

Health information on chronic diseases for societal impact: a blueprint for population data platforms

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Why do we need health information in Europe?

- To make policy makers accountable for the results obtained by the EU legislation and National policies
- To evaluate adherence to evidence-based guidelines and set achievable targets for quality of care and outcomes
- To share best practices and avoid common mistakes
- To benchmark the effect of local policies and health services organization against different alternatives, using standardized criteria
- To avoid drawing conclusions from random variation, which is more critical in countries that have a smaller population and a limited number of cases for any problem investigated

Which comparisons can be made across the EU today?

- Certainly not enough to monitor action and planning of prevention measures and health care for people with diabetes in Europe
- General data on diabetes prevalence (total number of people in diabetes at a specific point in time), poor data on incidence (how many new cases per year)
- Few indicators calculated from administrative data sources (e.g. hospital data), prone to bias due to financing mechanisms (e.g. DRGs)
- No indicators on intermediate and terminal outcomes (those that really matter for people with diabetes)

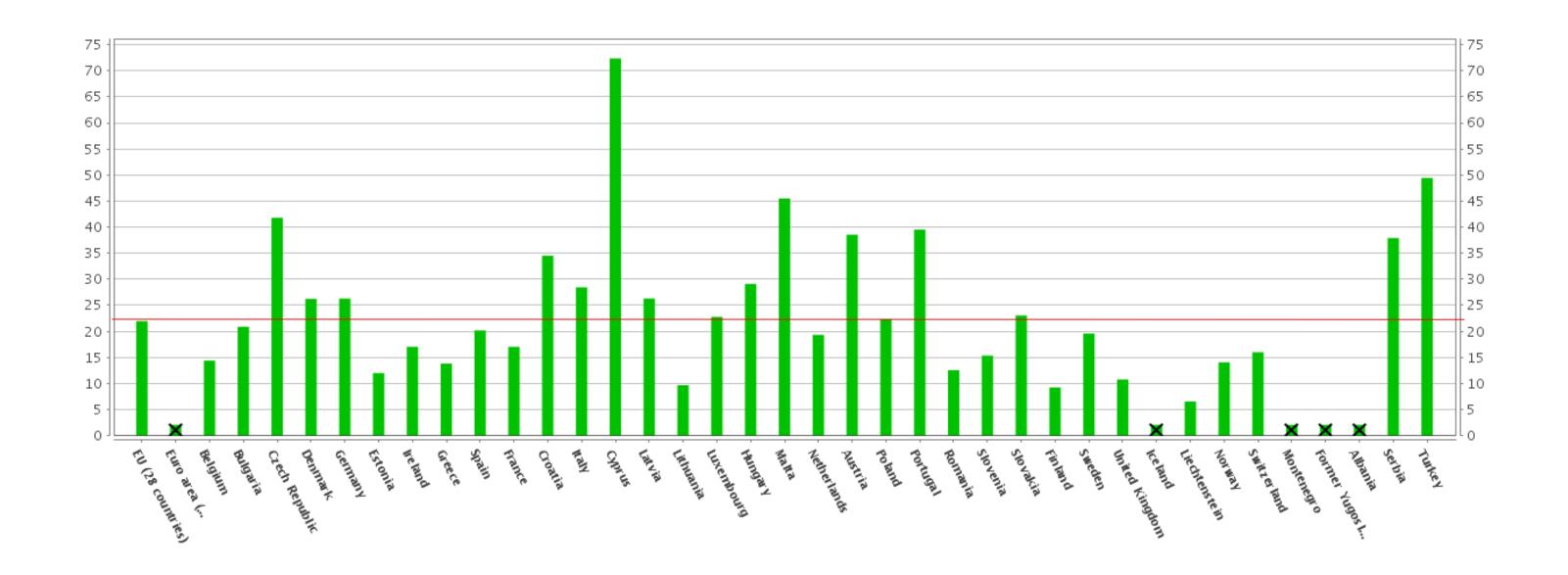
Insufficient diabetes information in Europe

...although the data available are already enough to seriously worry...

...and to urge countries to deliver and use more information on diabetes!

Deaths due to diabetes mellitus

Standardized death rate by 100 000 inhabitants, Year 2014 Source: Eurostat 2017

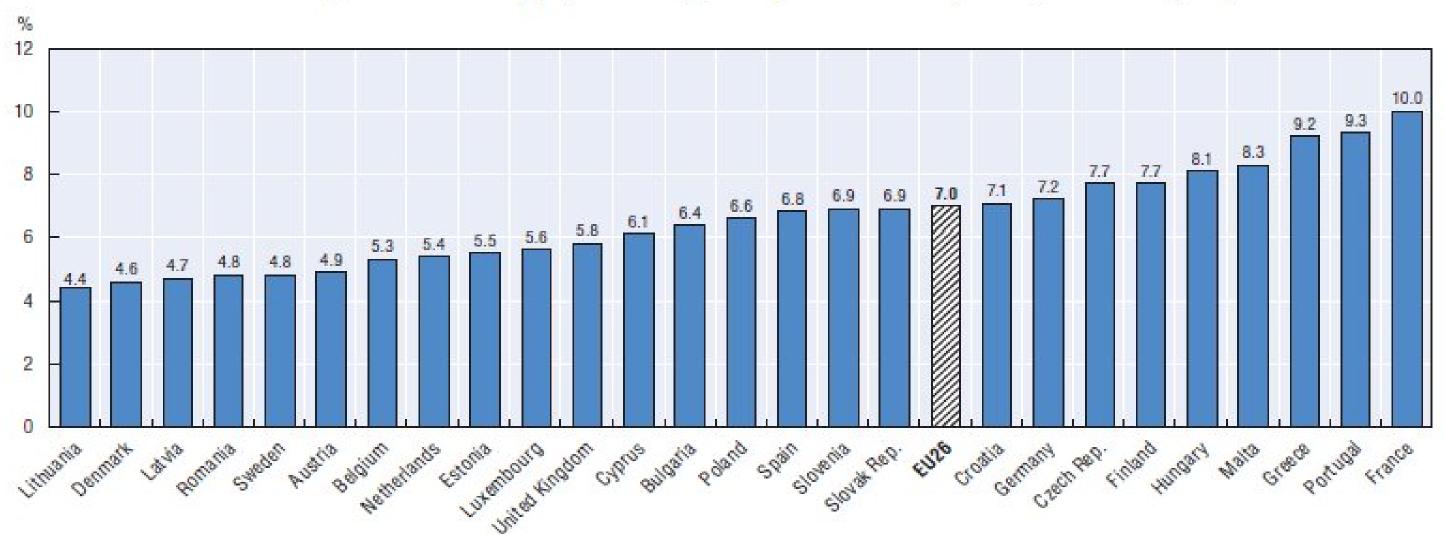


Diabetes Prevalence

Self-reported, Year 2014

Source: Eurostat (revised in "OECD Health at a Glance: Europe 2016")

3.34. Self-reported diabetes, population aged 15 years and over, 2014 (or nearest year)



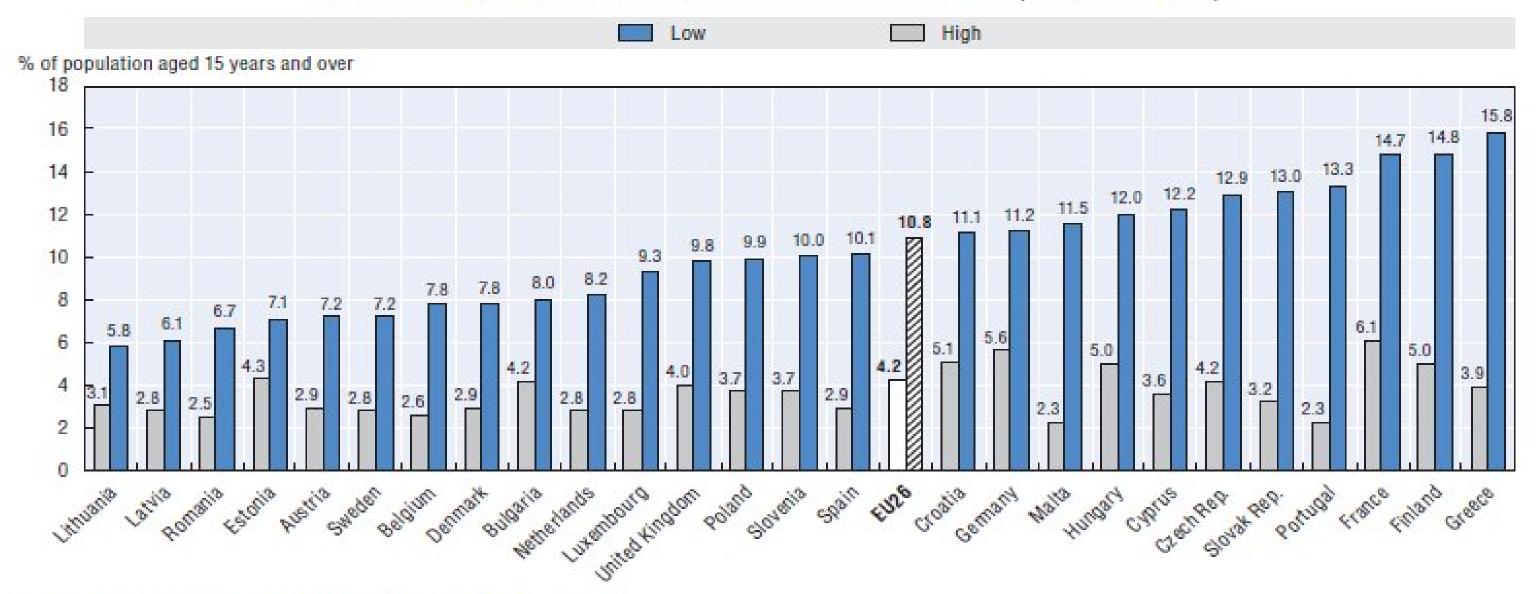
Source: Eurostat Database, based on Health Interview Surveys.

Diabetes Prevalence by level of education

Self-reported, Year 2014

Source: Eurostat (revised in "OECD Health at a Glance: Europe 2016")

3.35. Self-reported diabetes by level of education, 2014 (or nearest year)

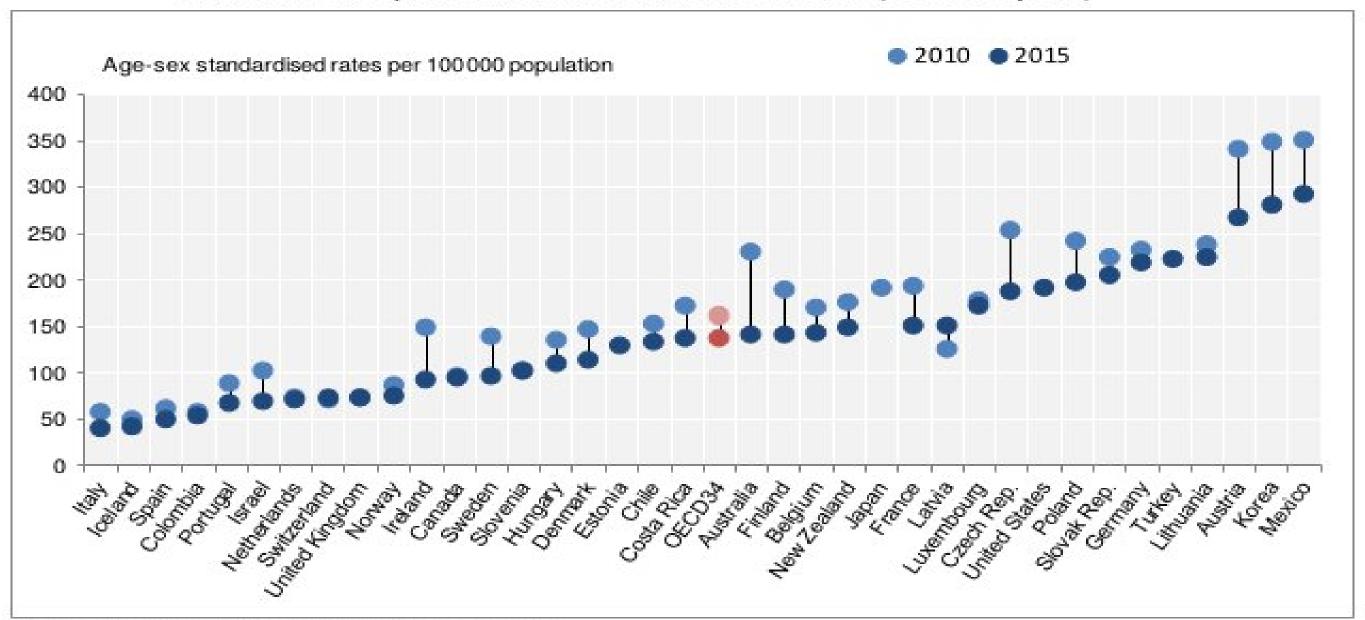


Source: Eurostat Database, based on Health Interview Surveys.

Diabetes Hospital Admissions, 2015

Source: OECD Health at a Glance 2017

6.11. Diabetes hospital admission in adults, 2010 and 2015 (or nearest years)



Note: Three-year average for Iceland and Luxembourg.

Source: OECD Health Statistics 2017.

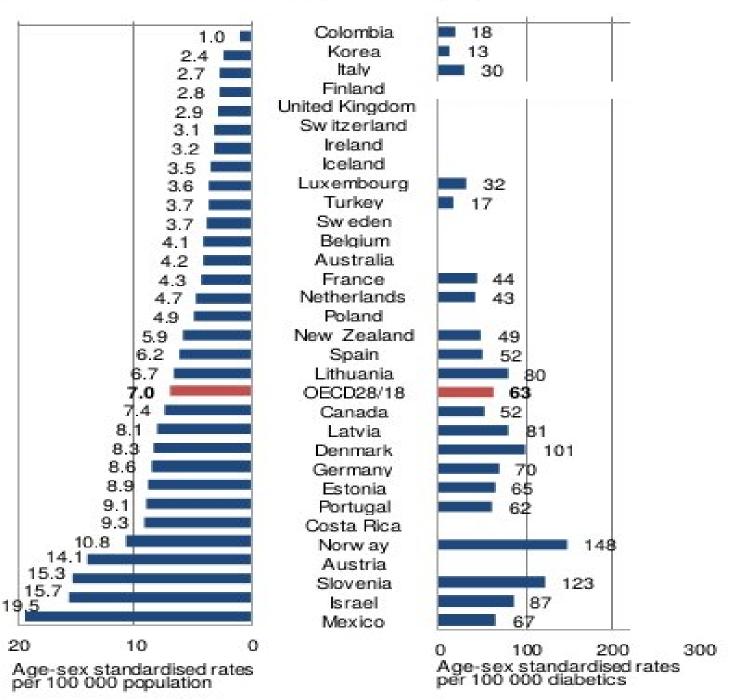
Prescription of hypertensive, Lower extremity amputations in diabetes, 2015

Source: OECD Health at a Glance 2017

6.12 People with diabetes with a prescription of recommended antihypertensive medication in the past year, 2015 (or nearest year)

91.1 Slovenia Portugal 89.7 Australia 89.6 New Zealand 88.7 86.6 Spain 85.8 Canada Ireland 85.8 Denmark 85.5 Sweden 85.4 Estonia 84.0 Turkey 83.0 Norway 82.3 Netherlands. 81.2 OECD17 80.2 79.9 Korea Italy 79.1 Belgium 73.8 Finland 59.4 Slovak Rep. 12.3 20 60 80 100 % of diabetic patients

6.13. Major lower extremity amputation in adults with diabetes, 2015 (or nearest year)



Note: Three-year average for Iceland and Luxembourg.

Source: OECD Health Statistics 2017.

Source: OECD Health Statistics 2017.

EU BIRO and EUBIROD projects

BIRO project (2005-2009) EU DG-SANCO co-funded public health project in diabetes

"to provide European health systems with an ad hoc, evidence and population-based diabetes information system"

EUBIROD project (2008-2012) EU DG-SANCO co-funded public health project in diabetes

"to implement a sustainable European Diabetes Register through the coordination of existing national/regional frameworks and the systematic use of the BIRO system in 20 European countries"

BIRO glossary

System. Federation of networks sharing a common distributed health information infrastructure

Region. A network in the system sharing a homogeneous set of standardized definitions for the collection of health information

Statistical Object. Element of a distributed information system carrying essential data in the form of one or more embedded aggregate components, specifically designed to produce a summary output for a population of interest

Data source. Unit within a region contributing to the system through the transmission of statistical objects to the higher level

Box. Standardized software installed in each data source to generate statistical objects from local data

An inspiring statistical reflection

Complete Sample

Box 3.4.2. Output Logistic Model on all observations

```
The LOGISTIC Procedure
Model Information
Data Set
                           WORK, MODEL
Response Variable
                            HI HBĀ
Number of Response Levels 2
Number of Observations
                          →17102
Model
                            binary logit
Optimization Technique
                            Fisher's scoring
Response Profile
Ordered Value
                 HI_HBA
                           Total Frequency
2
                 0
                           12246
Probability modeled is HI_HBA=1.
Analysis of Maximum Likelihood Estimates
Standard
                                         Chi-
                                                   Pr >
Parameter
                    Estimate Error
                                                   ChiSq
                                         Square
                    -0.6862
                              0.1028
                                        44.5243
                                                   <.0001
Intercept
GENDĖR.
                              0.0343
                    -0.2297
                                                   <.0001
CL AGE2
                     0.0916
                              0.1092
                                                   0.4019
                                        0.7027
CL<sup>T</sup>AGE3
                    -0.1465
                              0.1040
                                                   0.1589
                                        1.9842
CL_AGE4
                    -0.2491
                              0.1086
                                         5.2637
                                                   0.0218
```

Box 3.4.3. Output Logistic Model on aggregate data

	_			~~ ~	
The LOGISTI Model Inform	Set WORK.IN_SEDIS conse Variable HI_HBA ber of Response Levels 2 ber of Observations 16 ht Variable COUNT of Weights 17102 el binary logit nization Technique Fisher's scoring conse Profile sed Value HI_HBA Total Weight Total Frequency 1 8 4856.000 0 8 12246.000 ability modeled is HI_HBA=1. vsis of Maximum Likelihood Estimates dard Wald Chi Pr > meter DF Estimate Error Square ChiSq cept 1 -0.6862 0.1028 44.5243 < 0001				
Number of Re Number of O Weight Varia Sum of Weig Model	esponse bservation ble hts	ons	HI_HBA 2 16 COUNT 17102 binary logit		
Response Pr	of ile				
Ordered Valu 1 2	1 -	HBA	8	4858	3. 000
Probability m	odeled k	s HI_HB/	4=1 .		
Analysis of M	ponse Variable HI_HBA nber of Response Levels 2 nber of Observations 16 pht Variable COUNT nof Weights 17102 el binary logit mization Technique Fisher's scoring ponse Profile ered Value HI_HBA Total Weight Total Frequency 1 8 4856.000 0 8 12246.000 Dability modeled is HI_HBA=1. lysis of Maximum Likelihood Estimates Idard Wald Chi Pr > Imater DF Estimate Error Square ChiSq IDER 1 0.2297 0.0343 44.7555 <.0001 AGE2 1 0.0916 0.1092 0.7027 0.4019 AGE3 1 -0.1465 0.1040 1.9842 0.1589				
		Estimat	е Еггог		
Intercept GENDER CL_AGE2 CL_AGE3 CL_AGE4	1	0.2297 0.0916 -0.1465	0.0343 0.1092 0.1040	44.7555 0.7027 1.9842	5 <.0001 0.4019 0.1589

Combinations of Levels of Covariates

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

Centre	Den.	Num.	%Observed	% Expected	95% Lower	95% Upper	
1 2 3 4 5	7699 236 0 3 4 22 1239 2382	2189 1 000 916 222 529	28.4 42.4 26.8 17.9 22.2	28.5 28. 0 28.4 28.3 28.4	27.5 26.1 26.9 25.8 26.6	29.5 29.8 29.9 3 0 .8 3 0 .2	

Privacy by design

Di Iorio CT et al. Privacy Impact Assessment in the design of transnational public health information systems: the BIRO project, Journal of Medical Ethics, 2009 35: 753-76, http://jme.bmj.com/content/35/12/753

BIRO = Best Information through Regional Outcomes

Designed and implemented to report on quality of care and outcomes in diabetes in Europe

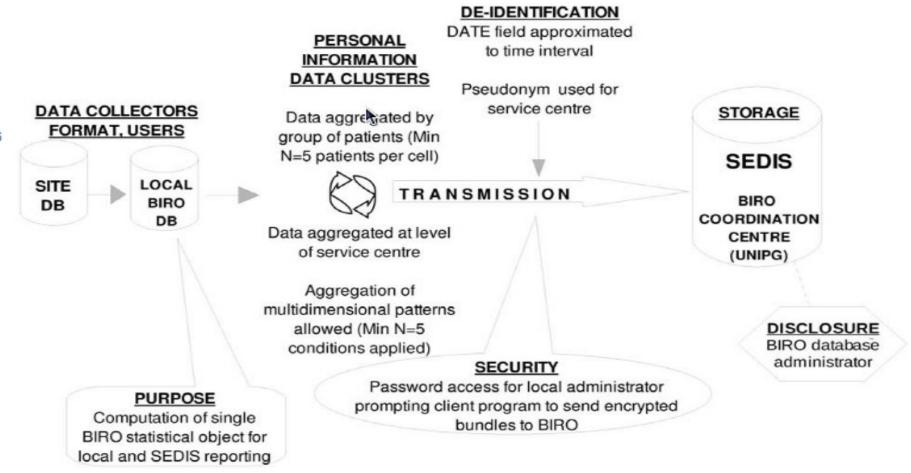
Law, ethics and medicine

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

Result of the BIRO Delphi panel:

best alternative identified to balance privacy protection and information content



EUBIROD Privacy Performance Assessment

DI IORIO CT, CARINCI F et al, European Journal Public Health, 4 May 2012

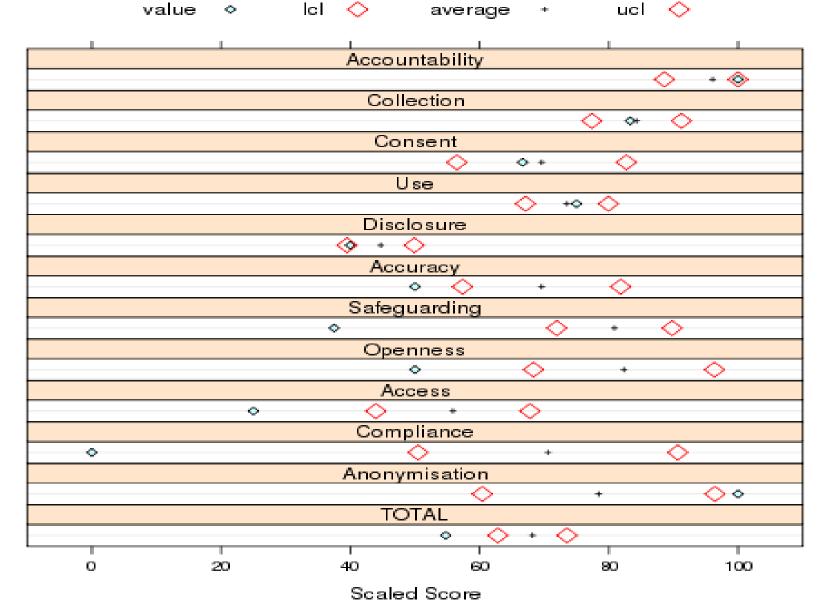
The European Journal of Public Health Advance Access published May 4, 2012

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Cross-border flow of health information: is 'privacy by design's enough? Privacy performance assessment in EUBIROD

Concetta Tania Di Iorio¹, Fabrizio Carinci¹, Massimo Brillante², Joseph Azzopardi³, Peter Beck⁴, Natasa Bratina⁵, Scott G. Cunningham², Carine De Beaufort⁶, Noemi Debacker⁷, Przemyslawa Jarosz-Chobot⁸, Michael Jecht⁹, Ulf Lindblad¹⁰, Tony Moulton¹¹, Želiko Metelko¹², Attila Nagy¹³, George Olympios¹⁴,

Register: Q - Privacy Self Evaluation Chart



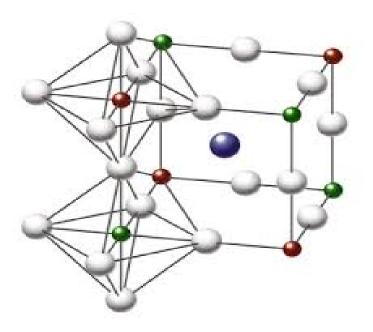
- Each register can compare own practice against the average of the overall sample and the maximum attainable score
- Example:
 - Maximum score in terms of accountability and anonymisation
 - Acceptable levels for collection, consent, use and disclosure
 - All other factors show poor privacy performance

Core Standards of the EUBIROD Project*

Defining a European Diabetes Data Dictionary for Clinical Audit and Healthcare Delivery

S. G. Cunningham¹; F. Carinci^{2,3}; M. Brillante¹; G. P. Leese¹; R. R. McAlpine¹; J. Azzopardi⁴; P. Beck⁵; N. Bratina⁶; V. Boucquet⁷; K. Doggen⁸; P. K. Jarosz-Chobot⁹; M. Jecht¹⁰; U. Lindblad¹¹; T. Moulton¹²; Ž. Metelko¹³; A. Nagy¹⁴; G. Olympios¹⁵; S. Pruna¹⁶; S. Skeie¹⁷; F. Storms¹⁸; C. T. Di Iorio¹⁹; M. Massi Benedetti²

¹University of Dundee, Scotland; ²Hub for International Health Research, Italy; ³University of Surrey, United Kingdom; ⁴University of Malta, Malta; ⁵Joanneum Research, Austria; ⁶University Children's Hospital Ljubljana, Slovenia; ⁷Centre Hospitalier de Luxembourg, Luxembourg; ⁸Scientific Institute of Public Health, Belgium; ⁹Medical University of Silesia, Poland; ¹⁰Havelhöhe Hospital, Germany; ¹¹Department of Primary Care, University of Gothenburg, Sweden; ¹²Adelaide and Meath Hospital, Ireland; ¹³Vuk Vrhovac University Clinic for Diabetes, Croatia; ¹⁴University of Debrecen, Hungary; ¹⁵Ministry of Health, Cyprus; ¹⁶Telemedica Consulting, Romania; ¹⁷NOKLUS, Norway; ¹⁸Dutch Institute for Healthcare Improvement (CBO), The Netherlands; ¹⁹Serectrix snc, Italy

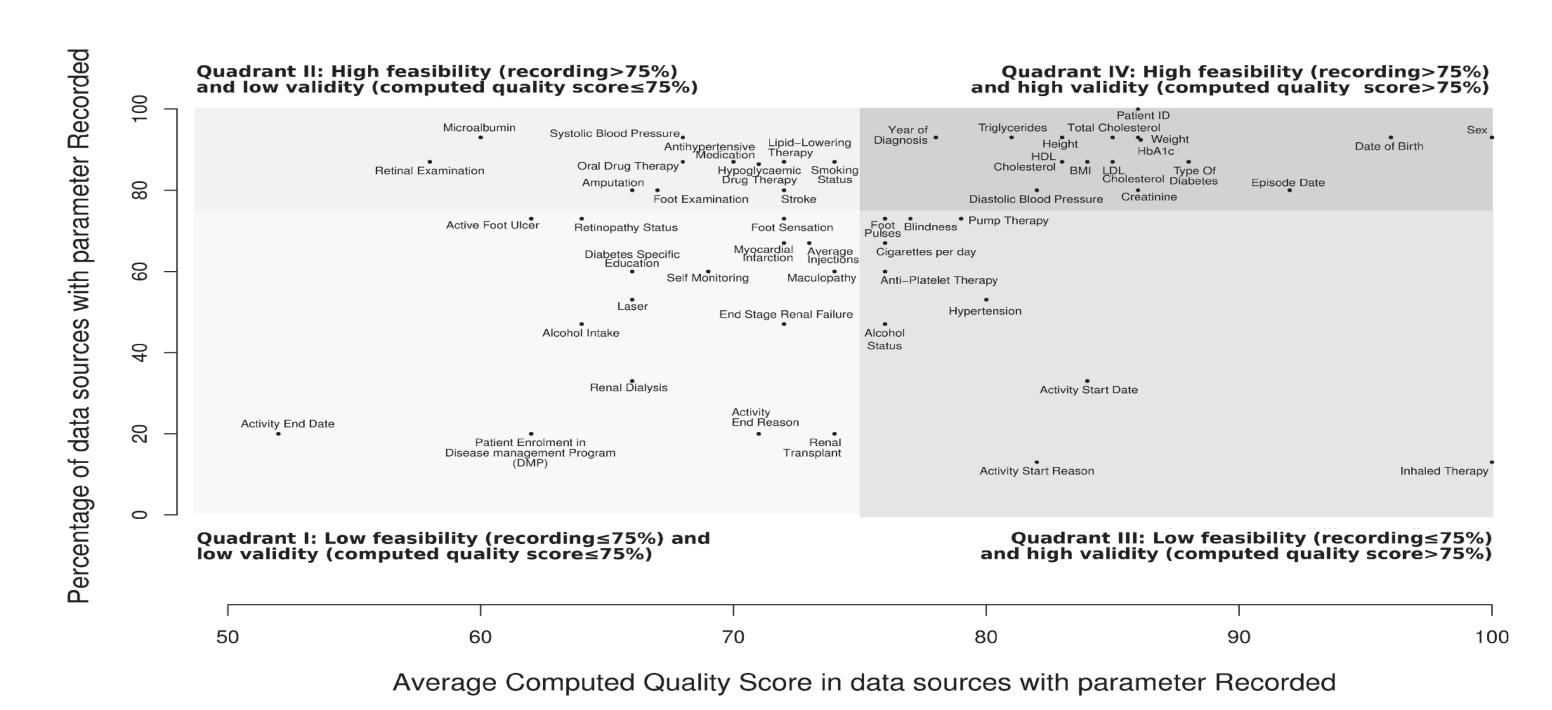


1 DEMOGRAPHIC CHARACTERISTICS	1.1 Basic demographics					
	2.1 Diabetes status					
	2.2	2.2.1 Obesity and Growth (most recent value in the last 12 months)				
2 CLINICAL CHARACTERISTICS	Risk factors for diabetes complicat ons	2.2.2 Lifestyle				
	complicat ons	2.2.3 Clinical measurements (most recent value in the last 12 months)				
		2.3 Diabetes complicat ons				
		3.1 Structure (provider level)				
		3.2 Structural quality				
3		3.3.1 Foot examinat on 3.3.2				
HEALTH SYSTEM		Eye examinat on 3.3.3				
	3.3 Processes	Measurement done (in the last 12 months)				
	110003503	3.3.4 Treatment (at least one prescript on in the last 12 months)				
		3.3.5 Management				
4 POPULATION		4.1 Area level				
	5.1 Epidemiology					
5 RISK	(in ad	5.2 Process quality (in adults with diabetes in the last 12 months)				
ADJUSTED INDICATORS	5.3 Outcome Quality: Intermediate outcomes (in adults with diabetes in the last 12 months)					
		5.4 utcome Quality: Terminal outcomes (in the last 12 months)				

Core Standards of the EUBIROD Project*

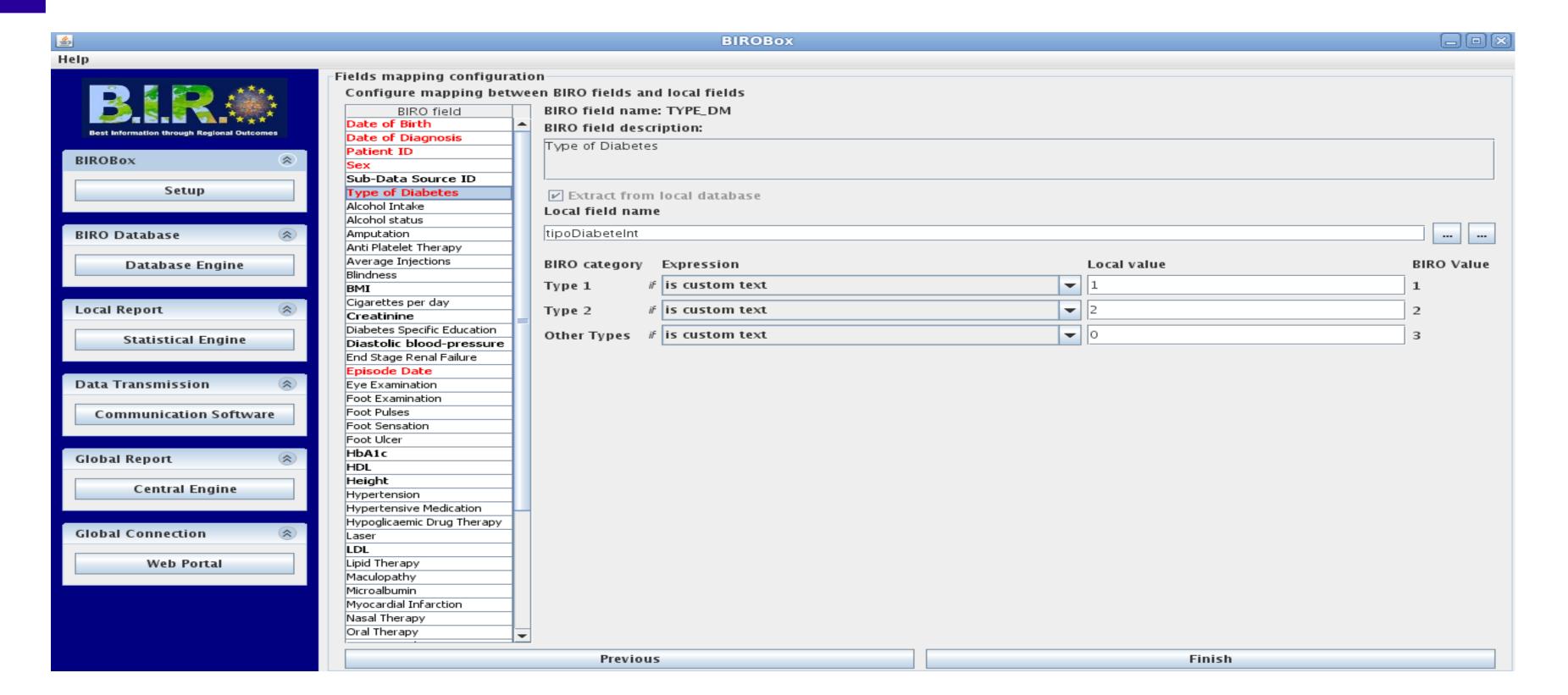
Defining a European Diabetes Data Dictionary for Clinical Audit and Healthcare Delivery

S. G. Cunningham¹; F. Carinci^{2,3}; M. Brillante¹; G. P. Leese1; R. R. McAlpine1; J. Azzopardi⁴; P. Beck⁵; N. Bratina⁶; V. Boucquet⁷; K. Doggen⁸; P. K. Jarosz-Chobot⁹; M. Jecht¹⁰; U. Lindblad¹¹; T. Moulton¹²; Ž. Metelko¹³; A. Nagy¹⁴; G. Olympios¹⁵; S. Pruna¹⁶; S. Skeie¹⁷; F. Storms¹⁸; C. T. Di Iorio¹⁹; M. Massi Benedetti²



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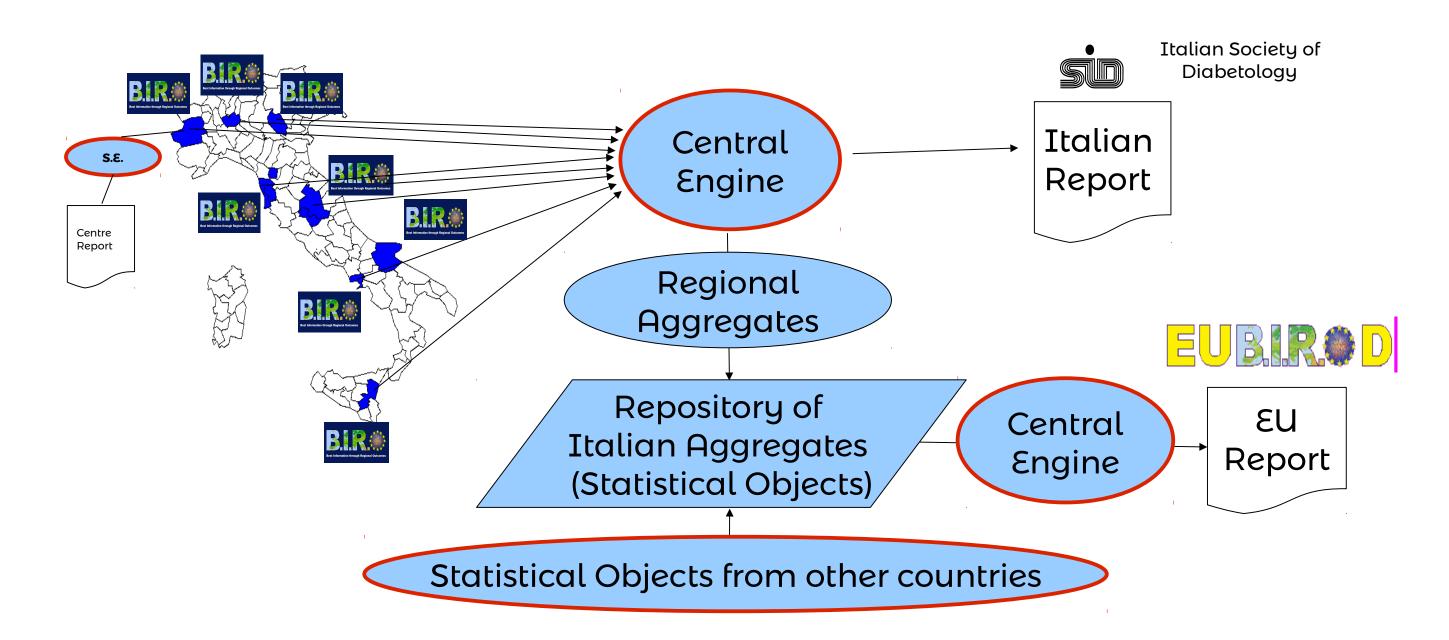
BIRO local "mapping"



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Applying BIRO in the EUBIROD project: National decentralised automated reporting

ITALY: BIRO installed in N=8 centres; S.E.=Statistical Engine
DATABASES OF INDIVIDUAL RECORDS STAY WITH THE ORIGINAL DATA CUSTODIAN



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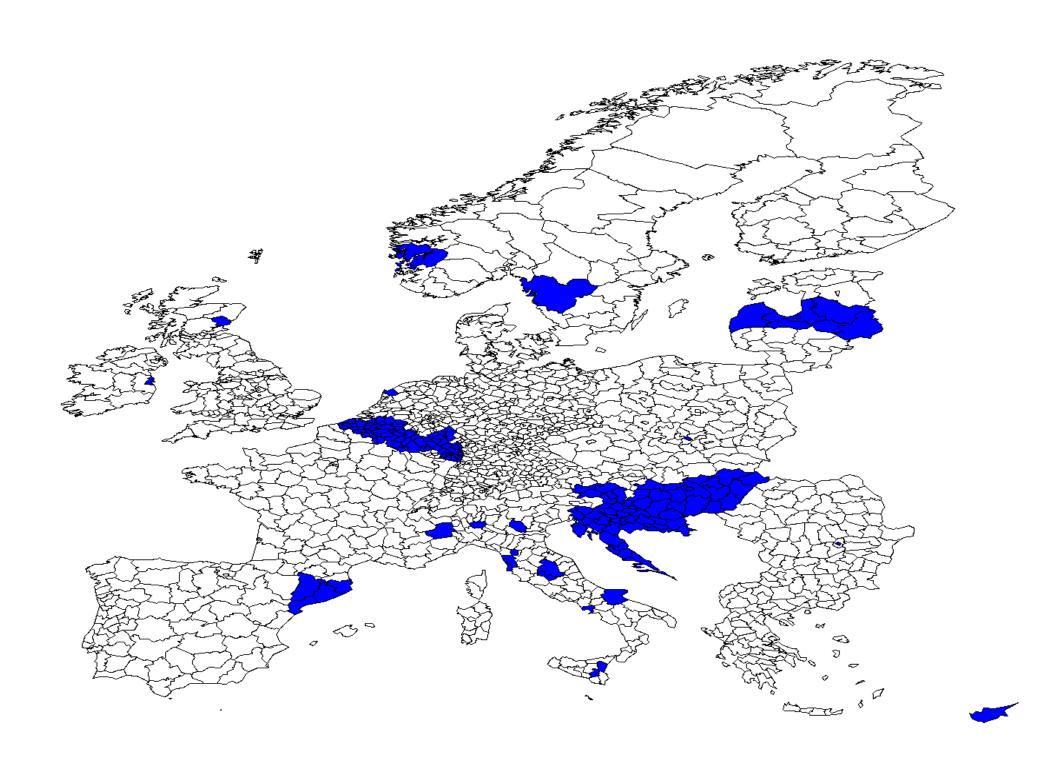
EUBIROD Report (2012)

8/2/2012: New BIRO Release 2.1.12

15/2/2012: Collection of statistical objects closed

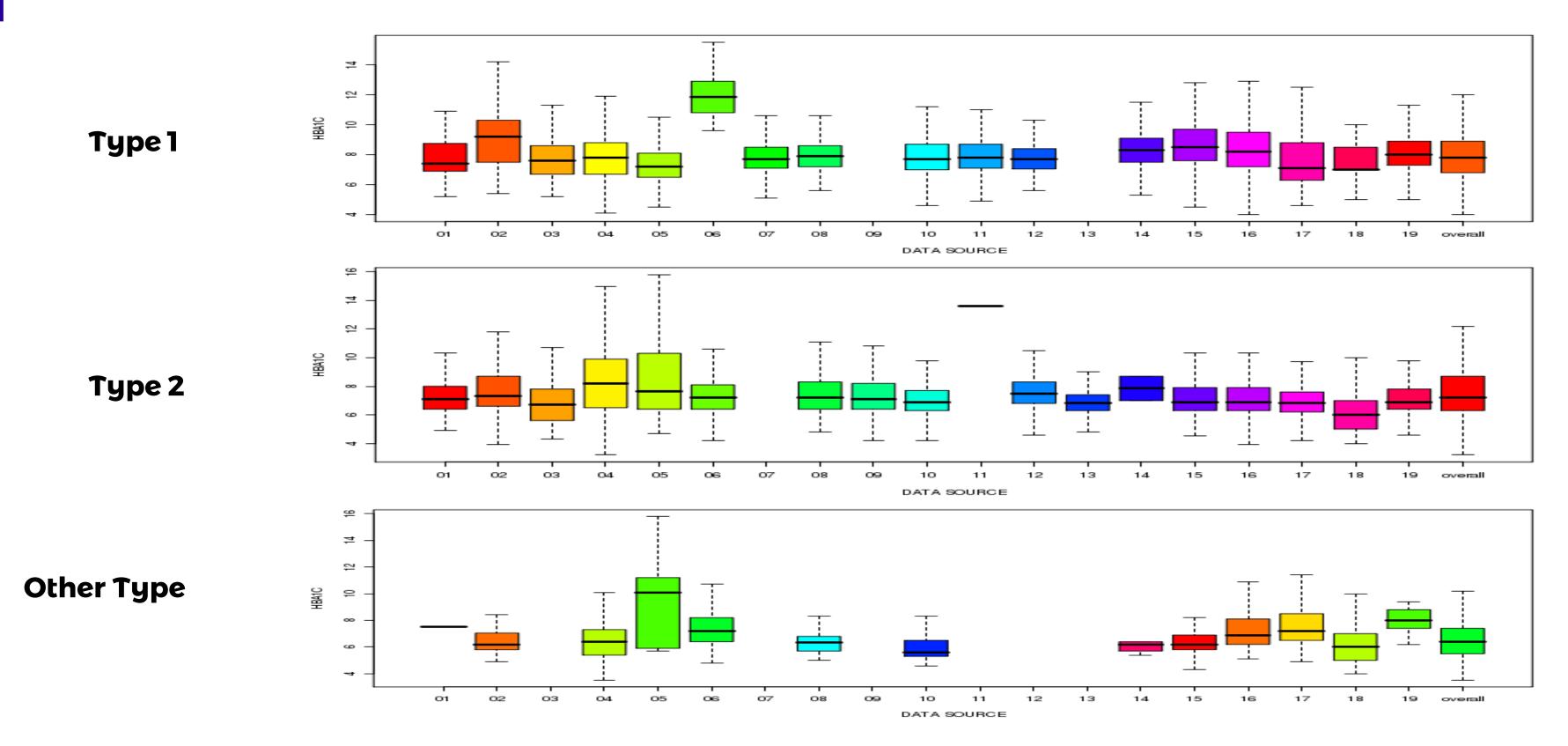
21/2/2012: EU Draft Report internally available (N=79 indicators)

13 Days from Software Release to Online Publication of the results!



Glycated Haemoglobin (HbA1c)

N=168,948
EUBIROD Diabetes Report 2010



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Bridge Health

www.bridge-health.eu

- Large project on Health Information in Europe (2015-2017). Consortium and workpackages based on existing networks. Coordinator: Institute of Public Health Belgium
- Task 8.2:
 - Main aim: 'to maintain and strengthen the implementation of population based registries for chronic diseases through the standardization of methodologies for producing standardized EU-wide indicators, taking selected clinical conditions as test cases for a new 'platform for population based registries'.
 - Specific objective: the provision of privacy-enhanced open source software for statistical analysis, data exchange, and automated calculation of indicators, locally and at EU level, based on the BIRO experience.

Definitions of the EU Joint Action PARENT on "Patient Registries"

A patient registry is ",... an organized system that collects, analyses, and disseminates the data and information on a group of people defined by a particular disease, condition, exposure, or health-related service, and that serves a predetermined scientific, clinical or/and public health (policy) purposes"

Disease or condition registries ",...are defined by patients having the same diagnosis, such as cystic fibrosis or heart failure, or the same group of conditions such as disability."

A Population Registry "... is a registry that intends to cover all residents in a given geographic area within a given time period. The coverage of the specific registry may, however, be incomplete, but it is nevertheless a population registry if the aim is to include all the individuals in the target population. A population is defined by geographical boundaries, but usually only residents (or citizens) within a given time period are included in the definition.".

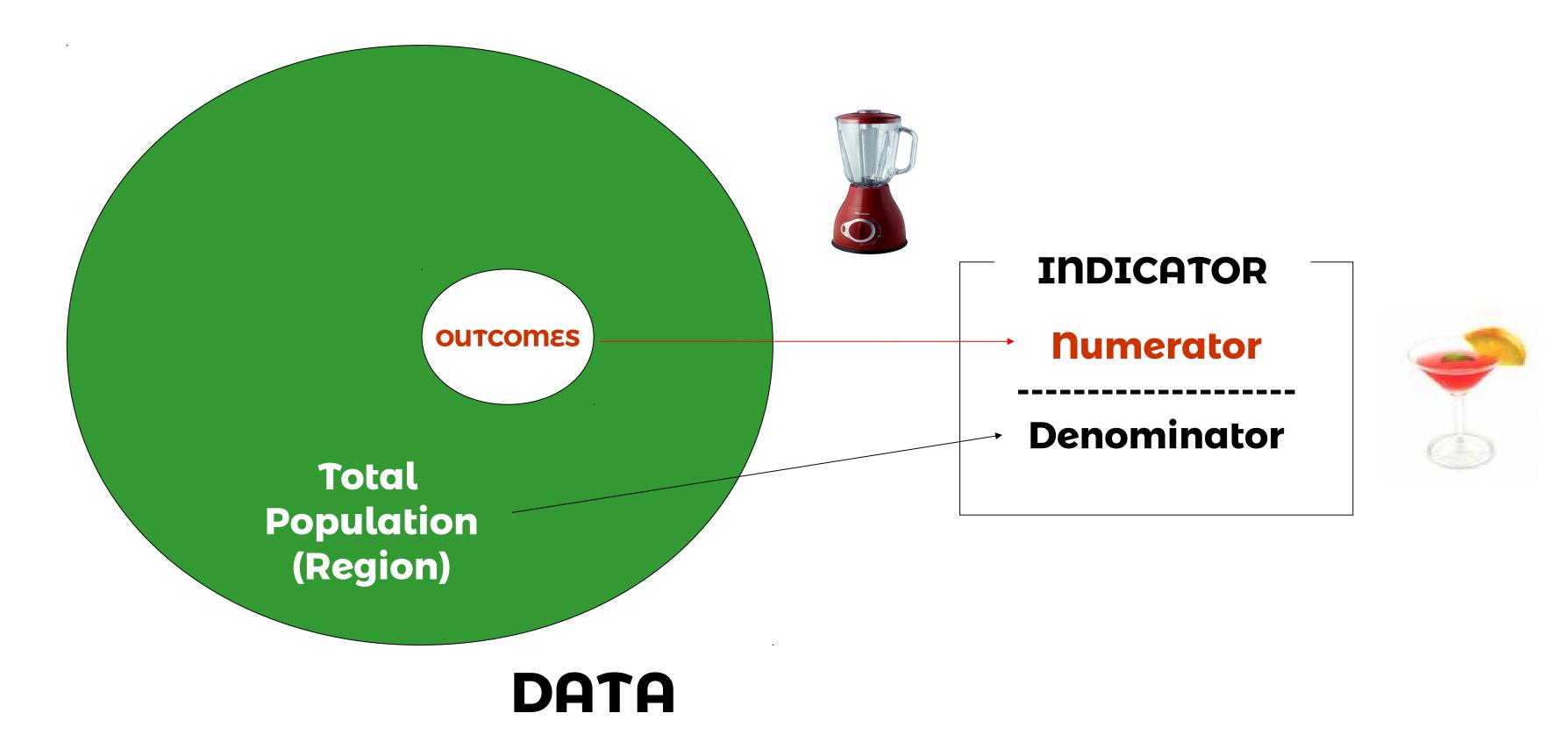
Definitions of the EU Joint Action PARENT on "Patient Registries"

A Population-based registry should be used "...when all persons with a given trait, exposure or event, are intended to be included in the registry. If the registry includes everyone in the population (even the oldest), it becomes a population registry. Intention rather than performance defines the terms. A population-based disease registry aims at including everyone with the disease in the population, be it self-reported, clinically diagnosed or detected at screening. Population and population-based registries may be further classified as of good or bad quality depending on coverage or other characteristics".

Why do we need a population-based disease register?

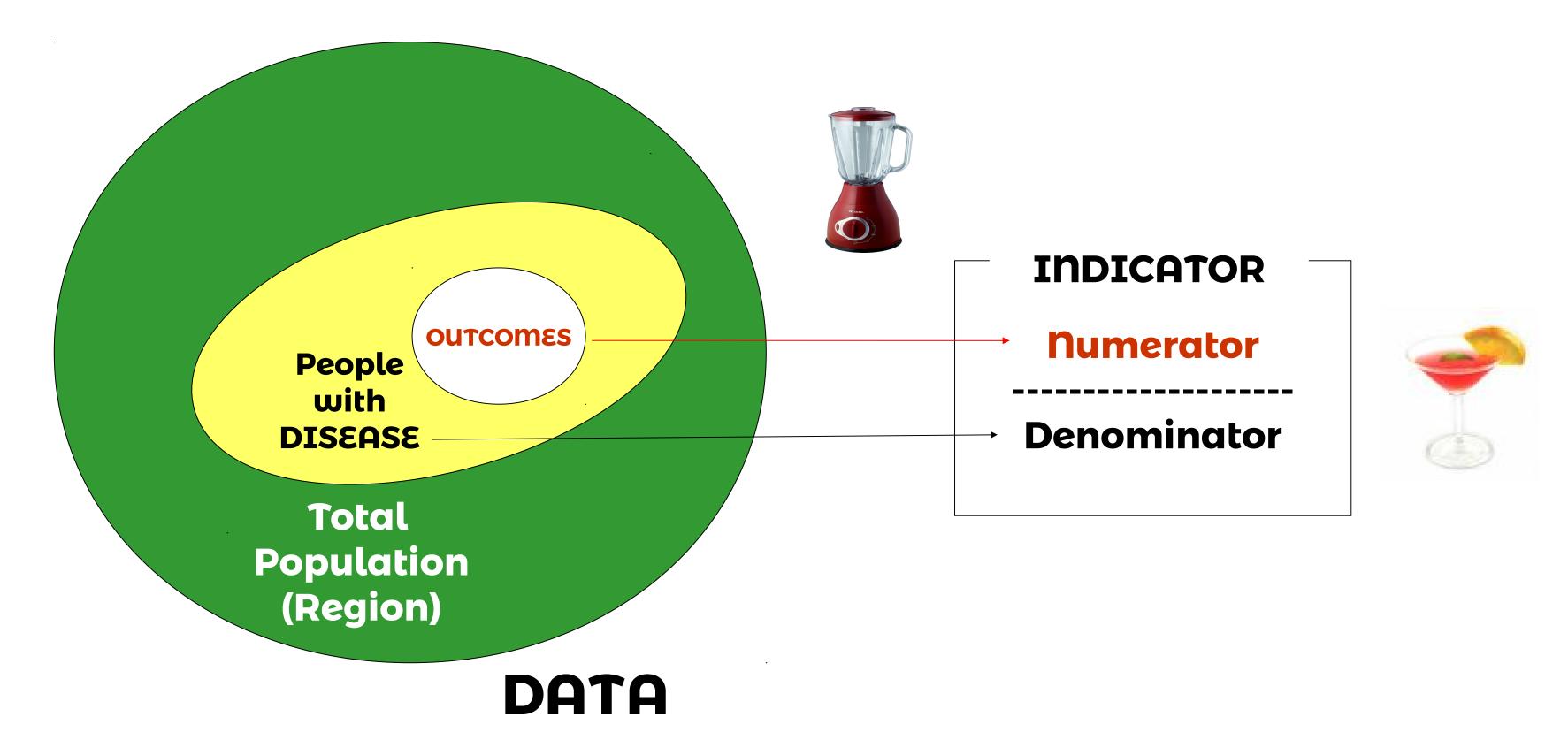


THIS IS A POPULATION-BASED REGISTER

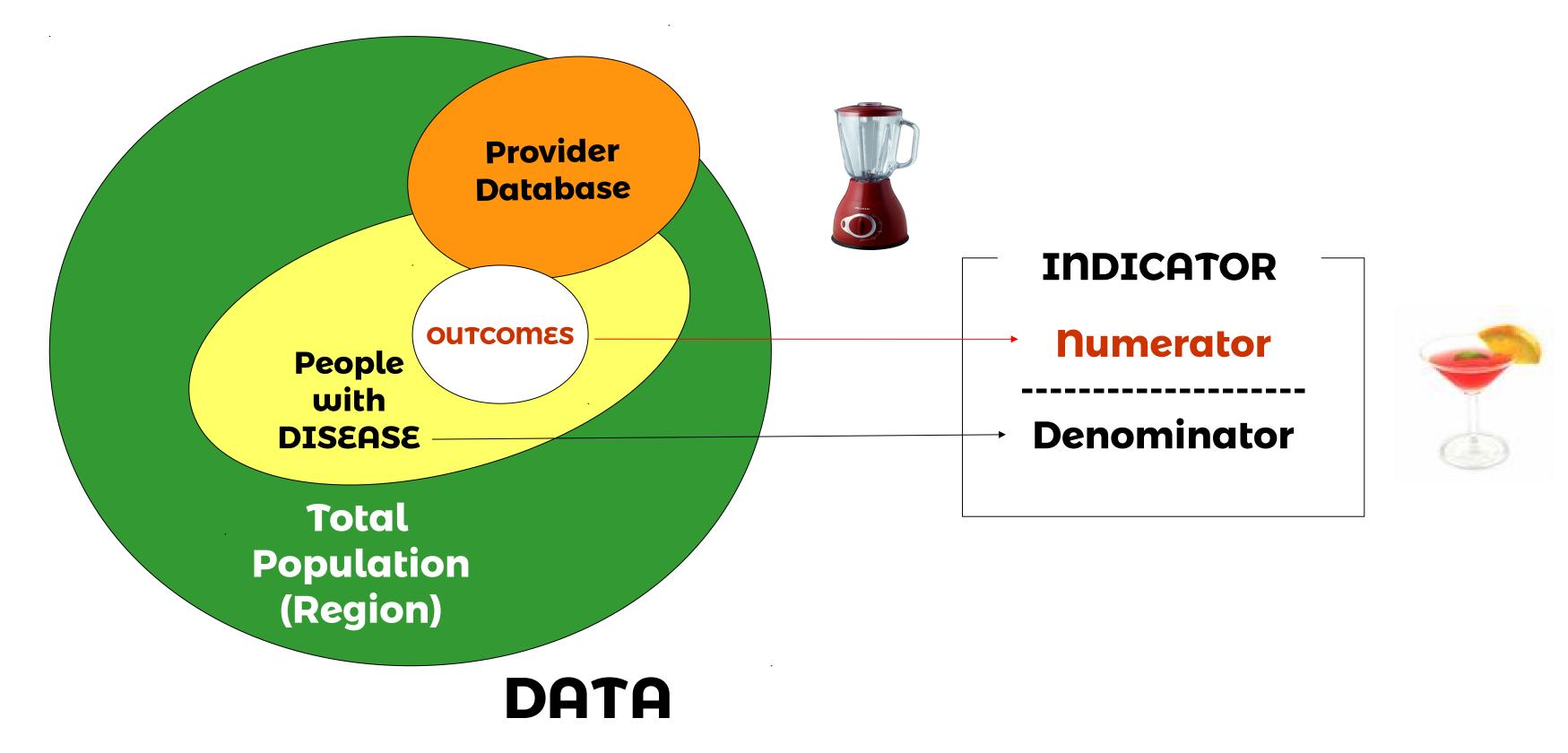


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THIS IS POPULATION-BASED DISEASE REGISTER

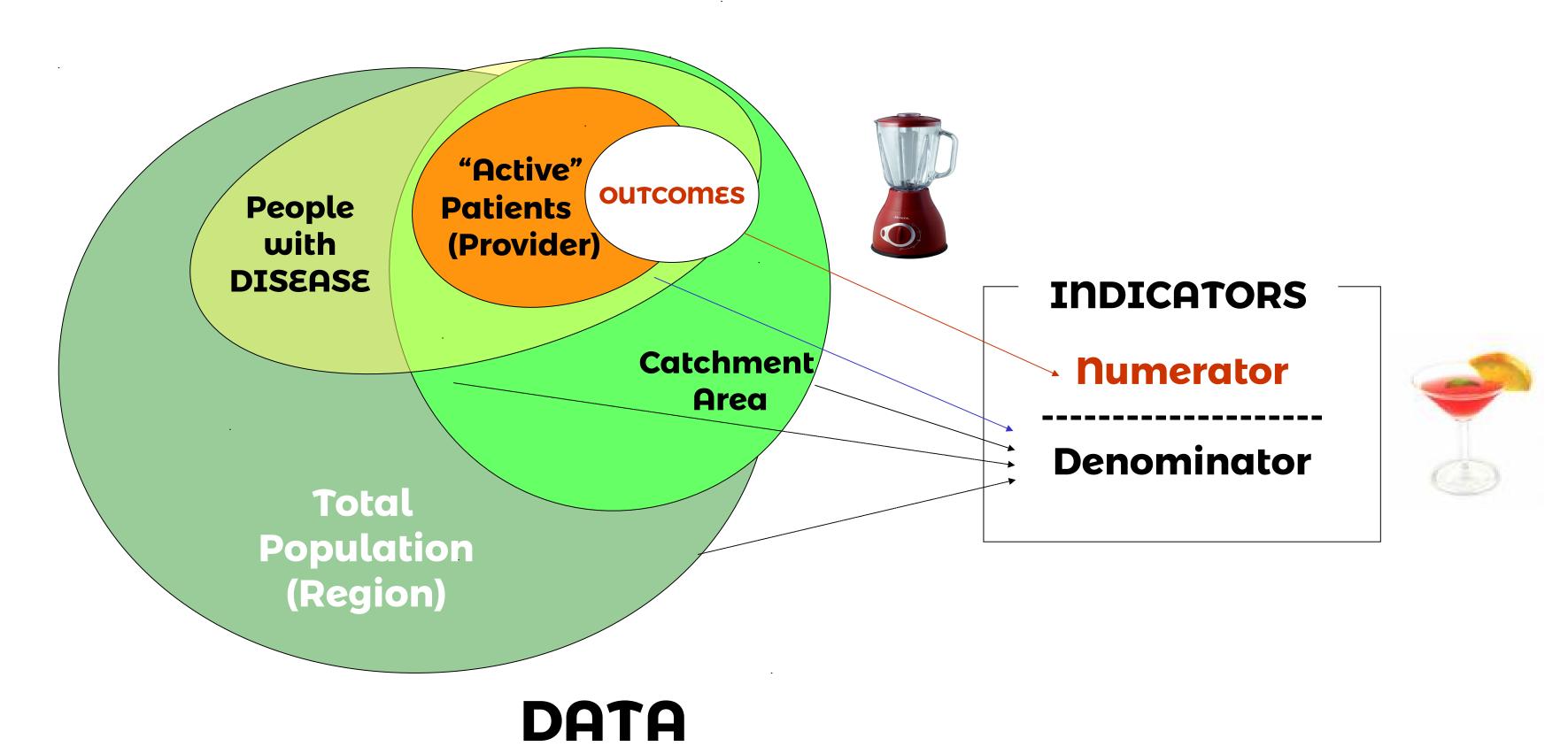


THIS IS A POPULATION-BASED DISEASE REGISTER LINKED TO A PROVIDER DATA SOURCE



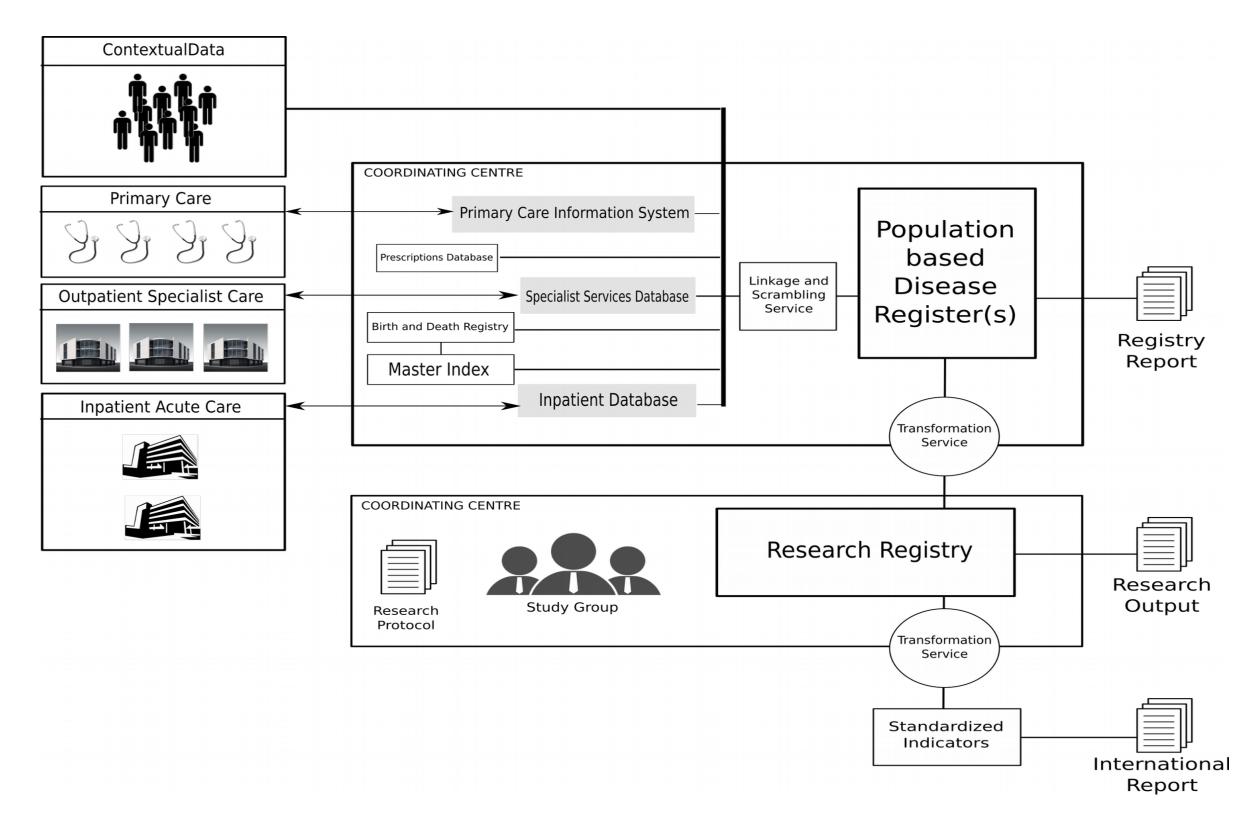
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PROVIDER-BASED DISEASE REGISTER



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Structure of population-based disease register



T8.2 Action 1. Survey of diabetes data sources in Europe

Instrument: Questionnaire including structured items on: Description; Scope of information; Governance; Technical Infrastructure; Outputs.

Data collection system: REDCap open source research server,

hosted in Slovenia

Timeframe: August-September 2017

Preliminary Taxonomy

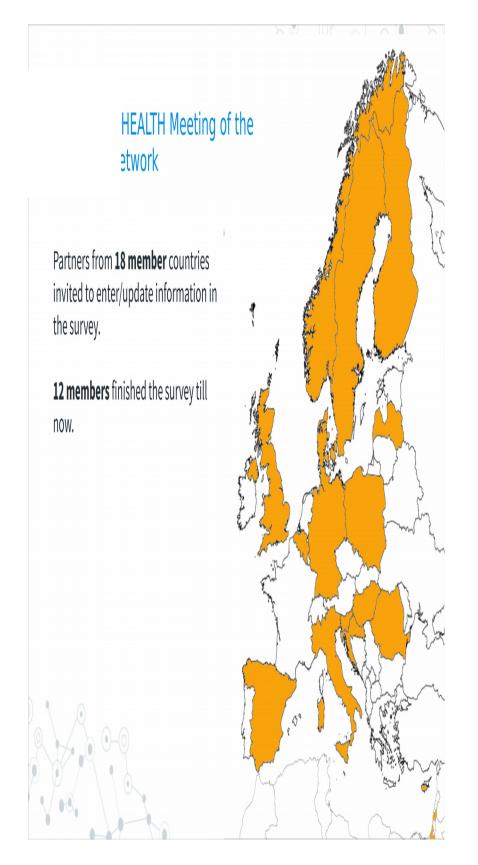
A. Population-based Registers. Croatia, Sweden, UK-Scotland

B. National Audits and surveillance systems. Belgium,

Germany, UK-England

C. National databases for quality indicators. Israel, Latvia

D. Different types and levels of data sources. Cyprus, Hungary, Israel, Italy, Malta, Poland, Romania, Slovenia



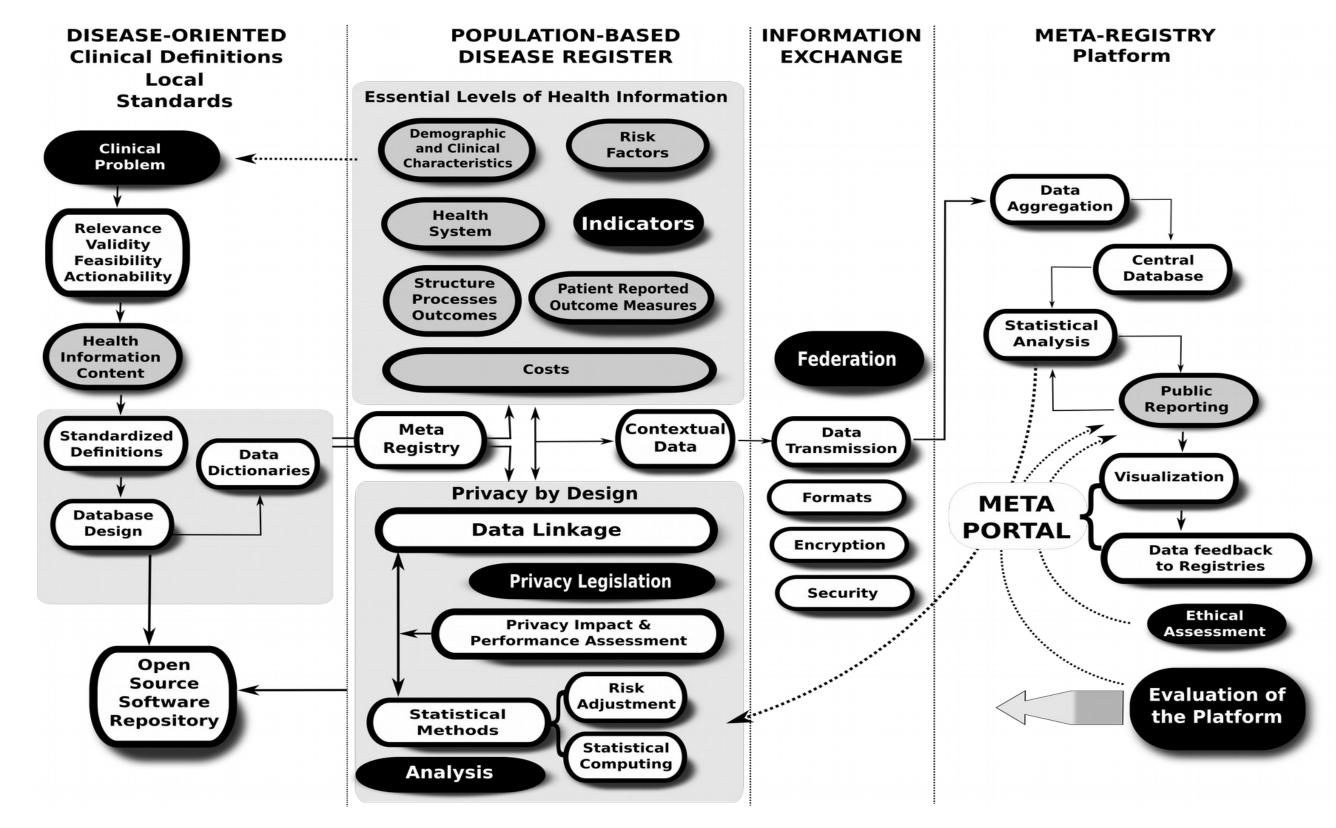
T8.2 Action 2. Generalisation of the BIRO approach

- Review your problem: construct an evidence-based framework
 - Describe the data structure of your network
 - Agree on reporting targets: specify report templates
 - Conduct a Privacy Impact Assessment
 - Identify the best information system architecture
 - Specify your data dictionary
 - Design and implement all software
 - **3** Analyse data and disseminate results
 - Transfer technology
 - Evaluate, improve and update

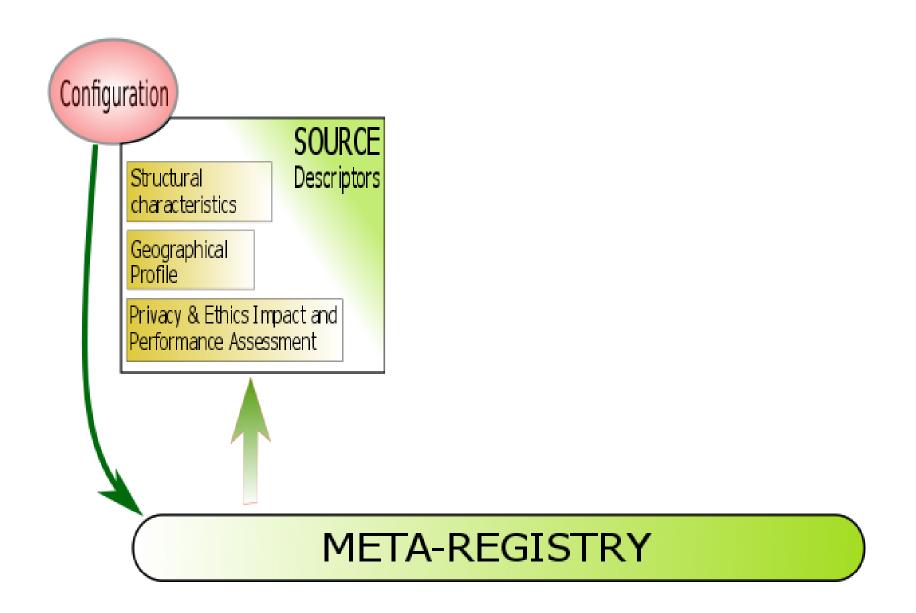
31

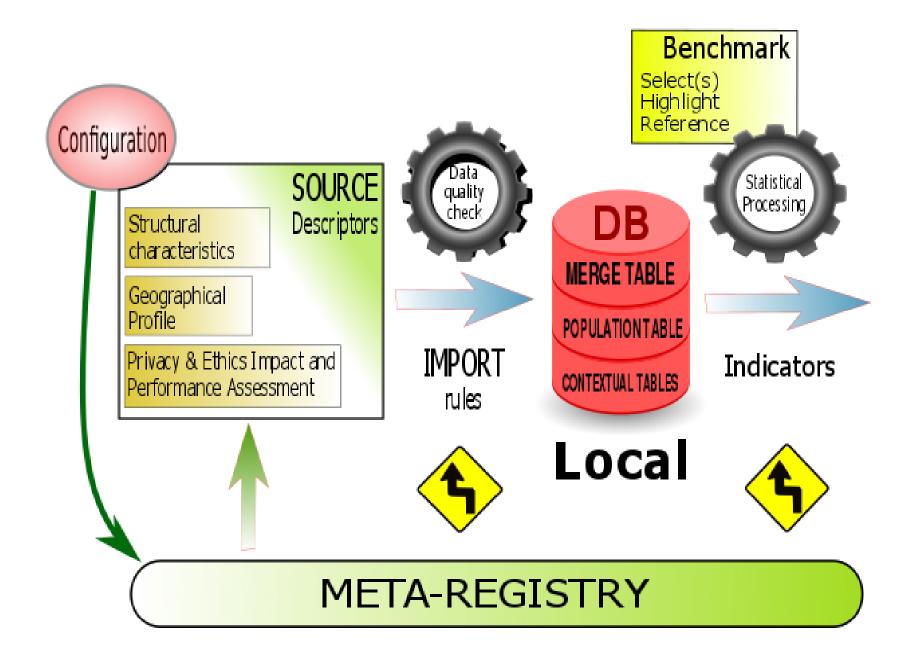
Essential levels of health information for chronic diseases

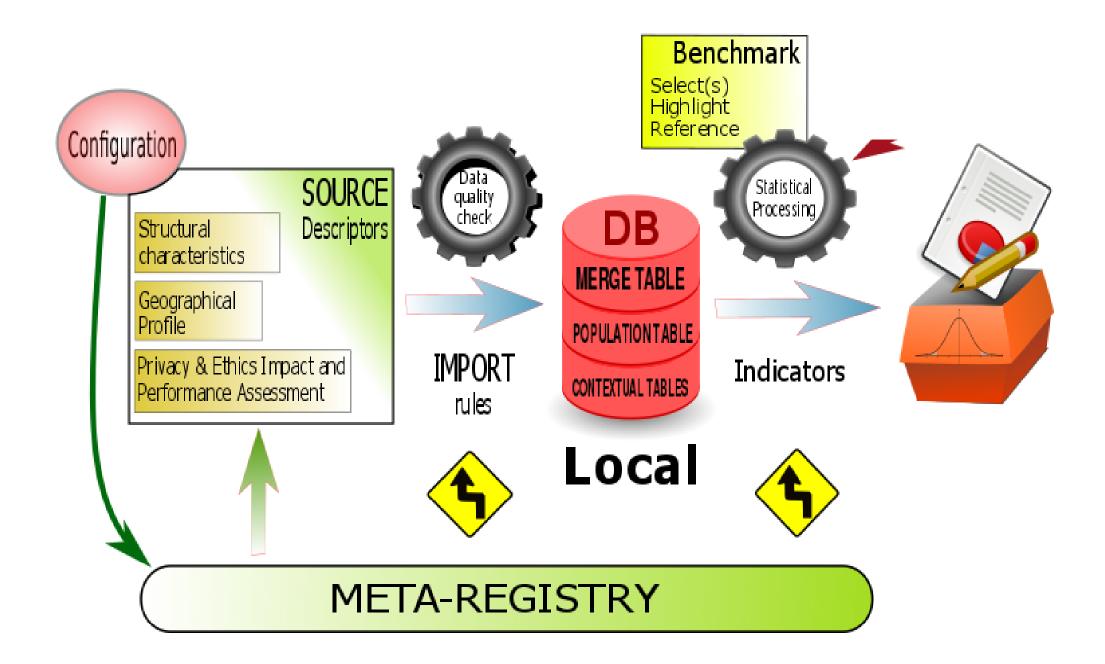
ADAPTED FROM: Carinci F, Essential levels of health information in Europe: an action plan for a coherent and sustainable infrastructure, Health Policy, 2015 Apr;119(4):530-8. Nov 28.

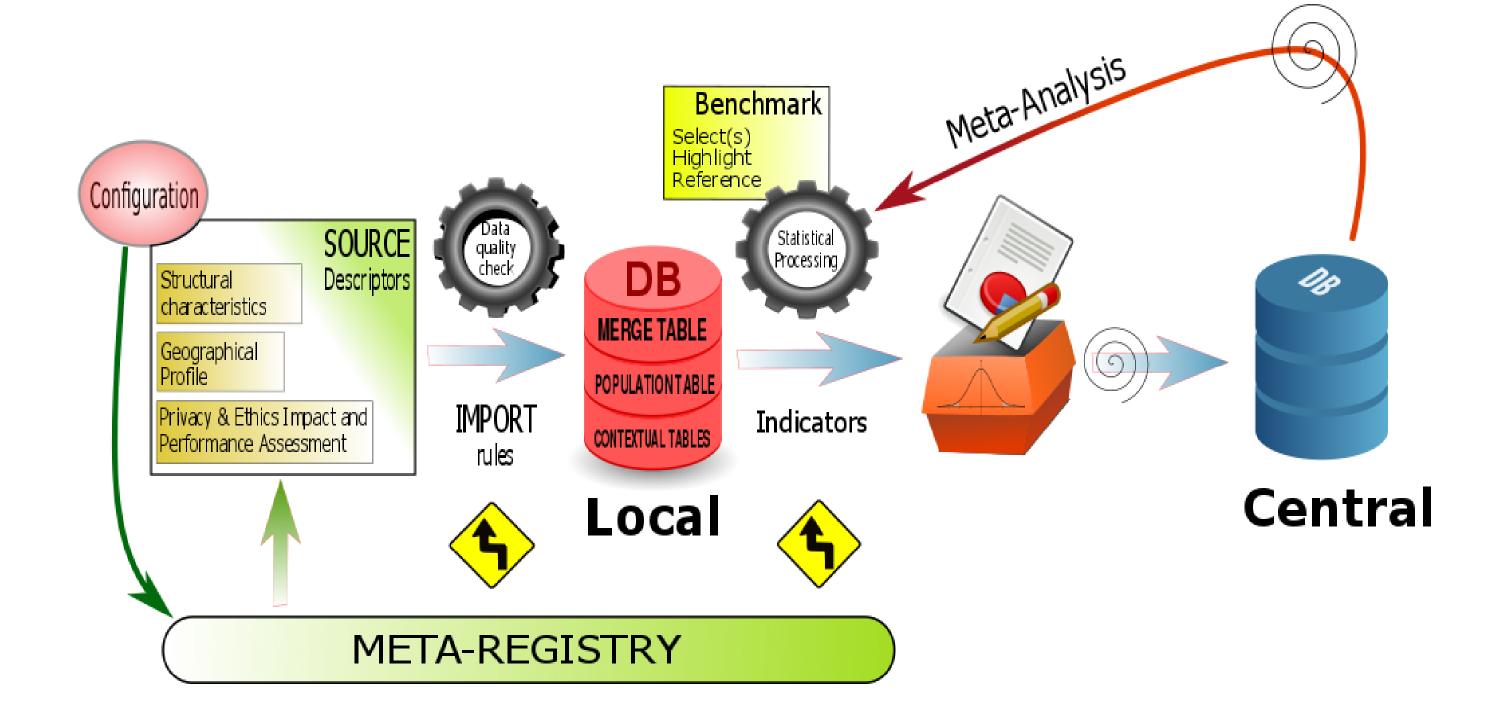


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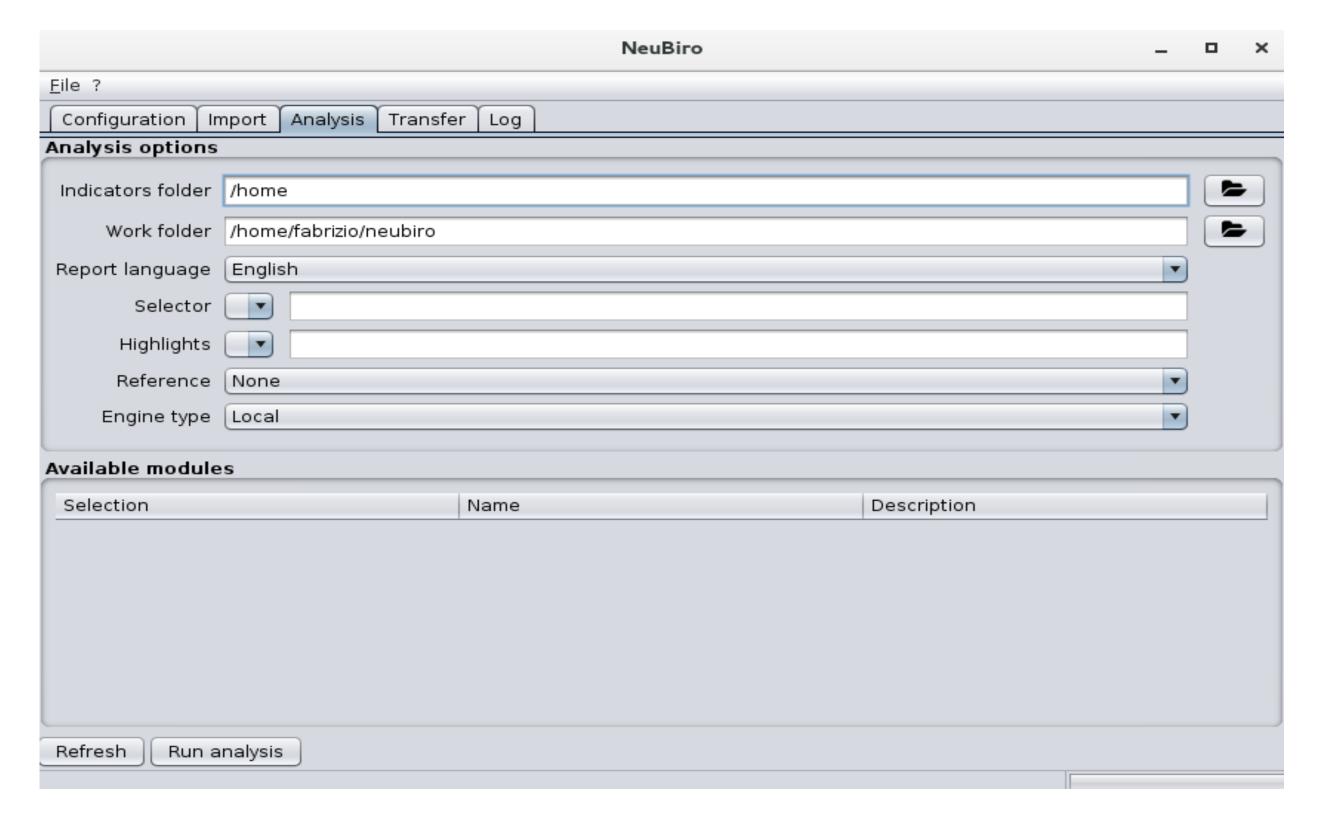






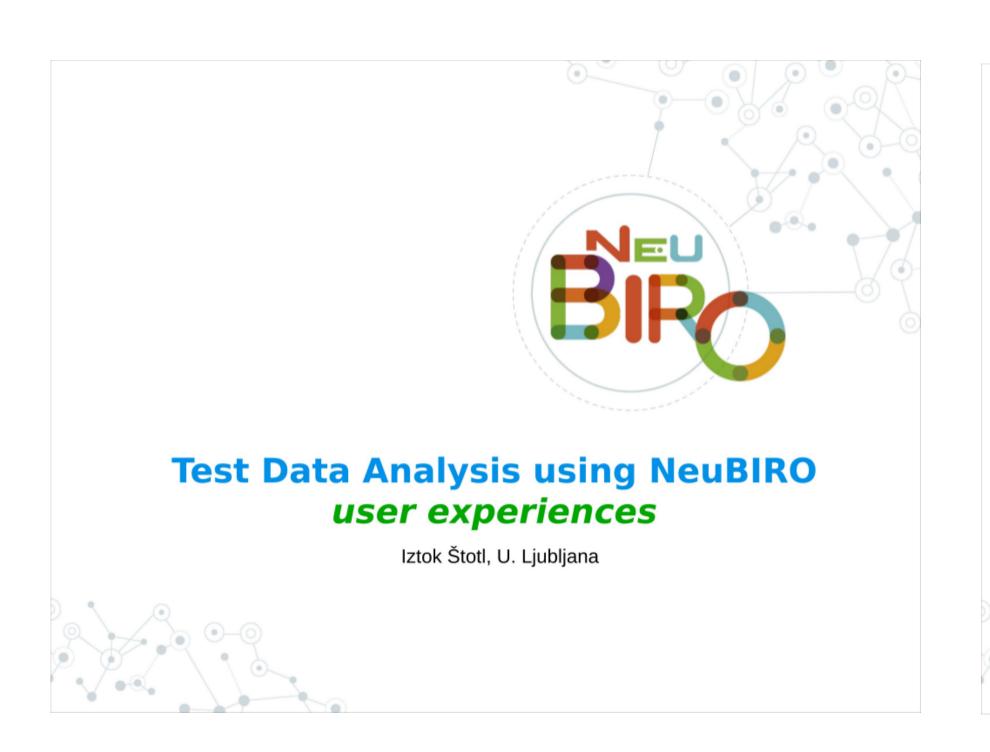
T8.2 Action 3. Software Development: NeuBIRO

https://github.com/eubirodnetwork/neubiro



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T8.2 Action 4. Road test (5 countries)





User experiences

Analysis of local sample

- 1,146 patients, 2,564 events
- Ouration of setup and analysis on old laptop:
 - ... less than 4 minutes ...

2.1.1 Type of Diabetes by Age

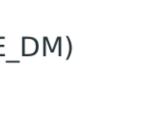
| Type of Diabetes | Age | | | | | | | | | | | | | |
|------------------|-----|-----|-------|------|-------|------|-------|------|-------|------|-----|------|-------|-------|
| | <15 | 5 | [15-4 | 5) | [45-5 | 5) | [55,6 | 5) | [65-7 | 5) | >=7 | 5 | | |
| | N | % | N | % | N | c/o | N | % | N | o/o | N | c/o | N | c/o |
| Type 1 | 0 | - | 114 | 74.0 | 48 | 33.3 | 21 | 7.2 | 9 | 3.0 | 1 | 0.5 | 193 | 17.5 |
| Type 2 | 0 | - | 31 | 20.1 | 85 | 59.0 | 245 | 83.9 | 269 | 90.9 | 205 | 94.0 | 835 | 75.6 |
| Other | 0 | - | 9 | 5.8 | 11 | 7.6 | 26 | 8.9 | 18 | 6.1 | 12 | 5.5 | 76 | 6.9 |
| TOTAL | 0 | 0.0 | 154 | 14.0 | 144 | 13.0 | 292 | 26.0 | 296 | 27.0 | 218 | 20.0 | 1,104 | 100.0 |

Analysis of local sample

- Simple and fast to:
 - install
 - change to new version
- Simply added/changed:
 - changed default indicators
 - added erase rules (e.g. wrong codes for TYPE_DM)
 - new indicators (e.g. LDL < 1.8)
- Just loved Gitlab version control
 - trasparent changes and communication







User experiences

Importing of new fields

Bariatric surgery import field

```
// BIRO REF: BIRO0XX - Bariatric surgery
    'BARIATRIC' {
    type = "smallint"
    }
```

Creating new indicators

| LDL Cholesterol | N | % |
|-----------------|-------|-------|
| Valid | 344 | 29.6 |
| Missing | 817 | 70.4 |
| TOTAL | 1,161 | 100.0 |

Table 2.2.3.7 LDL Cholesterol by Type of Diabetes

2.2.3.4 LDL Cholesterol by Type of Diabetes

| LDL Cholesterol | Type of
Diabetes
Type | | Туре | 2 | Othe | er | | |
|-----------------|-----------------------------|------|------|------|------|------|-----|-------|
| | N | c/o | N | % | N | % | N | % |
| <1.8 | 11 | 19.3 | 84 | 33.2 | 7 | 33.3 | 104 | 30.2 |
| >=1.8 | 46 | 80.7 | 169 | 66.8 | 14 | 66.7 | 240 | 69.8 |
| TOTAL | 57 | 17.0 | 253 | 74.0 | 21 | 6.0 | 344 | 100.0 |

Table 2.2.3.7 LDL Cholesterol by Type of Diabetes



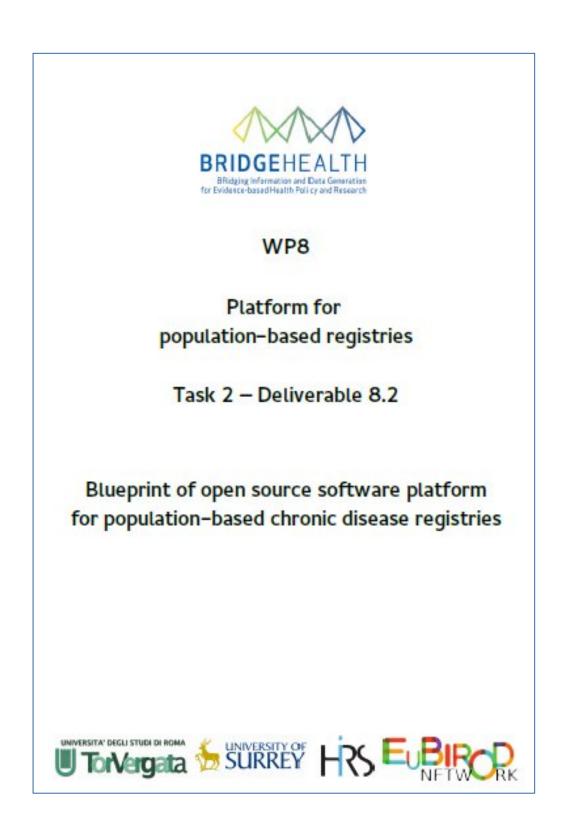
Long lasting implementation for NCDs?

THIS IS UP TO NATIONAL GOVERNMENTS INTERNATIONAL ORGANIZATIONS

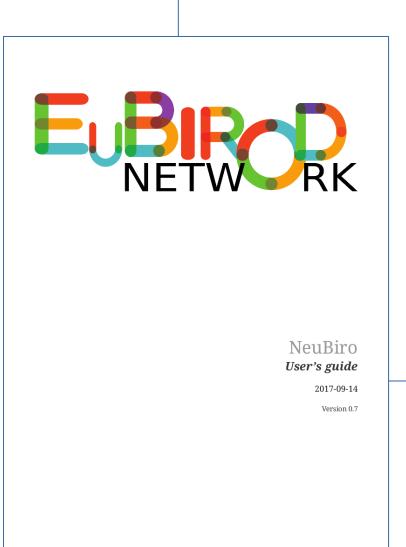
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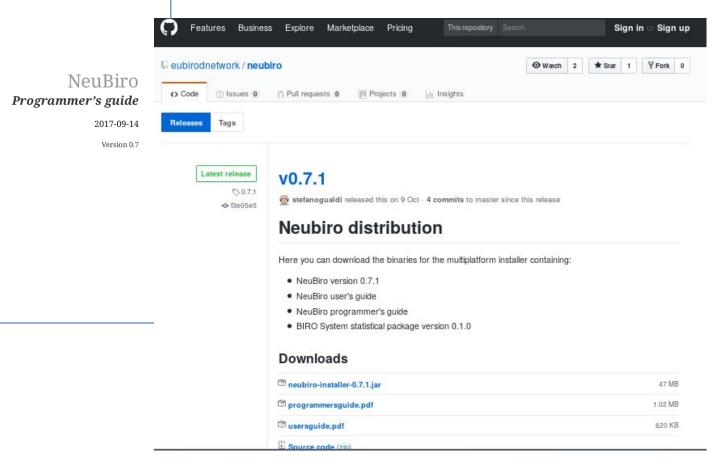
AND RELEVANT ASSOCIATIONS

Bridge Health Task 8.2 Deliverables













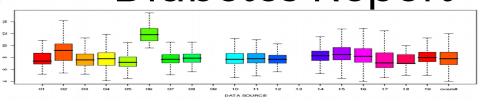
2005-2009

www.eubirod.eu

2012



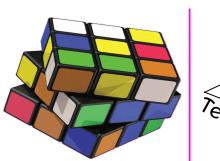
EUBIROD
Diabetes Report

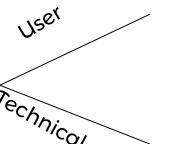




2016











www.bridge-health.eu



http://www.hirs-research.eu/eubirod.html

Joanneum Research, Austria International Diabetes Federation (IDF), Belgium Scientific Institute of Public Health, Belgium National Institute of Public Health, Croatia University of Zagreb, Croatia Ministry of Health, Cyprus Adult National Diabetes Register, Steno Centre, Denmark University of Debrecen, Hungary Ministry of Health, Israel Serectrix, Italy Ministry of Health, Latvia University of Malta, Malta NOKLUS, Norway Silesian University of Technology, Poland Telemedica Consulting, Romania University of Ljubljana, Slovenia IDIBAPS, Spain Foundation for Care Information, The Netherlands University of Dundee, UK University of Surrey, UK

Coordinating Centre



Sharing:

- Information
- Best practices
- Tools
- Methods

Creating Opportunities for:

- Targeted Research Partnerships
- Direct Involvement with EU/International Organizations

Building together:

Global platform for diabetes monitoring