | -1.6997 | 0.1144 | 44.7443 | <.0001 |
| GENDER | 1 | 0.2297 | 0.0343 | 44.7555 | <.0001 |
| CL_AGE2 | 1 | 0.0976 | 0.1062 | 0.7027 | 0.4019 |
| CL_AGE3 | 1 | -1.1465 | 0.1130 | 104.42 | 0.1146 |
| CL_AGE4 | 1 | -0.2497 | 0.1203 | 5.2037 | 0.0218 |

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


| Centre | Gen | N um | %OBSERVED | %EXPECTED | 95% Lower | 95% Upper |
|--------|------|------|-----------|-----------|-----------|-----------|
| 1 | 7099 | 2189 | 28.4 | 28.5 | 27.5 | 29.5 |
| 2 | 2300 | 1000 | 42.4 | 28.0 | 26.1 | 29.9 |
| 3 | 3422 | 916 | 26.0 | 30.4 | 26.5 | 34.3 |
| 4 | 1229 | 252 | 17.9 | 30.2 | 25.0 | 35.4 |
| 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




Perugia, 25th May 2009

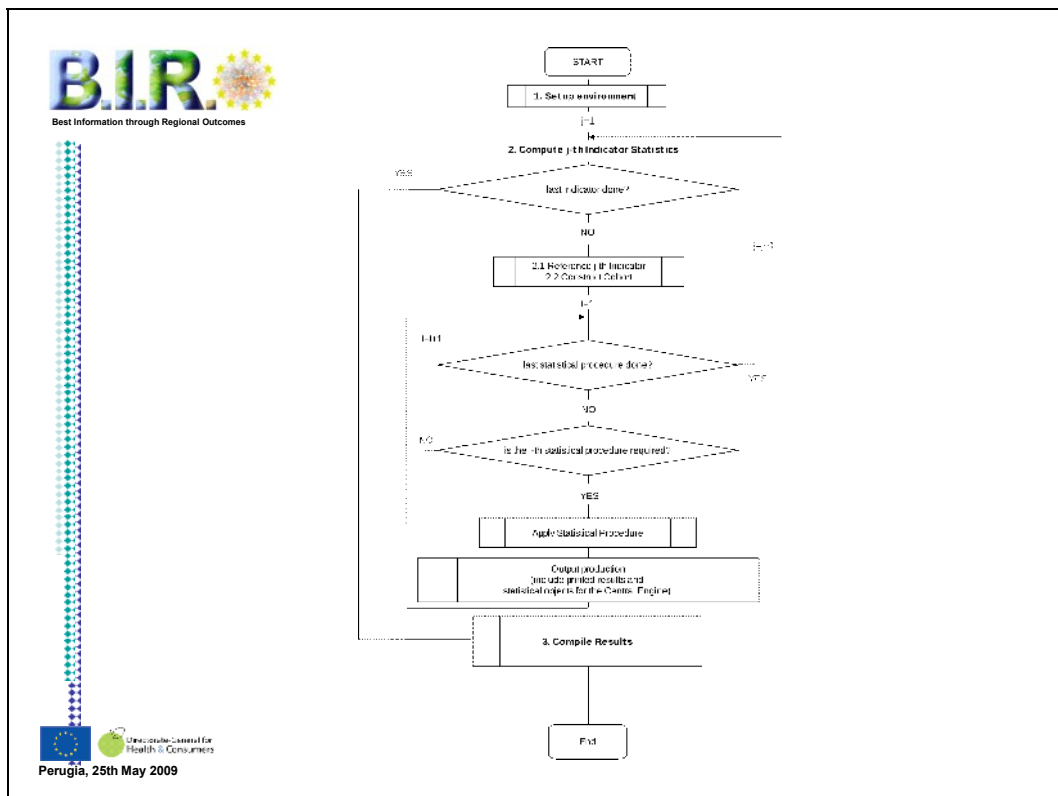
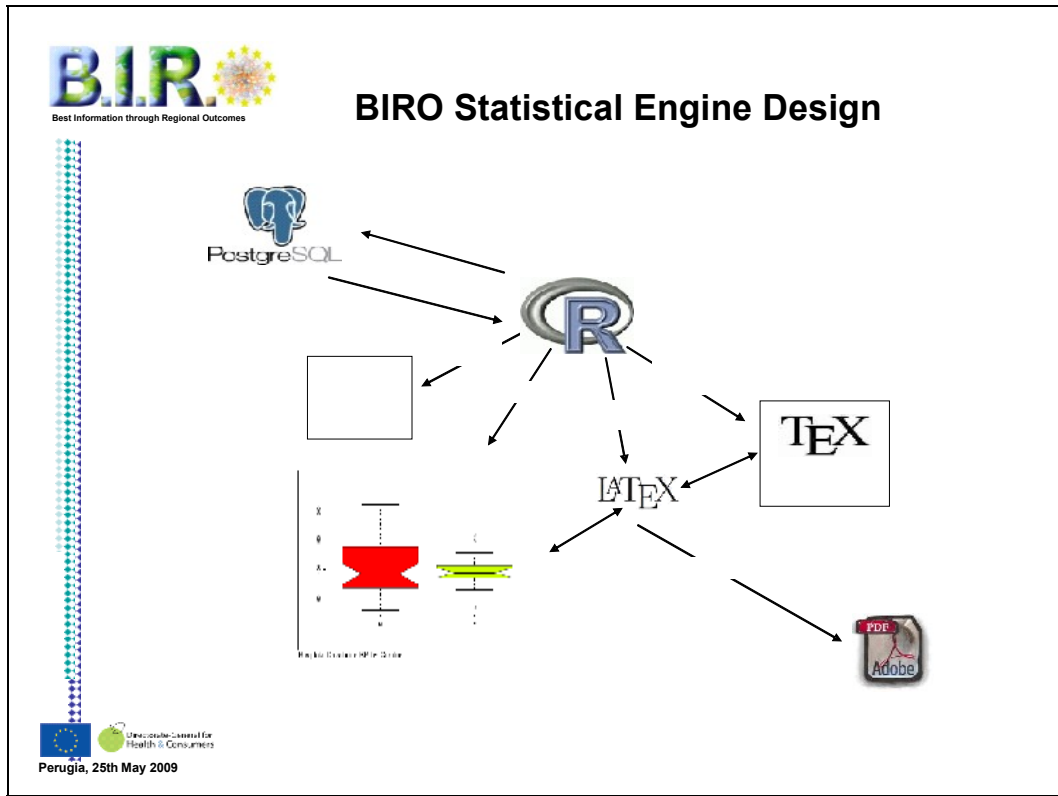


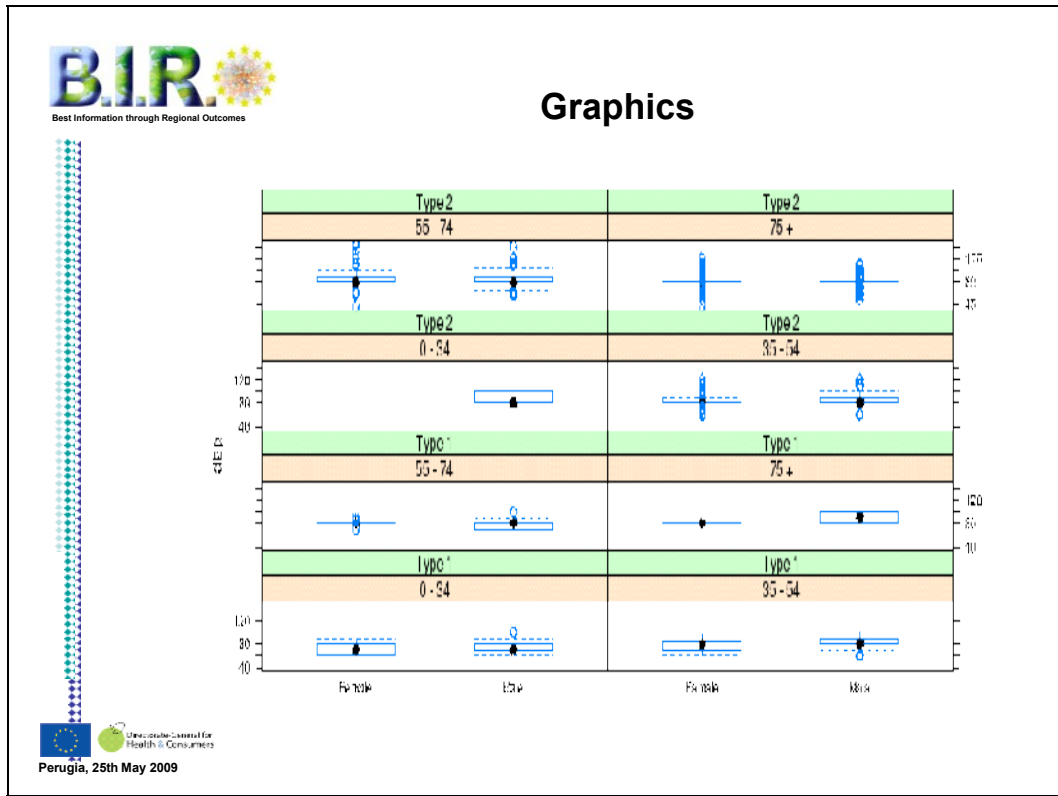
Arithmetic Mean

| | |
|-----------------------------|--|
| 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 |



Perugia, 25th May 2009





B.I.R.
Best Information through Regional Outcomes

Performance

| 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" |

LOCAL

| 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" |

GLOBAL

Perugia, 25th May 2009



B.I.R.O.
Best Information through Regional Outcomes

Web Portal



Biro Indicators
Best Information through Regional Outcomes

- Home
- Why B.I.R.O.
- B.I.R.O. model
- Diabetes Indicators
- Diabetes Indicators
- Data collection
- Work strategies
- Project partners
- Learning
- How to participate

User login

Username:

Content

B.I.R.O. - Best Information through Regional Outcomes

We live in an informal 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 practices 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 B.I.R.O. web portal provides access to the results produced by a supervised effort across countries, regional and national boundaries, involving citizens and the wider community through the support of the European Commission.

Next City
Head of the Health Information Unit
Health and Consumer Directorate-General, European Commission



European Commission for Health & Consumers

Perugia, 25th May 2009



B.I.R.O.
Best Information through Regional Outcomes

BIRO Report

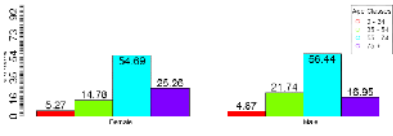
- Home
- Why B.I.R.O.
- B.I.R.O. model
- Diabetes Indicators
- Diabetes Indicators
- 1. Demographic characteristics
 - 1.1. Age (Classes)
 - 1.2. Gender
- 2. Clinical characteristics
- 3. Health system
- 4. Possible Mediators
- 5. Diabetes Indicators
- Data collection
- Work strategies
- Project partners
- Learning
- How to participate


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


1.1. Age (Classes)

Indicator Definition

| Age Classes | Female | Male | Total |
|-------------|---------------|---------------|---------------|
| 0 - 24 | 712 (18.11%) | 711 (18.18%) | 1386 (18.02%) |
| 25 - 34 | 2175 (33.46%) | 2485 (36.89%) | 4660 (59.41%) |
| 35 - 44 | 3649 (47.04%) | 3008 (38.99%) | 6657 (86.03%) |
| 45 - 54 | 3715 (57.76%) | 2796 (42.24%) | 6511 (84.87%) |
| 55 - 64 | 1719 (47.83%) | 1898 (52.17%) | 3617 (47.02%) |

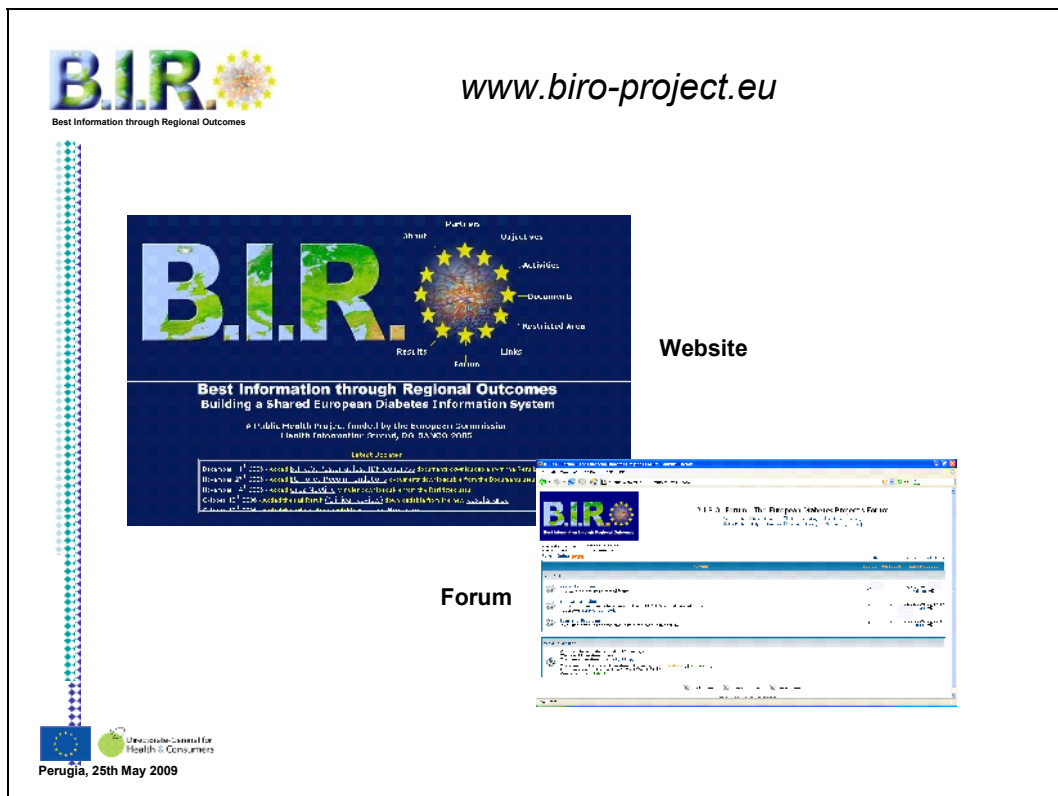
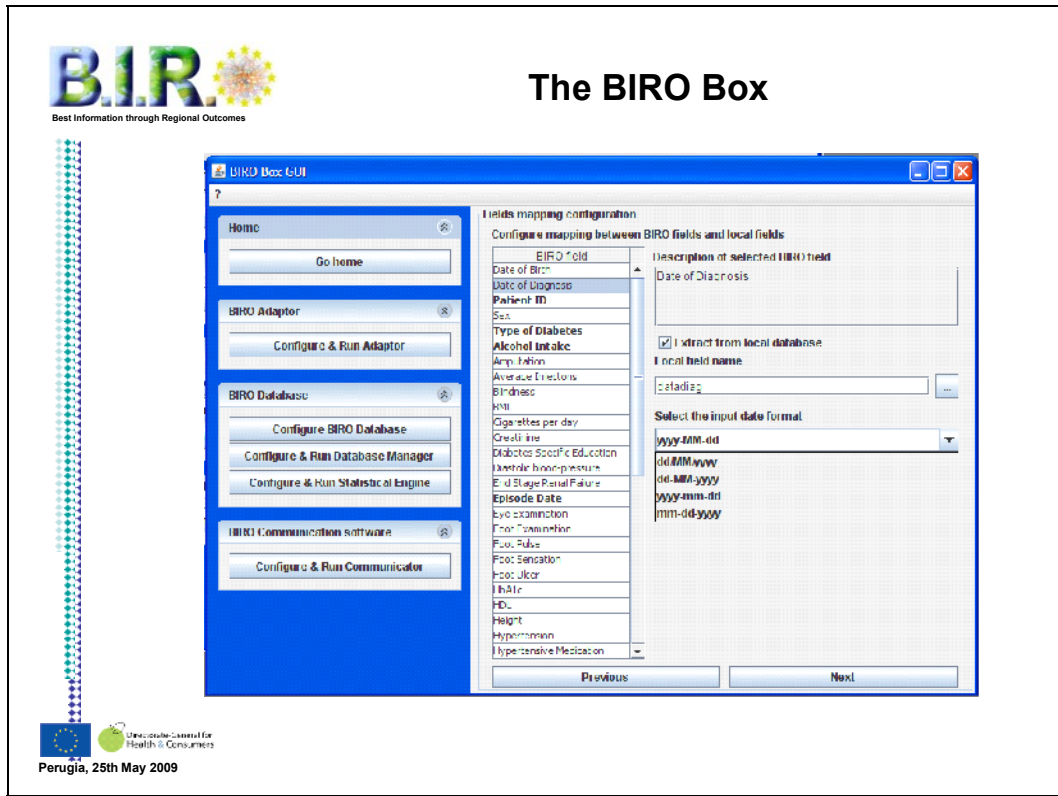


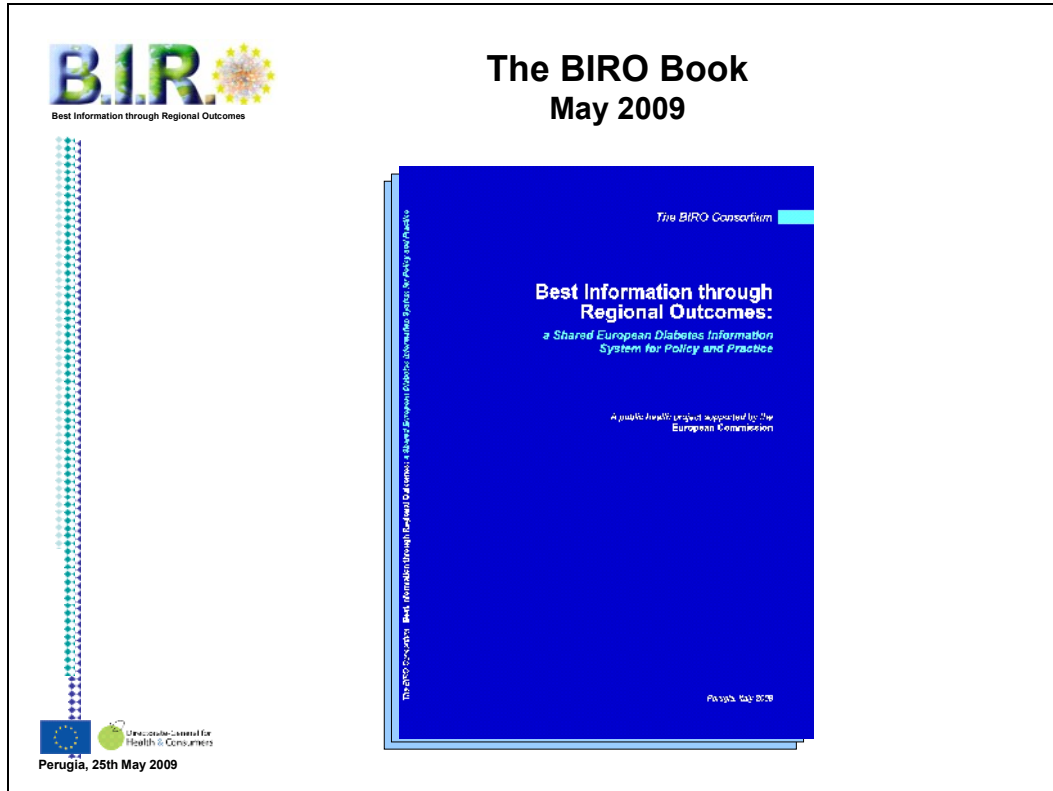




European Commission for Health & Consumers

Perugia, 25th May 2009





2.3.3 Using BIRO: the Cyprus experience




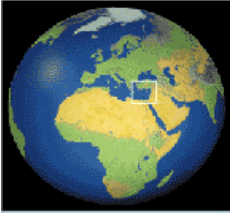


Using BIRO: the Cyprus experience

George Olympios


*"A Shared Information System for Diabetes in Europe:
final results of the B.I.R.O. Project"
Brussels, 7th May 2009*



Perugia, 25th May 2009

Population 855,000 (2007)



Perugia, 25th May 2009



Best Information through Regional Outcomes

Cyprus and BIRO

Prevalence of Diabetes in 2005 **10.3%**

(Loizou et al 2005)



Perugia, 25th May 2009



Best Information through Regional Outcomes

Health Care in Cyprus

Provided by

- a) Public Health System (*means tested*)
- b) Private Sector

All people with diabetes are entitled to receive free treatment irrespective of financial means on the public sector.



Perugia, 25th May 2009



Health Care in Cyprus

Provided by

- a) Public Health System (*means tested*)

- b) Private Sector

All people with diabetes are entitled to receive free treatment irrespective of financial means on the public sector.



Perugia, 25th May 2009



Health care Services in Cyprus

Public Sector

- Five Public Hospitals

- Thirty-two rural health centres

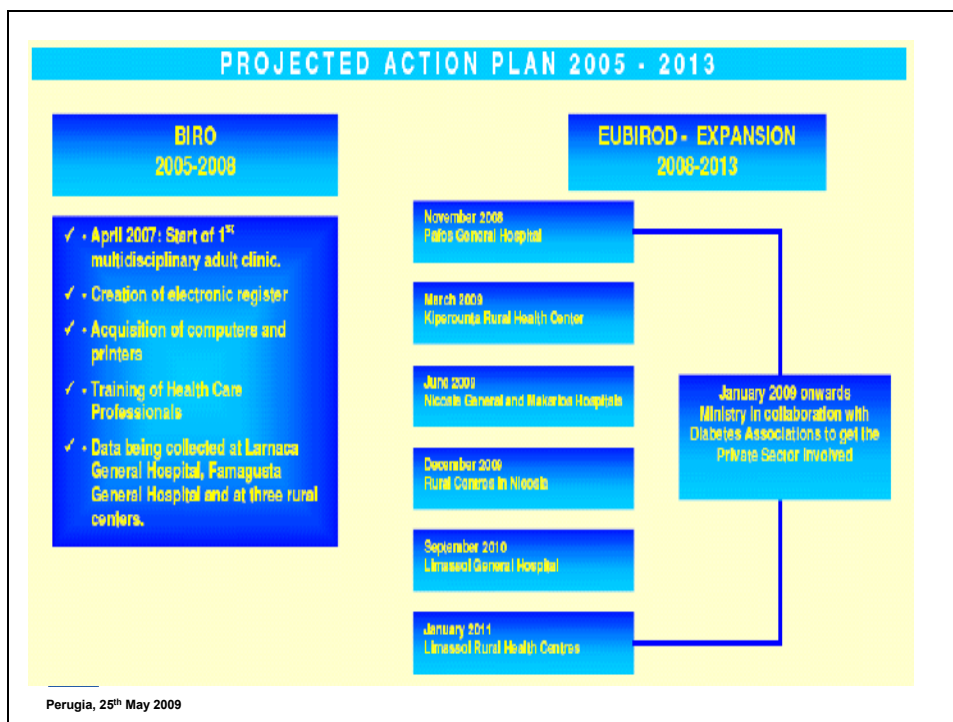
Private Sector


- Private Hospitals

- Private General Practitioners





Perugia, 25th May 2009





Electronic Database

- Created in April 2007 and developed according to BIRO Common Dataset (WP3)
- Data is collected and recorded manually. Later it is entered into the electronic database.
- The electronic database is kept on a stand alone computer at the Diabetes Centre in Larnaca Hospital.
- Every Patient whose data is entered in the electronic database has signed a consent form giving their permission.
- Entry into the system is password protected.

Diabetes Centre of
Famagusta

Perugia, 25th May 2009



Electronic Database

848 Patients' data entered....



2.3.4 Using BIRO: the Malta Experience



Best Information through Regional Outcomes


Using BIRO The Malta Experience

Professor Joseph Azzopardi
Mater Dei Hospital
University of Malta

*"A Shared Information System for Diabetes in Europe:
final results of the B.I.R.O. Project"*
Brussels, 7th May 2009





Perugia, 25th May 2009



Best Information through Regional Outcomes

Malta

Malta, Gozo, Comino
100 km from Sicily
290 km from North Africa
Population: 400,214

Perugia, 25th May 2009



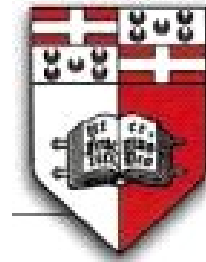
Malta

Parliamentary Democracy
Independence in 1964
A Tourist Centre
Freight Shipment Point
A Financial Hub
EU member since 2004



University of Malta

A long and distinguished
history related to Medicine
One of the oldest medical
schools in the world
Traces its origins to 1676





The Malta Health Services

Comprehensive 1^{ary}, 2^{ary} and 3^{ary} Health Service
Free at the point of delivery

1^{ary} Care is given mainly in 8 Centres

Preventive, Curative and Rehabilitative services

Principal Public Hospital is Mater Dei Hospital

A Private Health Service is also available



Perugia, 25th May 2009



Perugia, 25th May 2009



The Diabetes Services

People with diabetes are entitled to free treatment
Diabetes Clinics in Mater Dei & Peripheral Centers
Cover 95% of all people with Diabetes in Malta
In an ideal position for whole population studies



Perugia, 25th May 2009



The Diabetes Services

Eyes: Screening, Laser and vitreous replacement
Foot referral and a Peripheral Vascular Unit
Podology, Orthotics and Prosthetics Service
A joint Obstetrics – Diabetes Clinic
Paediatric clinic run by a Paediatric Diabetologist
Dialysis and Transplant Service



Perugia, 25th May 2009



Other Services

Education

- Type 1: Individual Education with relatives
- Type 2: Group Education
- Maltese Diabetes Association
- Various radio and television educational programs
- Under & post graduate educational programs

Dietetics: Only 2 part time dieticians

Limited free blood glucose monitoring service



The Diabetes Services

The Diabetes Clinic has a fully developed diabetes computerized management system

Good IT support

Pioneer of St Vincent DiabCare program

Present research interests

- Epidemiology of diabetes
- Coronary artery disease in diabetes
- Use of Information Technology in diabetes
- Genetic studies in nephropathy

Visit Details

Visit Details Finish

Name: [Redacted] Surname: [Redacted] ID: [Redacted] Age: 66 yrs DM Since: 2 yrs

| | | | | | | |
|---------------|-----|-------|--------|------|----------------|--|
| Diabetes Type | Sex | Waist | Height | BMI | Desired Weight | Desired BMI: M: 20-25 F: 19-25 Normal Waist Circ.: M: 94cm F: 80cm (Eurocid) |
| Type 2 | M | 109cm | 1.61m | 31.1 | | |

First Available: Review in: 3 (months)

Status: **DM History** | Clinic Visit & Drugs | Symptoms | Med. History | Physical | Complications | Diet | Laboratory | Education

Routine Parameters Summary

| | | | | | | | |
|--------------|-------|--------------|--------|-------------|-------|---------------|------|
| FBG (mmol/L) | 9.30 | RBG (mmol/L) | 0.00 | Weight (kg) | 80.70 | Urine Glucose | 0.00 |
| DBP (mmHG) | 78.00 | SBP (mmHG) | 121.00 | Acetone | 0.00 | Albumin | 0.00 |

Visit Details

Visit Date: 09/09/2008 Visit Type: First Clinic Visit Follow-Up Yearly Review

OGTT

FBG: 0.00 1hr BG: 0.00 2hr BG: 0.00

Status

IGT Advised on Life style Changes Review in: 0 (months)
 IFG Discharged
 No Diabetes
 Referred
 Defaulter

Diabetes Type: Type 2
 Complications: Coronary Artery, Retinopathy

Visit Details

Clinic Visit & Drugs Finish

Name: [Redacted] Surname: [Redacted] ID: [Redacted] Age: 66 yrs DM Since: 2 yrs

| | | | | | | |
|---------------|-----|-------|--------|------|----------------|--|
| Diabetes Type | Sex | Waist | Height | BMI | Desired Weight | Desired BMI: M: 20-25 F: 19-25 Normal Waist Circ.: M: 94cm F: 80cm (Eurocid) |
| Type 2 | M | 109cm | 1.61m | 31.1 | | |

First Available: Review in: 3 (months)

Status: **Clinic Visit & Drugs** | DM History | Symptoms | Med. History | Physical | Complications | Diet | Laboratory | Education

Clinic Visit & Drugs

| Date | Weight | Waist | BMI | SBP | DBP | FBG | RBG | Urine.. | Albu.. | Acet.. | HBA1C | Mic |
|------------|--------|-------|------|-----|-----|-----|-----|---------|--------|--------|-------|-----|
| 09/09/2008 | 80.7 | 109 | 31.1 | 121 | 78 | 9.3 | 0.0 | 0 | 0 | 0 | 0.0 | |

Current Diabetes Medications View All View Current

| Date | Drug Name | Action | AM | Noon | PM | Bed | As Req.. | Date St.. |
|------------|------------------|----------|-------|-------|-------|-----|----------|-----------|
| 09/09/2008 | Mellformin 500mg | Adjusted | 500.0 | 500.0 | 500.0 | 0.0 | 0.0 | 09/09/... |

Current Non Diabetes Medications View All View Current

| Date | Drug Name | Action | AM | Noon | PM | Bed | As Req.. | Date St.. |
|------------|------------------|-----------|-----|------|-----|------|----------|-----------|
| 09/09/2008 | Perindopril 4mg | Continued | 0.0 | 0.0 | 8.0 | 0.0 | 0.0 | 09/09/... |
| 09/09/2008 | Aspirin | Continued | 0.0 | 75.0 | 0.0 | 0.0 | 0.0 | 09/09/... |
| 09/09/2008 | Fluvastatin 40mg | Continued | 0.0 | 0.0 | 0.0 | 40.0 | 0.0 | 09/09/... |
| 09/09/2008 | Bumetanide 1mg | Continued | 1.0 | 0.0 | 0.0 | 0.0 | 0.0 | 09/09/... |

Comments

| Date | Comments |
|------------|---------------------------------|
| 09/09/2008 | To walk for 45 minutes per day. |



Why did Malta join BIRO?

- Interesting, ambitious and innovative project
- The possibility to analyse our data and compare with other centres
- Potential to identify and deal with deficiencies
- Reliable partners
- In retrospect, project brought successfully to an end



Is there a need for BIRO?





To deal with the Diabetes problem we need
dependable and comparable data

Deficiencies can then be recognized and
effective strategies put in place



Perugia, 25th May 2009



EU Recommendations

- Improve the collection & reporting of diabetes data
- Promote networking and data exchange
- Facilitate diabetes research and ensure wide dissemination of results



Perugia, 25th May 2009



Implementation

Cooperation among Member States
Establishment of a standard dataset
Development of information technology to
collect and analyze the data and
disseminate the results




Perugia, 25th May 2009



Hence BIRO




Perugia, 25th May 2009

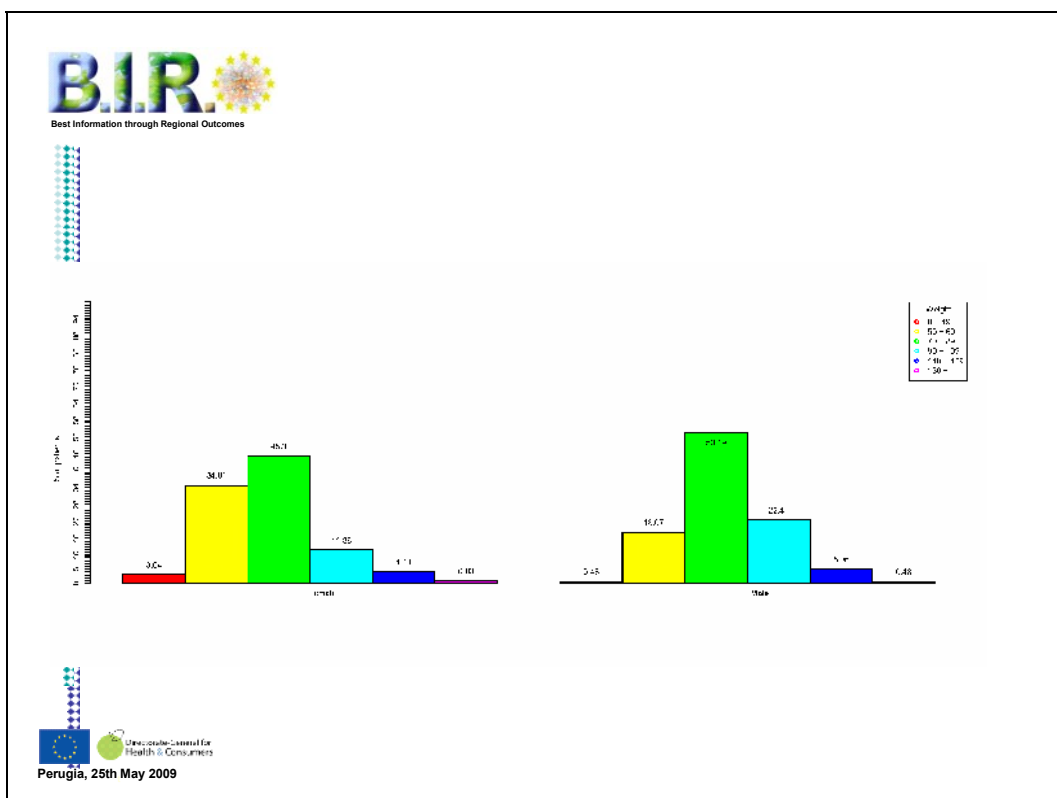



Best Information through Regional Outcomes

Software that links different datasets
 Analyses data and produces across region population based Diabetes reports
 Will help identify effective and not so effective patterns of care and prevention
 Supports the management of the disease on a continuous basis




Perugia, 25th May 2009





Next Steps

EUBIROD



Perugia, 25th May 2009



Software is freely available

Governments
Research institutions and scientific bodies
Health care Care Institutions
Private citizens

across the European Union, and beyond
Can eventually be used for other diseases



Perugia, 25th May 2009

2.4. Pictures





2.5. Press clippings

Here follows a list of articles regarding BIRO and the Plenary Session in Brussels:

- http://www.perugianews.it/it/sanita_u_e_migliore_qualita_nella_cura_del_diabete.html
- <http://kajsawilhelmsson.blogspot.com/2009/05/ biro-better-data-on-diabetes.html>
- http://www.regione.vda.it/notizieansa/details_i.asp?id=64883

3. Plenary session in Perugia

The official presentation of BIRO Project results in Perugia took place at the Dessau Conference Room of University of Perugia on 25th May 2009.

3.1. Agenda

| | |
|---------------|--|
| 10:00 - 10:30 | Welcome of Authorities |
| 10:30 - 10:45 | BIRO Objectives (<i>Prof. Massimo Massi Benedetti</i>) |
| 10:45 - 11:00 | Population-based diabetes registers (<i>Svein Skeie</i>) |
| 11:00 - 11:30 | The BIRO Project (<i>Fabrizio Carinci</i>) |
| 11:30 - 11:45 | Using BIRO: Malta experience (<i>Joseph Azzopardi</i>) |
| 11:45 - 12:00 | Using BIRO: Cyprus experience (<i>George Olympios</i>) |
| 12:00 - 12:15 | BIRO Technology Transfer (<i>Prof. Joseph Azzopardi</i>) |
| 12:15 - 12:30 | The BIRO System (<i>Valentina Baglioni</i>) |
| 12:30 - 13:00 | Discussion |

3.2. Summary report

The final act of the BIRO project took place in Perugia on 25th May 2009 at the University Headquarters. Speakers on behalf of the Consortium included coordinators Prof. Massi Benedetti and Dr. Carinci (Italy), Prof. Azzopardi (Malta), Dr. Olympios (Cyprus) and Dr. Skjie (Norway).

Participants included representatives of the Consortium and local stakeholders interested in diabetes and regional policy and planning. Presentations matched overviews provided in Brussels, including snapshots of the whole project, highlights of its relevance for clinical practice, and how to translate it into action for public health in regional areas.


The audience appeared particularly interested in applying results at the level of the regional register, coordinated by the same Department of Internal Medicine managing the BIRO project.

The Perugia plenary session gave the occasion to celebrate the official closure of the project.

The BIRO monograph was distributed to all participants, along with an executive summary of the results

3.3. Presentations

3.3.1 Population Based Diabetes Registers




Best Information through Regional Outcomes


Population-based diabetes registers

Svein Skeie MD PhD
NOKLUS/The Norwegian Diabetes Registry for adults
Bergen, Norway


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



Perugia, 25th May 2009



Perugia, 25th May 2009




Best Information through Regional Outcomes


Questions for Policy and Practice

You cannot manage what you cannot measure

Can you improve what you cannot manage?



Perugia, 25th May 2009



Perugia, 25th May 2009



Best Information through Regional Outcomes

Population-based diabetes registers

“It has been recommended that regional diabetes registers are established in the United Kingdom to facilitate systematic, population based monitoring of outcomes of diabetes and to ensure that diabetes care is effective, efficient, and equitable”

[The report of the Joint Department of Health and British Diabetic Association Task Force for Diabetes. London: Department of Health, British Diabetic Association, 1995]



Perugia, 25th May 2009



Best Information through Regional Outcomes

How should we treat diabetes?

- Early diagnosis
- Prevent vascular complications
 - treat risk factors
- Diagnose and treat complications early



Perugia, 25th May 2009

B.I.R.
Best Information through Regional Outcomes

Case Study: Scotland
Source: R.McAlpine, Tayside Diabetes Network

Tayside

~ 3000 mile²
~7800 km²

Perugia, 25th May 2009

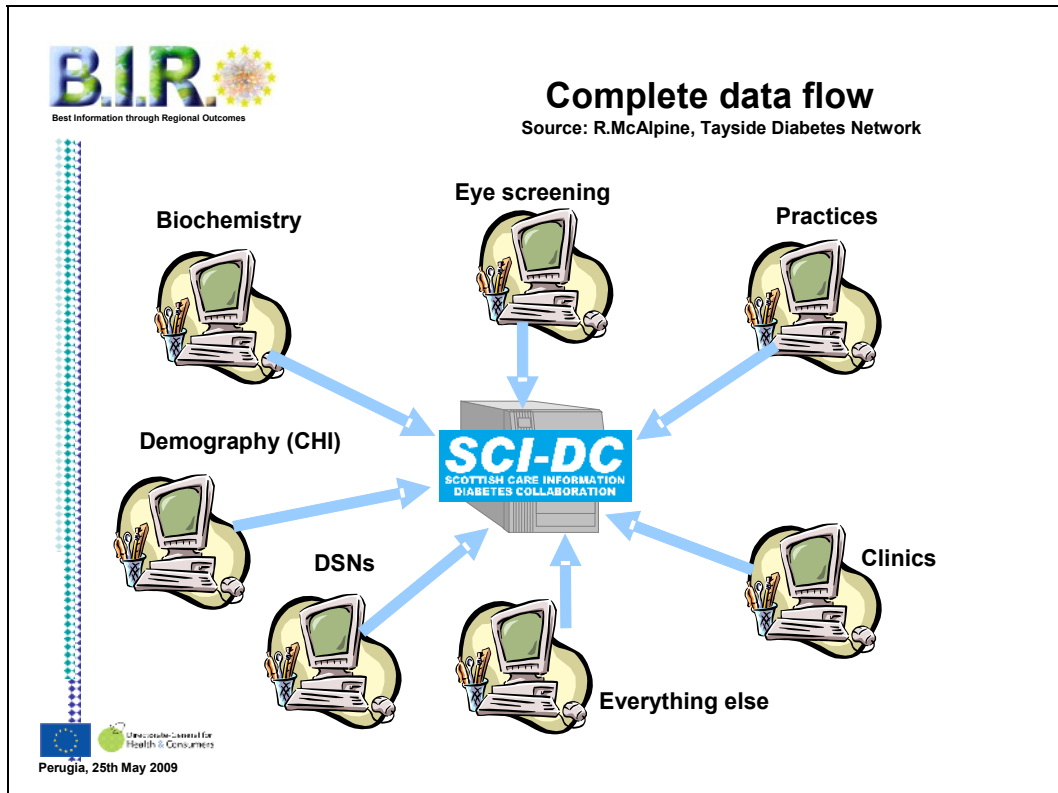
B.I.R.
Best Information through Regional Outcomes

Progressive transition
Source: R.McAlpine, Tayside Diabetes Network

Research → Local Clinical Network → National Clinical Network

DARTS Tayside Regional Diabetes Network (TRDN) Scottish Care Information - Diabetes Collaboration (SCI-DC)

Perugia, 25th May 2009



B.I.R.
Best Information through Regional Outcomes

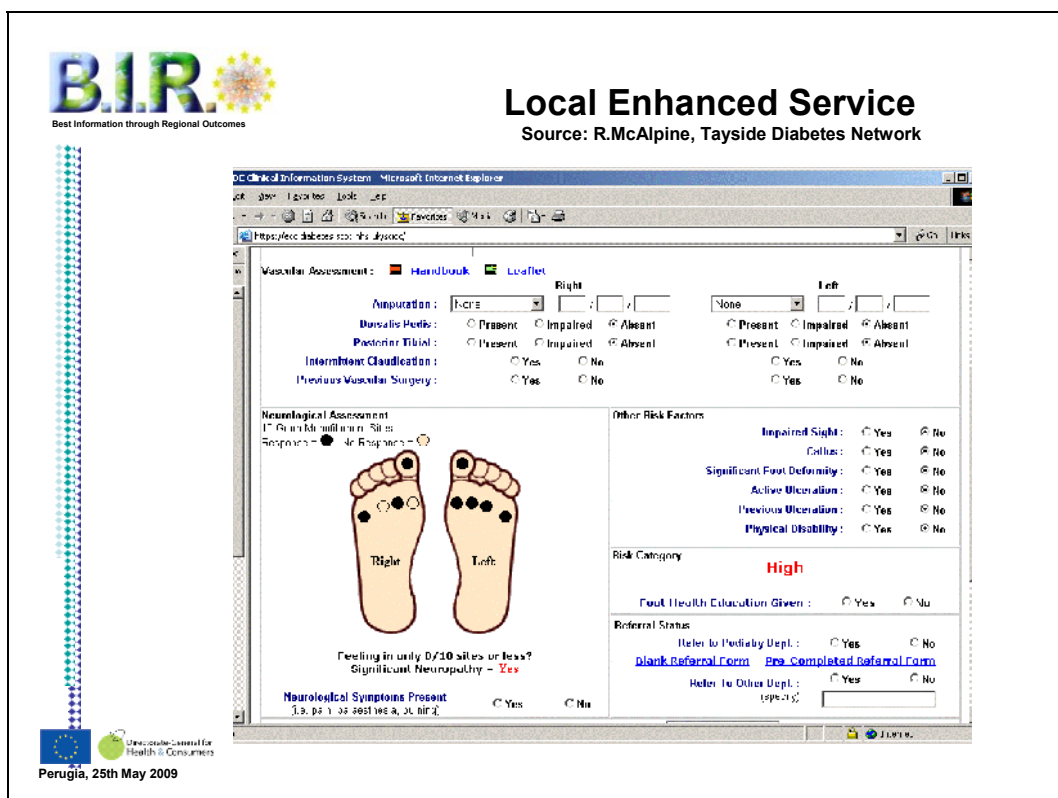
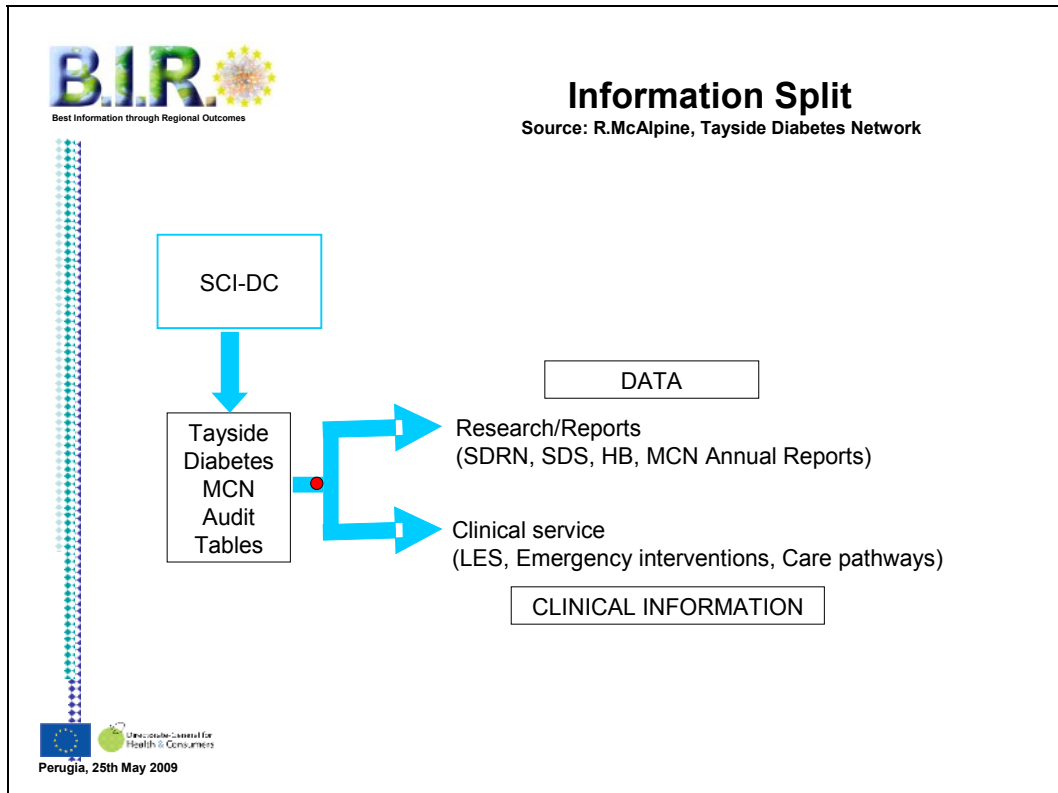
Case Study: Scotland
Source: S.Cunningham, Tayside Diabetes Network


COMMON LANGUAGE

- Standardised dictionary of terms
- Clear and unambiguous clinical definitions

The slide includes a vertical bar of colored dots on the left and a cover image of the 'SCOTTISH DIABETES CORE DATASET' (JANUARY 2003) from NHS SCOTLAND. The cover image shows a purple background with a white arc and a cluster of white dots.

Perugia, 25th May 2009

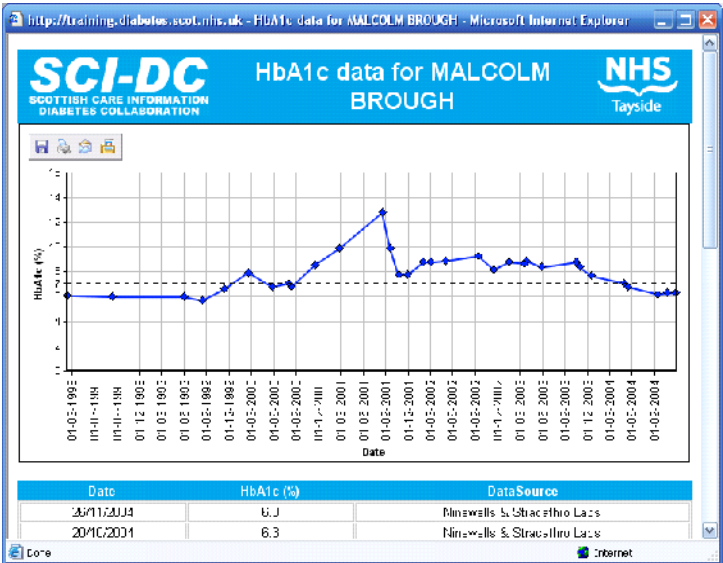




Best Information through Regional Outcomes


Patient Log

Source: S.Cunningham, Tayside Diabetes Network




The screenshot shows a line graph of HbA1c (%) for MALCOLM BROUGH from 2000 to 2004. The y-axis ranges from 6.0 to 8.0. A dashed horizontal line is drawn at approximately 7.2%. The data points show fluctuations, with a notable peak in early 2001. Below the graph is a table with the following data:

| Date | HbA1c (%) | Data Source |
|------------|-----------|-----------------------------|
| 20/11/2004 | 6.2 | Pinewalls & Strachutho Lacs |
| 20/10/2001 | 6.3 | Pinewalls & Strachutho Lacs |



United Kingdom
Department for Health & Consumers

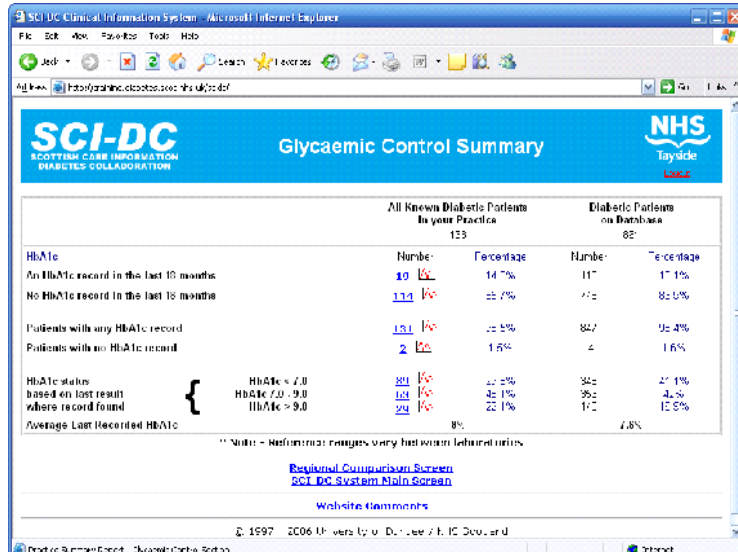
Perugia, 25th May 2009



Best Information through Regional Outcomes

Automated Regional Comparisons

Source: S.Cunningham, Tayside Diabetes Network




The screenshot displays a 'Glycaemic Control Summary' comparing 'All Known Diabetic Patients in your Practice' (n=123) with 'Diabetic Patients on Database' (n=82). The data is summarized in the following table:

| | All Known Diabetic Patients in your Practice (123) | | Diabetic Patients on Database (82) | |
|--|--|------------|------------------------------------|------------|
| | Number | Percentage | Number | Percentage |
| An HbA1c record in the last 18 months | 19 | 14.7% | 17 | 17.1% |
| No HbA1c record in the last 18 months | 104 | 85.3% | 65 | 82.9% |
| Patients with any HbA1c record | 131 | 107.3% | 84 | 102.4% |
| Patients with no HbA1c record | 2 | 1.6% | 4 | 4.9% |
| HbA1c status based on last result where record found | HbA1c < 7.0 | 20 (15.4%) | 34 (40.2%) | 41.5% |
| | HbA1c 7.0 - 9.0 | 13 (10.6%) | 32 (39.0%) | 39.0% |
| | HbA1c > 9.0 | 24 (19.5%) | 17 (20.7%) | 20.7% |
| Average Last Recorded HbA1c | 8% | | 7.8% | |

Note: ** Note - Referential ranges vary last known laboratory.

Links: [Regional Comparison Screen](#), [SCI-DC System Main Screen](#), [Website Comments](#)

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United Kingdom
Department for Health & Consumers

Perugia, 25th May 2009

B.I.R.
Best Information through Regional Outcomes

http://www.diabetes-healthnet.ac.uk

NHS Tayside Diabetes MCN

Home page | Login

Change text size: A A A

Main Menu

- Home page
- Meet the Team
- Handbook
- Specialist Clinics
- Patient Information
- Children's Services
- Professional Education
- Eye Screening
- Footsteps
- MCN
- Latest News
- Research
- Links
- Search this Site
- Admin Home

Welcome to the website of NHS Tayside's Diabetes Managed Clinical Network (MCN).

The MCN is a coordinated network of professionals involved in providing diabetes care across the region. Within this network, patients and professionals work together to continually develop and improve their care. This website provides local information about diabetes and diabetes care for both healthcare professionals and patients.

We hope you find the site useful and would appreciate feedback on any aspect of the site or the information provided. Please send your comments to: [Leanne Wilson](mailto:Leanne.Wilson@nhs.uk)

Meet the Team
Team members of the Tayside Diabetes Clinical Network.

Specialist Clinics
Specialists: Diabetes Clinics across Tayside

Children's Services
Services and guidelines for children

Eye Screening
Details of the Retinopathy screening programme

Latest News
Latest Tayside Diabetes news and events

Links
Details Web Links

Search this Website
Powered by ©Google Custom Search

Handbook
Guidelines for diabetes care

Patient Information
Information for patients including patient leaflets, brochures, guides

Professional Education
Information about educational opportunities, conferences, locally for jobs.

Footsteps
Primary Self Management Education Programme

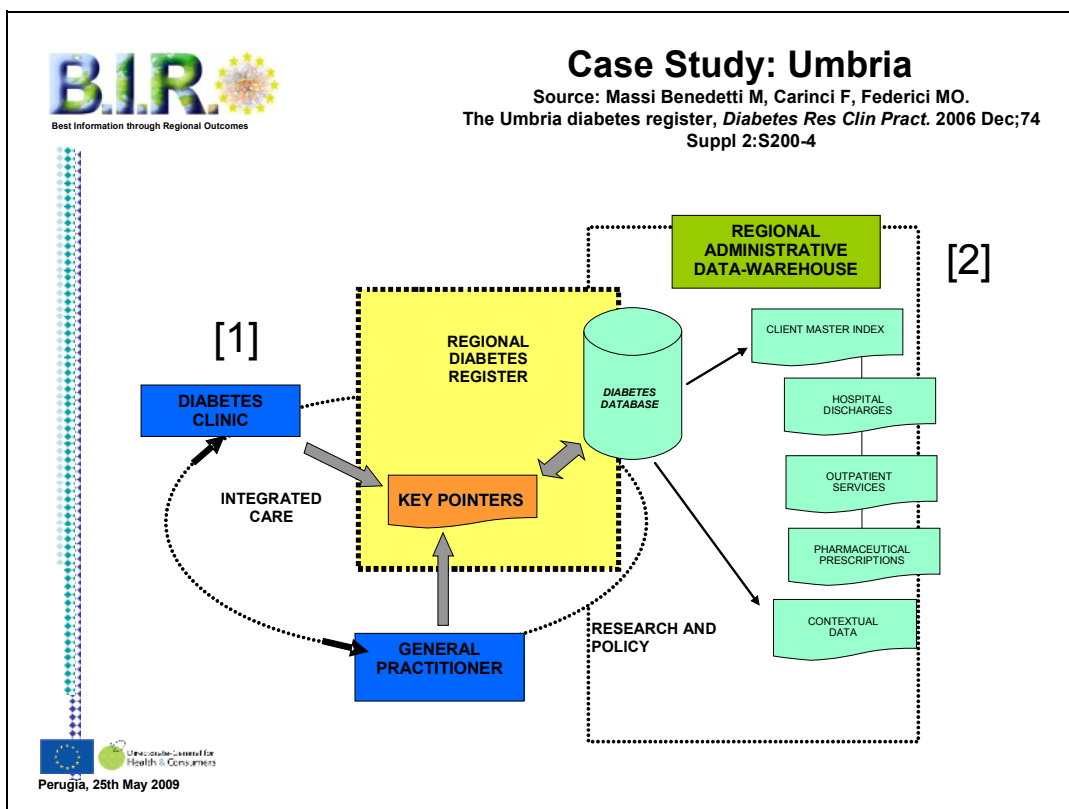
Research
Diabetes research in Tayside


MCN
Managed Clinical Network Documents including strategy, annual reports.

Latest News
May 2009
Read more...

NHS Tayside

United Kingdom
Perugia, 25th May 2009







The Norwegian Diabetes Registry for Adults

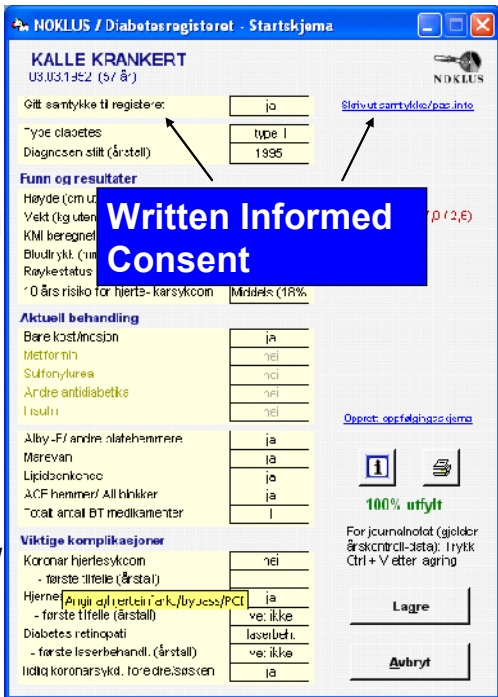

NOKLUS Diabetes


A structured documentation tool for general practices, specialist practices and hospitals

Magne Rekdal, MD
IT Consultant NDV
Owner Emetra AS
magne@emetra.no


- Simple setup, core dataset in common for practices and hospitals
- A clinical tool
- Cooperation with the diabetes association
- Annual data collection, benchmarking/feedback
- Privacy




BIRO Report Template

A “template” is a document or file having a preset format, used as a starting point for a particular application so that the format does not have to be recreated each time it is used



Perugia, 25th May 2009



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 | Table, <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> |

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 | Table, <u>histogram</u> |
| 2.2 Risk factors for diab. complications | |
| 2.2.1 Obesity | |
| 2.2.1.1 Weight | Table, <u>lines</u> , <u>starplot</u> , <u>boxplot</u> |
| 2.2.1.2 BMI | Table, <u>lines</u> , <u>starplot</u> , <u>boxplot</u> |

Underlined preferred output

Different output according to target audience




Perugia, 25th May 2009



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)


 Directorate-General for Health & Consumers
 Perugia, 25th May 2009



Web Portal Homepage


Biro Indicators

Biro Indicators

- Home
- Why BIRO
- BIRO model
- Discharge info
- Discharge indicators
- Discharge summary
- Work packages
- Project partners
- E-learning
- How to participate

Content

BIRO - Best Information through Regional Outcomes

We live in a chronic 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 signal early, 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 consortium of 14 countries, regional and professional boundaries, involving citizens and the wider community through the support of the European Commission.

Nick Frithy
 - coordinator of the Health Information Unit
 - Health and Consumers Directorate-General, European Commission


 Directorate-General for Health & Consumers
 Perugia, 25th May 2009



Web Portal Data Dictionary



Biro Indicators

Biro Indicators

- Home
- Why B.I.R.O.
- B.I.R.O. model
- Diabetes info
- Diabetes Indicators
- Data dictionary
- Work packages
- Project partners
- Collaborating
- How to participate

User login

Username:


Password:

[Update new account](#)

Home - Data dictionary - Data dictionary


Data dictionary

| Reference | Name | Parameter | Datatype | Units |
|-----------|-----------|-------------------------|-------------|-------------------|
| BIRC001 | PAT_ID | Patient ID | String (12) | |
| BIRC002 | DS_ID | Data Source ID | String (10) | |
| BIRC003 | TYPE_DM | Type Of Diabetes | Enumerated | |
| | Code | Value | | |
| | 1 | Type 1 | | |
| | 2 | Type 2 | | |
| | 3 | Other Types of Diabetes | | |
| BIRC004 | SEX | Sex | Enumerated | |
| BIRC005 | DOD | Date of Birth | Date/Time | |
| BIRC006 | DT_DIAG | Date of Diagnosis | Integer | |
| BIRC007 | EPI_DATE | Episode Date | Date/Time | |
| BIRC008 | SMOK_STAT | Smoking Status | Enumerated | |
| BIRC009 | CIGS_DAY | Cigarettes per day | Integer | |
| BIRC047 | ALC_STAT | Alcohol Status | Enumerated | g/week |
| BIRC010 | ALCOHOL | Alcohol Intake | Integer | g/week |
| BIRC011 | WEIGHT | Weight | Real | kg |
| BIRC012 | HEIGHT | Height | Real | m |
| BIRC019 | DMI | Body Mass Index | Real | kg/m ² |




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Perugia, 25th May 2009



Web Portal Reports



Biro Indicators

Biro Indicators

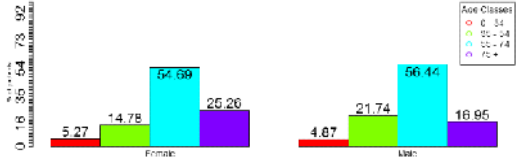
- Home
- Why B.I.R.O.
- B.I.R.O. model
- Diabetes info
- Diabetes Indicators
- 1. Demographic characteristics
- 1.1. Age (Classes)
- 1.2. Gender
- 2. Clinical characteristics
- 3. Health systems
- 4. Population (Area level)
- 5. Plus adjusted indicators
- Data dictionary
- Work packages
- Project partners
- Collaborating
- How to participate

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

1.1. Age (Classes)

Indicator Definition

| Age Classes | Female | Male | Total |
|-------------|----------------|----------------|----------------|
| 0 - 34 | 775 (9.81%) | 78 (50.18%) | 1536 (5.06%) |
| 35 - 54 | 2176 (38.43%) | 3188 (61.63%) | 5634 (18.41%) |
| 55 - 74 | 3046 (47.05%) | 4956 (58.93%) | 11704 (35.41%) |
| 75 + | 3776 (57.14%) | 2726 (42.87%) | 6436 (20.32%) |
| | 14719 (47.83%) | 16049 (50.17%) | 30766 |



| Age Class | Female | Male |
|-----------|--------|-------|
| 0-34 | 5.27 | 4.87 |
| 35-54 | 14.78 | 21.74 |
| 55-74 | 54.69 | 56.44 |
| 75+ | 25.26 | 16.95 |



European Council for Health & Consumers

Perugia, 25th May 2009

3.3.2 The BIRO Project

Slides presented in Perugia are the same of Brussels Plenary session (see Section 2.3.2)

3.3.3 Using BIRO: the Malta experience

Slides presented in Perugia are the same of Brussels Plenary session (see Section 2.3.4)

3.3.4 Using BIRO: the Cyprus experience

Slides presented in Perugia are the same of Brussels Plenary session (see Section 2.3.3)

3.3.5 B.I.R.O. Technology Transfer in New Member States




Best Information through Regional Outcomes

B.I.R.O. Technology Transfer in new member States

S. Pruna, J. Azzopardi and G. Olympios


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




Best Information through Regional Outcomes

Objectives Technology Transfer



- Migration of data, from various local data sources
- To create local/regional reports from aggregated data
- To create national reports on a set of internationally comparable healthcare quality indicators






Situation in the collection and management of diabetes data


- For each of the three countries we have reported about:
 - The diabetes health care management
 - How data is defined (data dictionary, items, minimum dataset, standards), Information systems



Diabetes Information Systems

- Health information systems in diabetes tend to be fragmented, inaccurate, cumbersome, untimely, and isolated
- A barrier for BIRO implementation







Best Information through Regional Outcomes

The Challenge

- The vast majority of software development tools used in the diabetes sector today do not support data exchange mechanisms




Directorate-General for Health & Consumers




Best Information through Regional Outcomes

How to implement BIRO technology?

- We analysed:
 - The steps for set-up and execution of the BIRO software tools
 - How to create and deliver structured data in XML format (exchange of aggregate data) from local data sources
 - How to process these data with BIRO statistical reporting engines.




Directorate-General for Health & Consumers



The steps in exporting of data from a database to XML

1. Connect to the database
2. Specify the SQL to run to retrieve the data
3. Specify the location of the flat file (XML)
4. Export the data



BIRO implementation

- During Technology Transfer training we used sample data from Cyprus, Malta and Romania





The slide features the B.I.R. logo and tagline at the top left. The main title "What have we learned from Technology Transfer" is centered in large blue letters. Below the title is a bulleted list of two points. At the bottom left, there are logos for the European Union and the Directorate-General for Health & Consumers.

What have we learned from Technology Transfer

- No special programming knowledge is needed for use BIRO BOX GUI
- Structured information (XML format) can be generated by non-technical personnel



Open Source technologies

- BIRO takes advantage of new Open Source technologies (free license and access to the source code)
- Involves the unidirectional migration of data, from diabetes care locations to the BIRO local data warehouse
- Sends data to central database for analysis with various reporting tools and statistical applications developed through the project.



Thank you!



Romania, Bucharest




3.3.6 The BIRO System



The BIRO System


Valentina Baglioni
Università degli Studi di Perugia

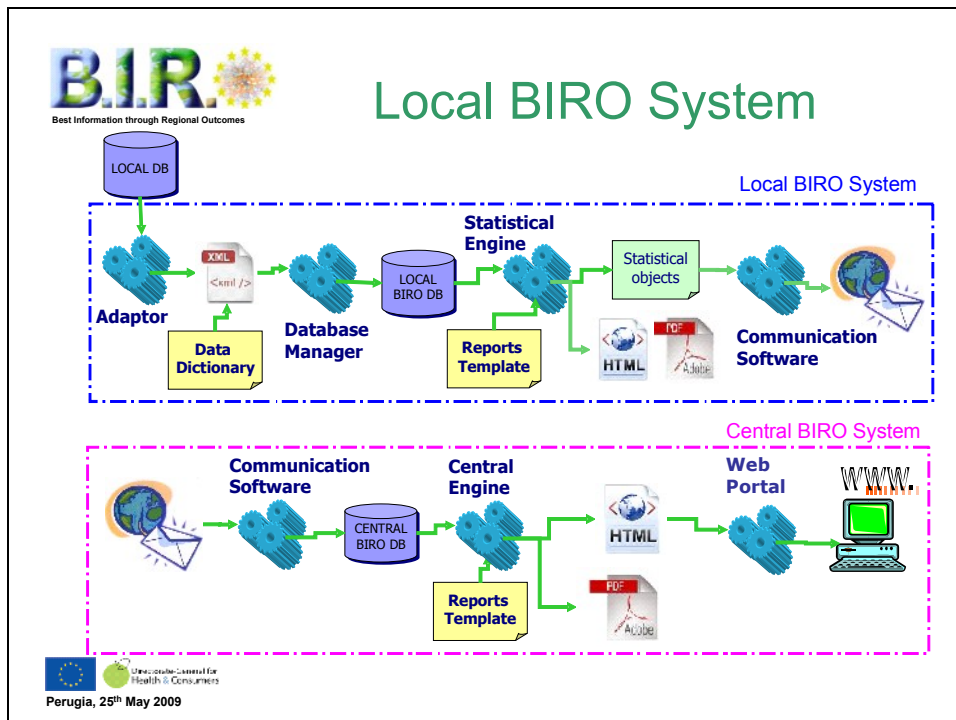
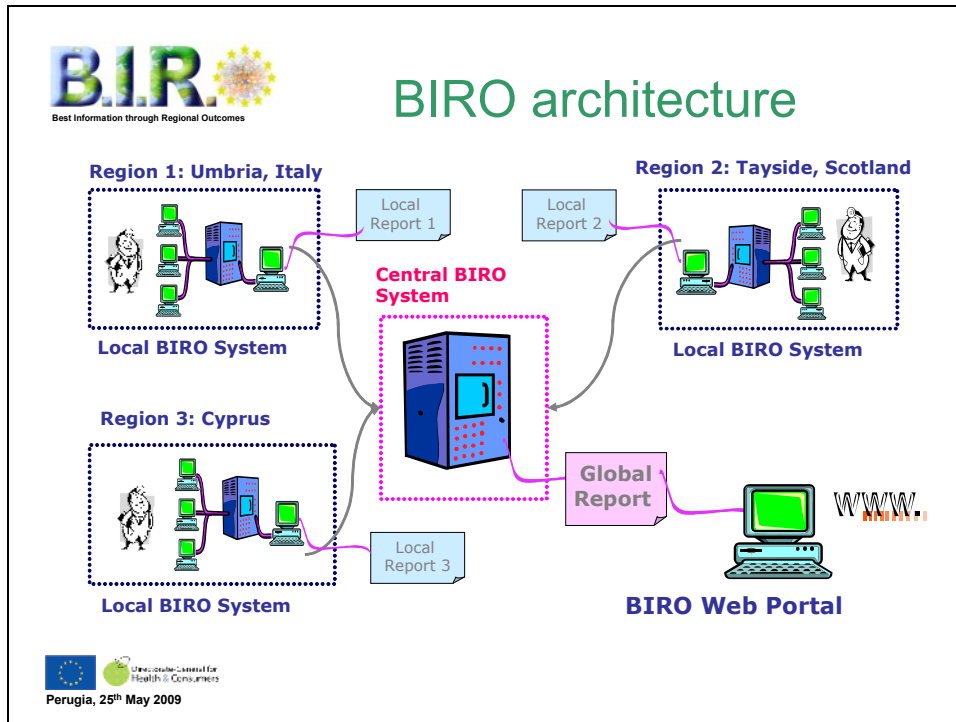
“A Shared Information System for Diabetes in Europe:
final results of the B.I.R.O. Project”
Dessau Conference Room
Perugia, 25th May 2009

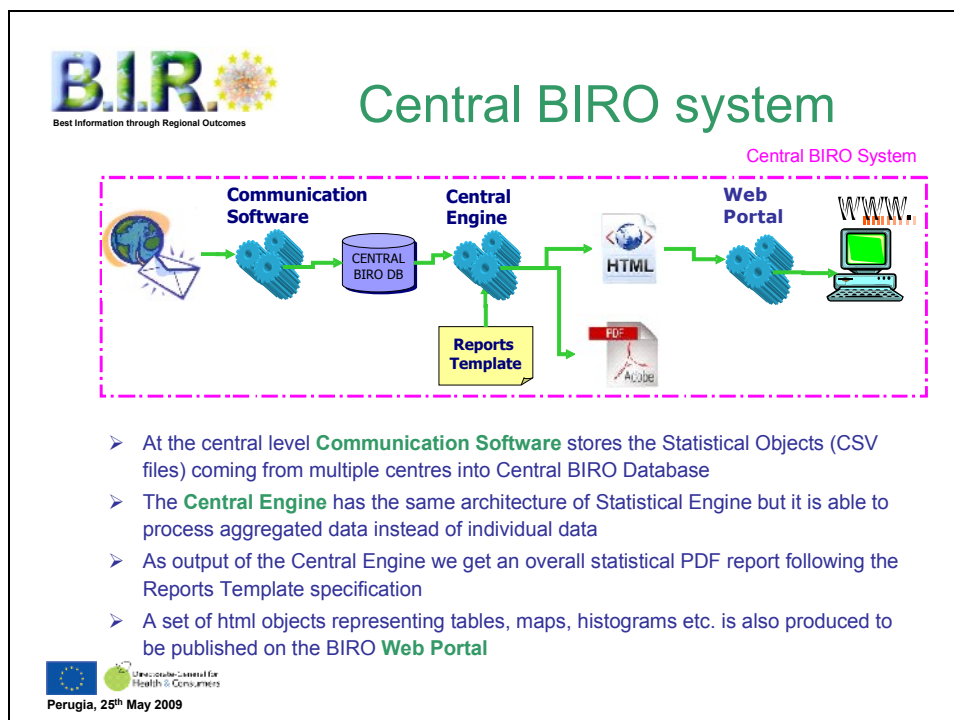
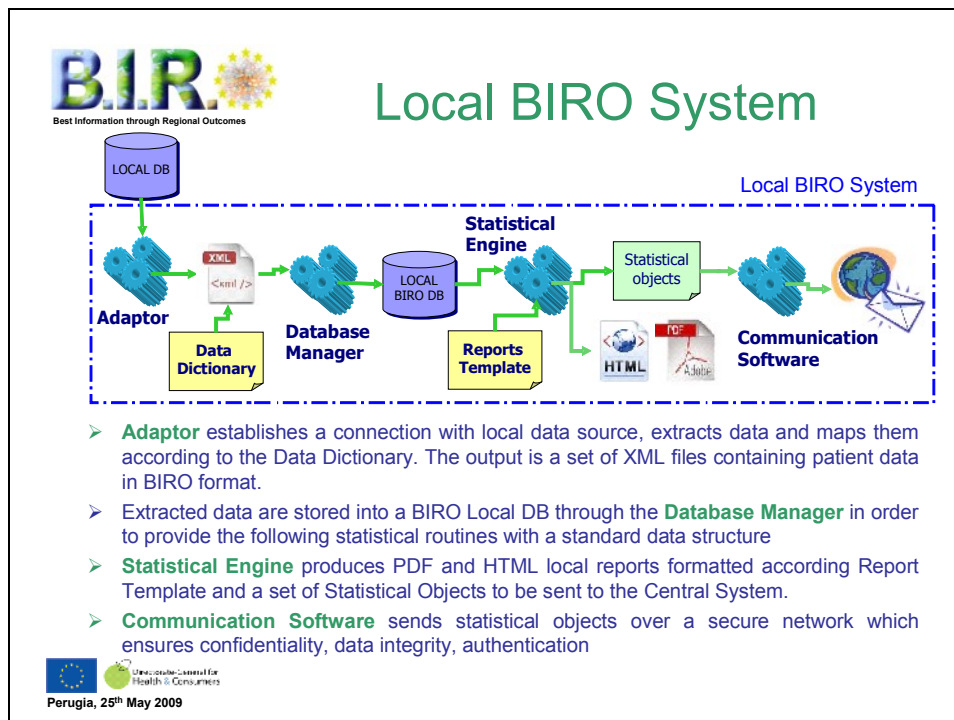


The BIRO system

- BIRO system aims to be a viable solution towards the construction of a **common infrastructure for standardized information exchange in diabetes care** at the lowest cost through the active involvement of regional networks
- The BIRO architecture consists of two different modules: Local BIRO System and Central BIRO System
- The **Local BIRO System** should be implemented by each participating centre and allows standardized processing of local data and production of a comparable statistical reports for selected BIRO indicators
- The **Central BIRO System** collects and compiles data sent by local modules to derive an overall statistical report









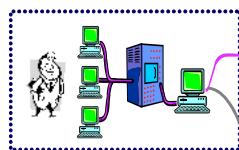
BIRO system strenghts

- **secure** → according to PIA no sensitive individual data are transferred out of the boundaries of the local system but only aggregated data. Communication Software provides all fundamentals of information-security: confidentiality, integrity, authentication
- **inexpensive** → only open source tools, Java and R as a main programming languages have been chosen to produce a cost effective solution
- **non-invasive** → the use of the local BIRO System does not require any change in the way data are gathered locally
- **scalable** → it can be potentially used recursively to organize the network within countries and/or regions



The local network

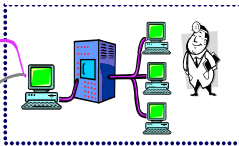
Centre 1: Perugia, diabetes centre



Local BIRO system

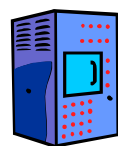
Local Report 1

Centre 2: Orvieto, diabetes centre

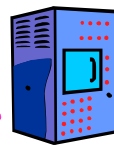


Local Report 2

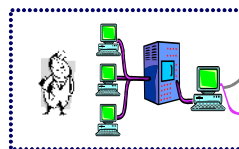
Central BIRO System for Umbria



Central BIRO System for Europe



Centre 3: Terni, diabetes centre



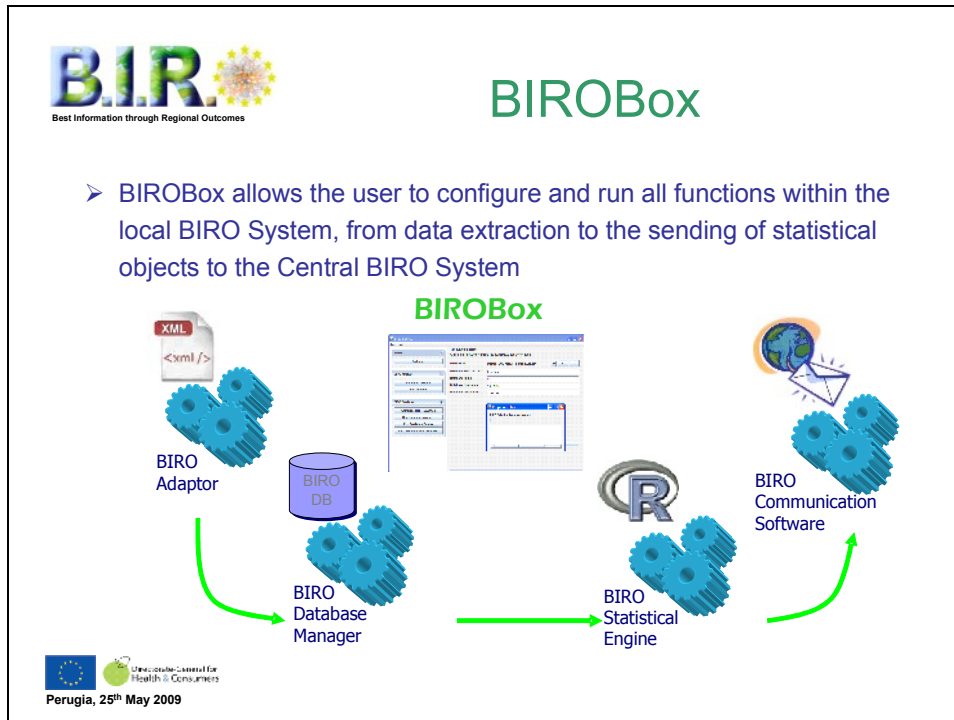
Local Report 3

WWW



BIRO Web Portal





3.4. Pictures









3.5. Press clippings

Here follows a list of articles regarding BIRO and the Plenary Session in Perugia:

- <http://www.iltamtam.it:80/Generali/Salute/LUniversita-di-Perugia-capofila-di-progetti-contro-il-diabete-in-Europa.aspx>
- http://www.progettodiabete.org/indice_ie1000.html?news/2009/n2009_035.html
- <http://www.unipg.it/ufstampa/wwwnew/comunicati%202009/ biro1.htm>
- <http://www.ansa.it/salute/regionali/umbria/20090525165434885502.html>

Il Messaggero 26 maggio 2009

—| MEDICINA&RICERCA |—

Perugia capofila nella lotta al diabete

Perugia è stata capofila di un progetto per la lotta al diabete ed in particolare per un nuovo sistema informativo europeo. Il progetto, denominato **Biro** (Best information through regional outcomes), realizzato dal Centro di coordinamento del dipartimento di Medicina interna della facoltà medica, sotto la direzione del professor Massimo Massi Benedetti, ha avuto una durata di 40 mesi e ha coinvolto atenei e istituzioni scientifiche di Scozia, Austria, Malta, Cipro, Norvegia e Romania. «Finanziato dalla Commissione europea e dalla Regione - ha spiegato il professor Massimo Massi Benedetti - ha permesso di creare, tramite il software **Biro**, gratuito e open source, un sistema che collega i diversi registri re-

gionali e fornisce, su base automatica e continuativa, una griglia di indicatori che possono essere di grande aiuto nel migliorare, nei singoli Paesi, le modalità attuate per la cura del diabete». «**Biro** - ha aggiunto Massi Benedetti - che facilita il trattamento dei dati e la produzione di rapporti statistici uniformi secondo regole comuni, consente di estrarre e analizzare, nel rispetto delle normative sulla privacy, cartelle cliniche e amministrative, consentendo di confrontare dati a livello europeo». Gli studi e la ricerca proseguiranno con un nuovo progetto, **Eubirod**, sempre sotto l'egida della Commissione europea e con il supporto della Regione, che coinvolgerà 21 Paesi, con Perugia ancora capofila.

ms

Corriere dell'Umbria 26 maggio 2009

L'Università mette a punto un registro informatico per migliorare la cura del diabete **Si chiama "Biro" ma è una banca dati**

PERUGIA - Una buona assistenza nel campo della salute passa anche attraverso un valido sistema informatico, come ha dimostrato l'Università di Perugia che è a capo di un progetto europeo denominato B.I.R.O. (Best information through regional outcomes) insieme a sette diversi partners. E' stata creata una banca dati innovativa per consentire, in particolare, una migliore qualità nella cura del diabete nell'Unione europea.

Un lavoro durato 40 mesi e ieri la presentazione alla sala Dessau dell'Università di Perugia dell'esito del progetto realizzato dal Centro coordinamento del dipartimento di Medicina interna sotto la direzione del professor

Massimo Massi Benedetti e reso possibile grazie al finanziamento congiunto di Commissione europea e Regione dell'Umbria.

In sostanza, è stato costruito un sistema che collega i diversi registri regionali e fornisce su base automatica e continuativa una griglia di tabelle di indicatori che - ha spiegato il professor Benedetti - nel rispetto delle normative sulla privacy possono essere di aiuto per migliorare nei singoli paesi le modalità attuate per la cura del diabete. "E' una raccolta dati - ha aggiunto - derivante da database diversi. Tuttavia, l'analisi dei dati viene messa a disposizione non solo a livello centrale, ma anche locale e nazionale. Ciò permette di

generare un confronto su realtà diverse". Attraverso Biro, dunque, i metodi di epidemiologia, statistica e informatica si integrano. "Non produciamo mera tecnologia - ha precisato il professor Benedetti - ma informazioni cliniche per diversi livelli di utilizzo: decisionale politico-strategico e amministrativo". In altre parole, "informazioni per migliori decisioni che possano ridurre gli esiti sfavorevoli del diabete e bloccare se non sconferire gradualmente una patologia che continua a crescere a ritmo allarmante". Il software biro è gratuito e può essere usato liberamente dalle regioni e dai centri interessati.

G.Nic.

Il Giornale dell'Umbria 26 maggio 2009

Ricerca Perugia capofila nel progetto "Biro" Cartelle cliniche in rete, i Paesi dialogano per vincere il diabete

PERUGIA - La città di Perugia capofila di un progetto per la lotta al diabete ed in particolare per un nuovo sistema informativo europeo.

I risultati dell'iniziativa "Biro" (Best information through regional outcomes), sono stati presentati ieri.

Il progetto, che ha coinvolto atenei e istituzioni scientifiche di Scozia, Austria, Malta, Cipro, Norvegia e Romania,

come chiarisce una nota dell'Università degli studi di Perugia è stato realizzato dal Centro di coordinamento del dipartimento di Medicina interna della facoltà medica di

Università
Protagonista
il dipartimento
di Medicina

Perugia, sotto la direzione del professor Massimo Massi Benedetti, ed ha avuto una durata di 40 mesi. "Finanziato dalla Commissione europea e dalla Regione Umbria - ha spiegato il professor Massi



Esami medici per rilevare il diabete

trattamento dei dati e la produzione di rapporti statistici uniformi secondo regole comuni, consente di estrarre e analizzare, nel rispetto delle normative sulla privacy, cartelle cliniche e amministrative, consentendo di confrontare dati a livello europeo".

Gli studi e la ricerca indirizzati alla lotta contro il diabete proseguiranno con un nuovo progetto, dal titolo "Eubirod", che sarà realizzato sempre sotto l'egida della Commissione europea e con il supporto della Regione Umbria, e coinvolgerà 21 Paesi, ancora una volta con Perugia come capofila.

Il diabete nel mondo - sottoleneano gli esperti - uccide una persona ogni quaranta secondi. Nel giro di dieci anni si prevede che i malati raddopieranno, passando dai 200 milioni attuali a 400 milioni".

indicatori che possono essere di grande aiuto nel migliorare, nei singoli Paesi, le modalità attuate per la cura del diabete".

"Biro - ha aggiunto ancora Massi Benedetti - facilita il

Benedetti - l'iniziativa ha permesso di creare, tramite il software gratuito e open source Biro, un sistema che collega i diversi registri regionali e fornisce, su base automatica e continuativa, una griglia di

ms

Umbria Settegiorni 29 maggio 2009

Importanti risultati dell'Università sul piano della ricerca e dell'assistenza Lotta al diabete, Perugia è capofila del nuovo sistema informativo europeo

■ R.C.

Il diabete è in forte aumento: nel mondo uccide una persona ogni quaranta secondi. Nel giro di dieci anni i malati raddoppieranno, passando dai 200 milioni attuali a 400 milioni. Nella lotta a questa malattia l'Università degli Studi di Perugia sta operando con impegno ottenendo significativi risultati sul piano della ricerca e dell'assistenza clinica. Nella sala Dessau di Palazzo Murena, sono stati presentati i risultati del progetto BIRO (Best information throug Regional Outcomes), realizzato dal Centro di Coordinamento del Dipartimento di Medicina Interna della Facoltà medica di Perugia, sotto la direzione del professore Massimo Massi Benedetti; ha avuto una durata di 40 mesi e ha coinvolto Atenei e istituzioni scientifiche di Scozia, Austria, Malta, Cipro, Norvegia e Romania, con Perugia che ha avuto il ruolo di capofila. "Il progetto, finanziato dalla



Commissione Europea e dalla Regione Umbria, ha permesso di creare, tramite il software BIRO, gratuito e open source, un sistema che collega i diversi registri regionali e fornisce, su base automatica e continuativa, una griglia di indicatori che possono essere di grande aiuto nel migliorare, nei singoli paesi, le modalità attuate per la cura del diabete - ha sottolineato il professor Massi Benedetti - . BIRO, che facilita il trattamento dei dati e la produzione di rapporti statistici uniformi secondo regole comuni, consente di estrarre e analizzare, nel rispetto delle normative sulla privacy, cartelle

cliniche e amministrative, consentendo di confrontare dati a livello europeo; con la possibilità, dunque, di avere maggiore informazioni in modo da prendere le migliori decisioni per ridurre gli esiti sfavorevoli del diabete e quindi bloccare e sconfiggere gradualmente una patologia che sta crescendo a un ritmo allarmante". Nel corso dell'incontro i referenti del progetto hanno evidenziato come, attraverso BIRO, è possibile migliorare l'organizzazione delle cure, come ha dimostrato il caso di Cipro dove è nata la prima clinica di diabetologia ed è stato istituito un registro del diabete che in pochi mesi è diventato operativo e sta rapidamente coprendo il territorio di quel Paese. Gli studi e la ricerca non sono affatto conclusi. A BIRO seguirà, infatti, un nuovo progetto, EUBIROD, sempre sotto l'egida della Commissione Europea e con il supporto della Regione Umbria, che coinvolgerà 21 paesi, con Perugia ancora capofila.