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Implementing Outcomes-based Healthcare

Crowne Plaza Brussels - Le Palace
18th October 2018



The approach to building a disease registry: the EUBIROD Project and the ICHOM Diabetes Standard Set

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Objectives

Overview of outcomes measurement in diabetes and reflections upon the barriers and enablers to building a pan-European diabetes registry

Why do we need health information in Europe?

- To provide broader and faster access to an ever increasing amount of information of critical importance to **researchers working in the public interest**
- To make **policy makers accountable** for the results obtained by the EU legislation and National policies
- To evaluate **adherence to evidence-based guidelines**
- **To set achievable targets** for quality of care and outcomes, taking into account the costs and benefits of different alternatives
- 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

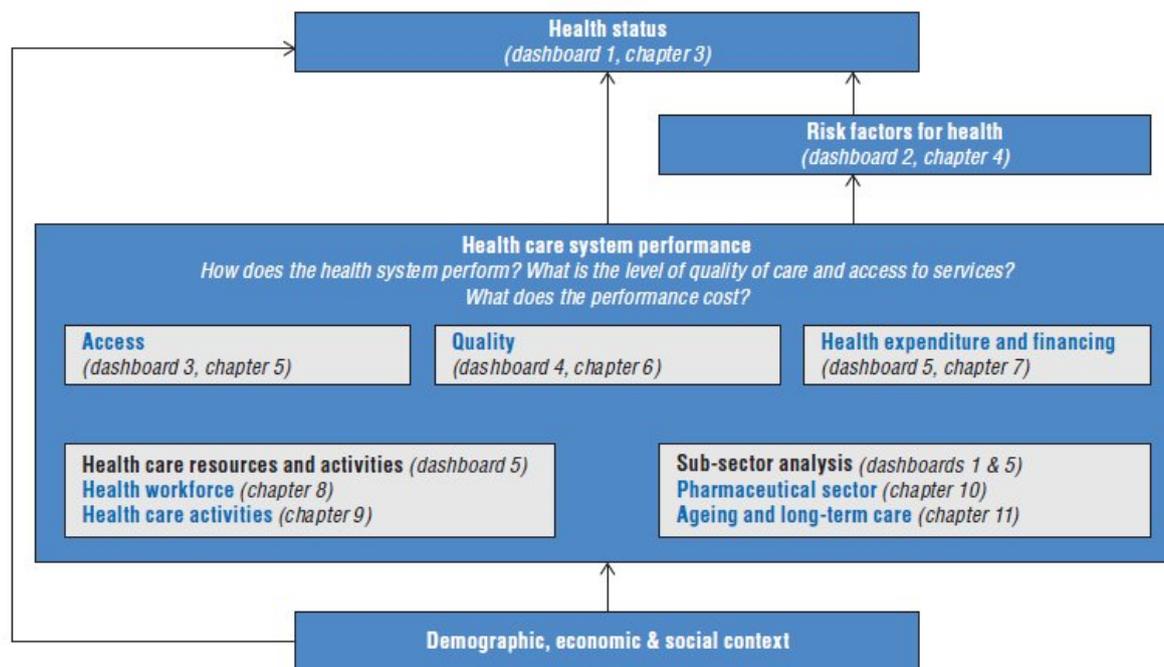
OECD Health at a Glance 2017

http://www.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance-2017_health_glance-2017-en

Policies are assessed using information that is not available on a routine basis !



Conceptual framework for health system performance assessment



Source: Adapted from Carinci, F. et al. (2015), "Towards Actionable International Comparisons of Health System Performance: Expert Revision of the OECD Framework and Quality Indicators", *International Journal for Quality in Health Care*, Vol. 27, No. 2, pp. 137-146.

OECD Health System Performance Framework 2015

International Journal for Quality in Health Care Advance Access published March 10, 2015

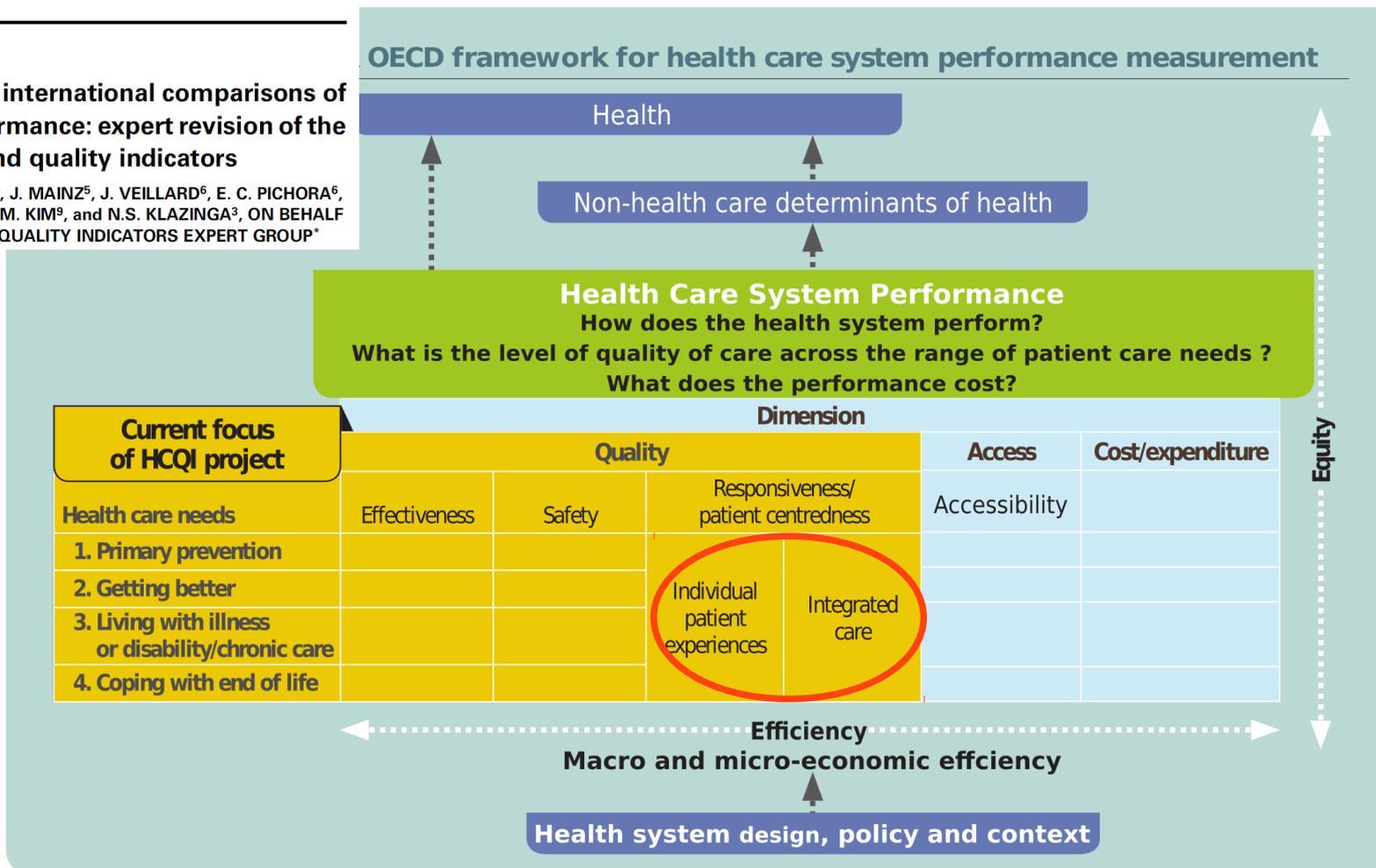


International Journal for Quality in Health Care, 2015, 1–10
doi: 10.1093/intqhc/mzv004
Article

Article

Towards actionable international comparisons of health system performance: expert revision of the OECD framework and quality indicators

F. CARINCI^{1,2}, K. VAN GOOL^{3,4}, J. MAINZ⁵, J. VEILLARD⁶, E. C. PICHORA⁶, J. M. JANUEL⁷, I. ARISPE⁸, S. M. KIM⁹, and N.S. KLAZINGA³, ON BEHALF OF THE OECD HEALTH CARE QUALITY INDICATORS EXPERT GROUP*



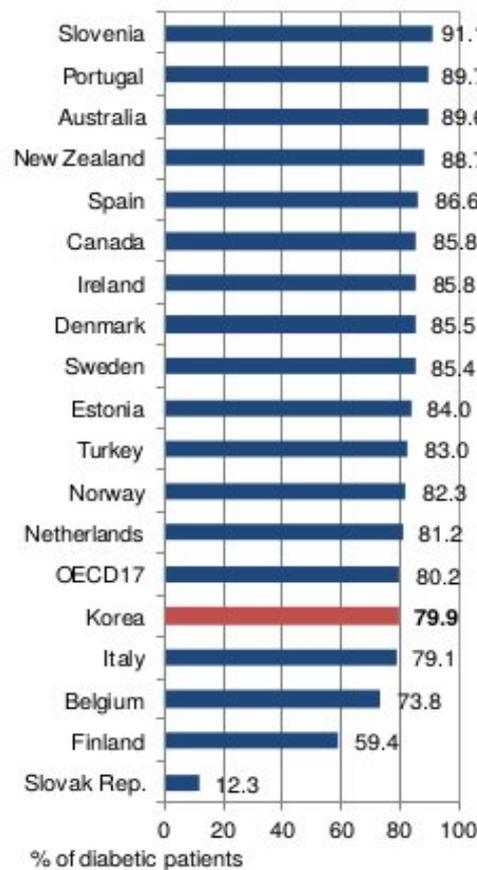
Diabetes in Europe: which international comparisons are routinely available today?

- 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)

Prescription of hypertensive and Lower extremity amputations in diabetes, 2015

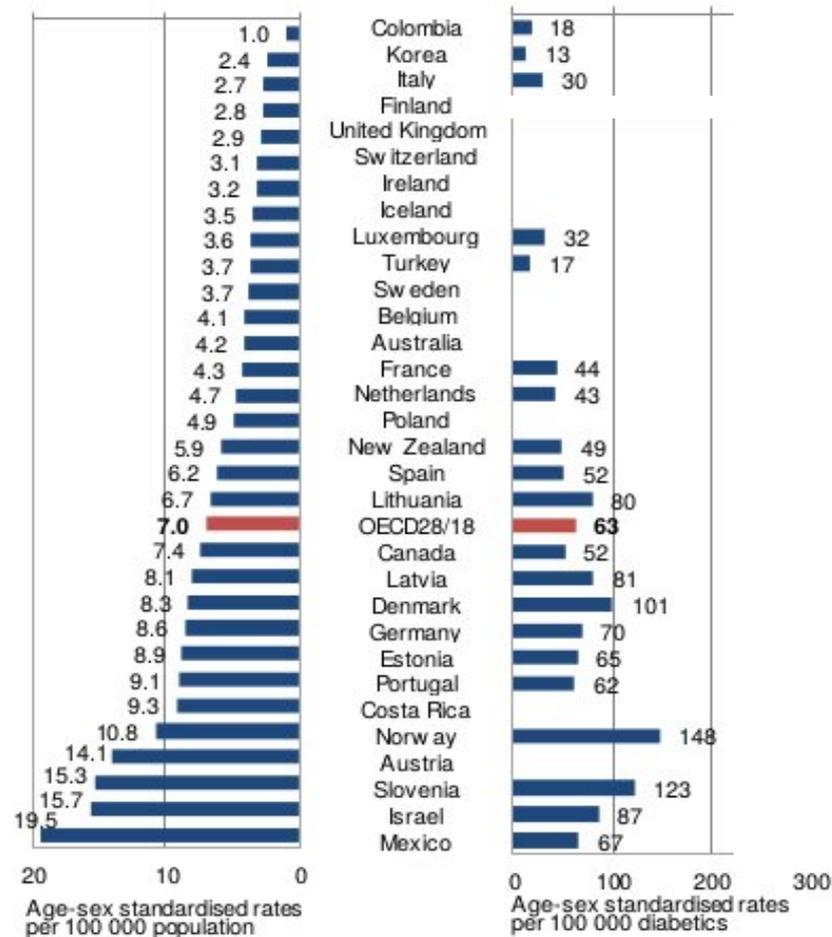
Source: OECD Health at a Glance 2017

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



Source: OECD Health Statistics 2017.

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.

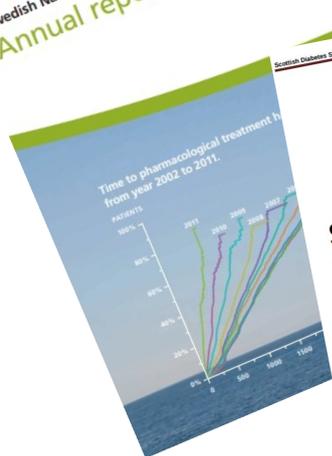
Why do we need a EU infrastructure for diabetes information?

- To monitor actions and plan accordingly **USING MORE GRANULAR DATA OF CLINICAL RELEVANCE**
- **Diabetes is a valid model** for complex multidimensional and longitudinal monitoring of chronic diseases:
 - 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)
 - Summary results on selected 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)
- **Does relevant information exist? YES, but is stored in different silos (networks) and/or dispersed at the national or even sub-national level!**

Diabetes Registers in Europe

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Swedish National Diabetes Register
Annual report 2013



Scottish Diabetes Survey 2016

Scottish Diabetes Survey Monitoring Group



Norsk diabetesregister for voksne
Årsrapport for 2016 med
plan for forbedringstiltak

KARIANNE FIELD LØVÅAS¹, TONE VONHEIM MADSEN², JOHN COOPER^{3,4}, GEIR THUE^{5,6,7} OG SVERRE SANDBERG^{1,8,9}

¹Norsk kvalitetsforbedring av laboratorieunderøkelser (Noklus), Br
²Stavanger Universitetssykehus, Helse Stavanger
³Institutt for global helse og samfunnsmedisin, UiB
⁴Oasen legesenter DA
⁵Haukeland Universitetssykehus, Helse Bergen

20. september 2017



Dansk Diabetes Database

Dansk Voksen Diabetes Database (DVED)
Dansk Register for Børne- og Ungdomsdiabetes (DanDiakKids)
Landsdækkende Klinisk kvalitetsdatabase for screening af
diabetisk retinopati og neuropati (Diabase)

National Årsrapport 2016/2017
1. marts 2016 - 28. februar 2017

HIGH QUALITY INFORMATION ... but...

- Heterogeneous
- Fragmented
- Heavily Regulated
- Serving local interests
- Skeptical about sustainability of regular international comparisons
- Hard to share data on a regular basis
- Mainly available in national language only

PERSON CENTRED HEALTH SYSTEMS

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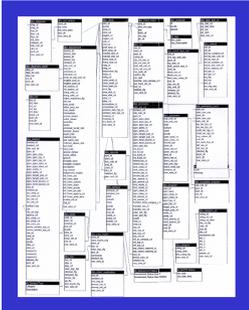


At the OECD Health Ministerial 2017, Health Ministers from around the globe:

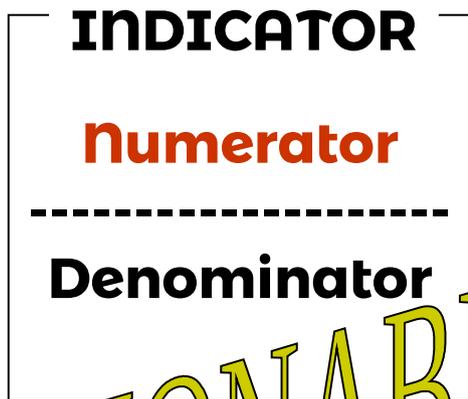
- committed to realize person-centre health systems
- expressed their interest to measure person reported outcomes and costs for each individual with a specified target condition (fundamental prerequisite for Value-based Health Care)

What do we need to measure for person-centred value-based health care ?

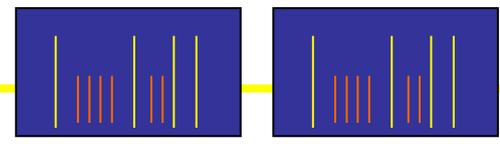
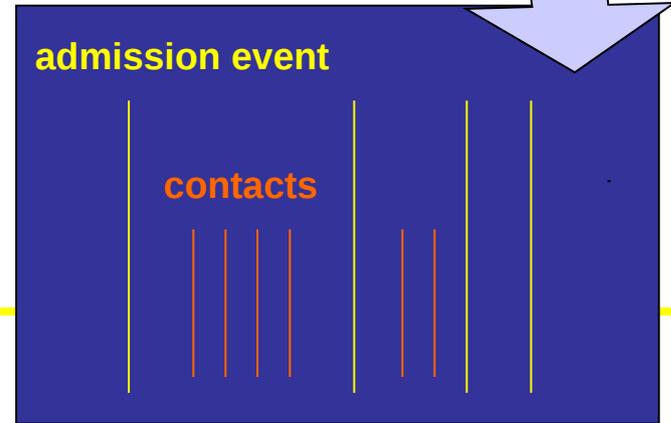
BARRIER



DATA
(LINKAGE)



ACTIONABLE

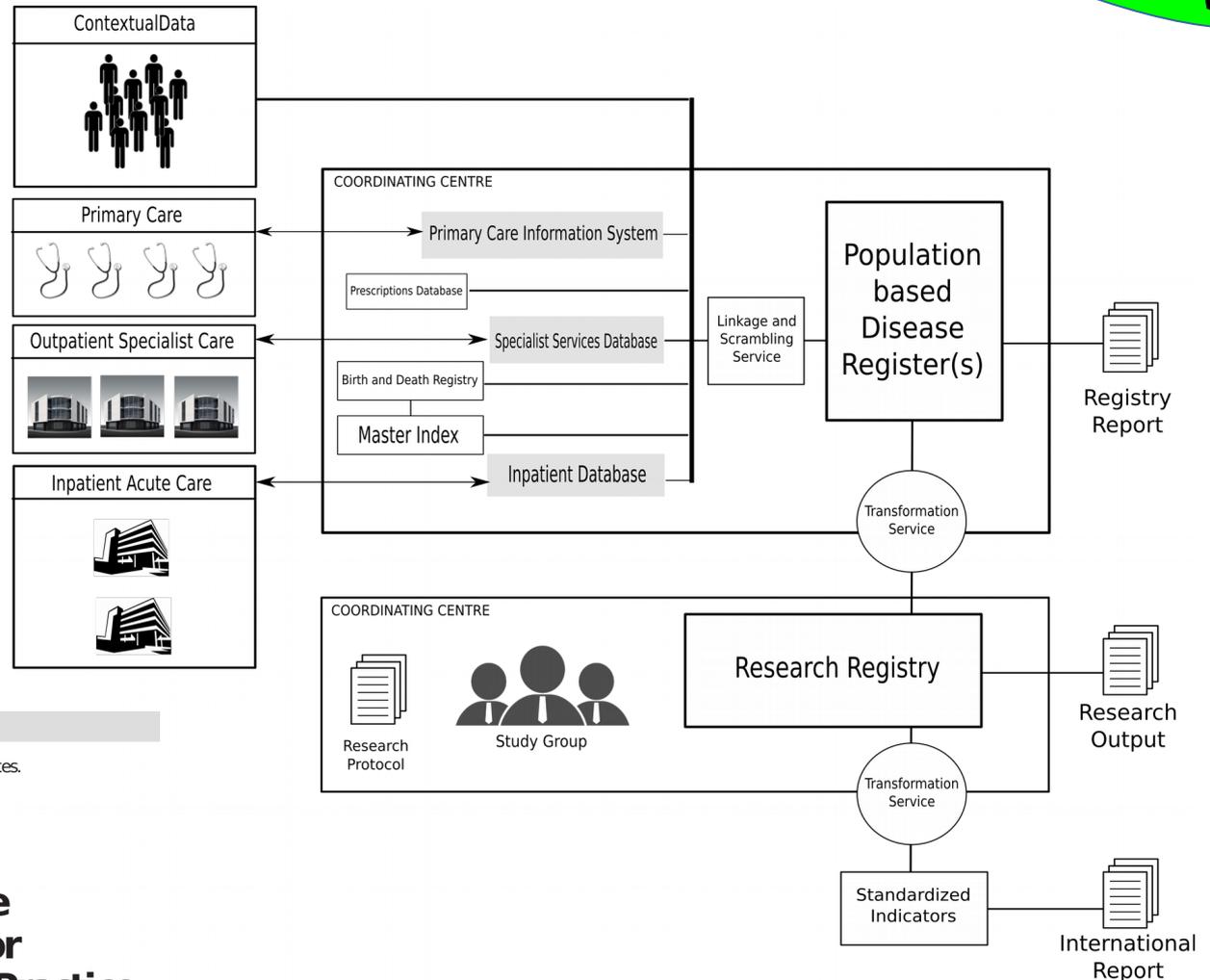


time

Structure of a population-based disease register

ENABLER

Allows collecting a range of measures in a rigorous manner!



Bruttomesso D, Grassi G (eds): Technological Advances in the Treatment of Type 1 Diabetes. Front Diabetes. Basel, Karger, 2014, vol 24, pp 1-14 (DOI: 10.1159/000363520)

Standardized Information Exchange in Diabetes: Integrated Registries for Governance, Research, and Clinical Practice

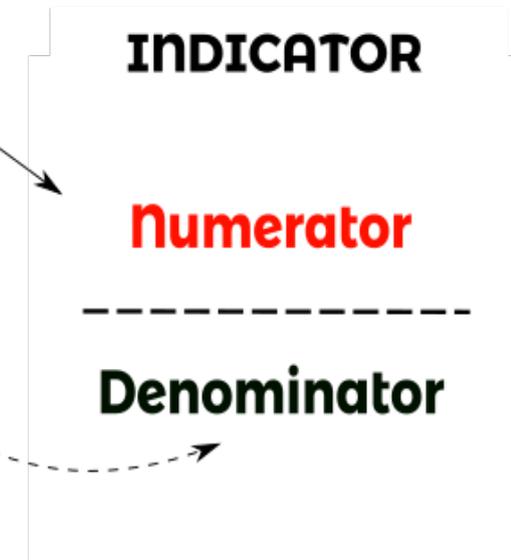
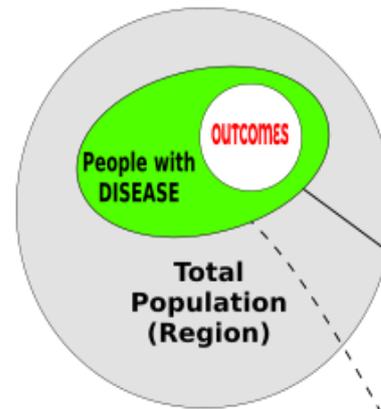
F. Carinci^a • C.T. Di Iorio^a • M. Massi Benedetti^b

^aSerectrix snc, Pescara, ^bHub for International Health Research, Perugia, Italy

DATA

STATISTICAL OUTPUT

**POPULATION-BASED
DISEASE REGISTER**

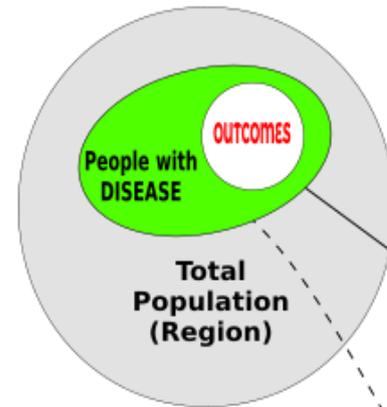


But different types of models for data collection may bias the results...

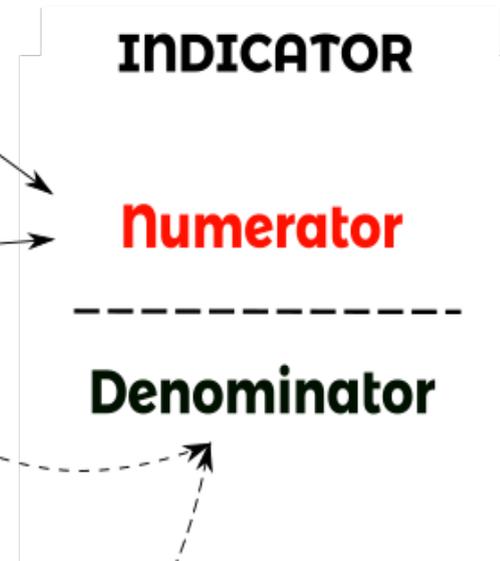
DATA

STATISTICAL OUTPUT

**POPULATION-BASED
DISEASE REGISTER**



**POPULATION-BASED
DISEASE REGISTER
LINKED TO A
PROVIDER SOURCE**

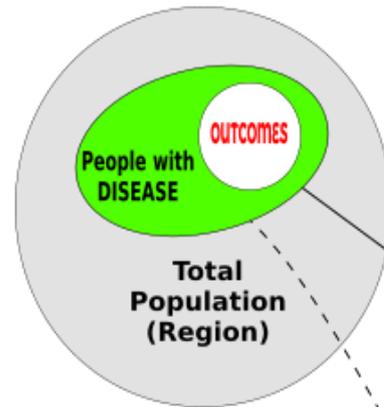


Different data sources
may lead to very
different results...

DATA

STATISTICAL OUTPUT

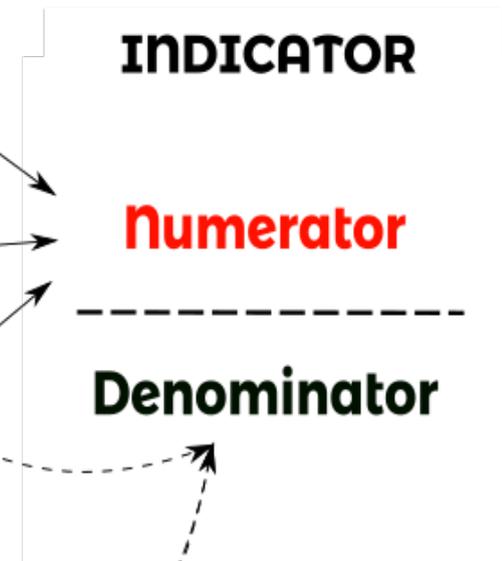
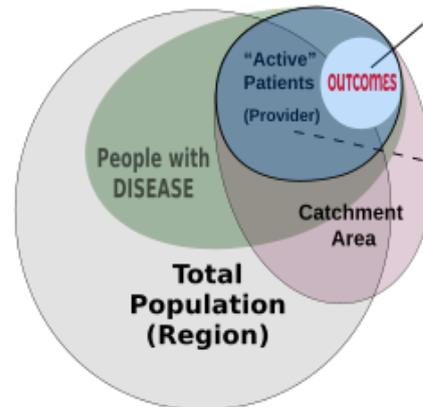
POPULATION-BASED DISEASE REGISTER



POPULATION-BASED DISEASE REGISTER LINKED TO A PROVIDER SOURCE



PROVIDER-BASED SOURCE



Survey of diabetes data sources in Europe

Source: EUBIROD Network 2017

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

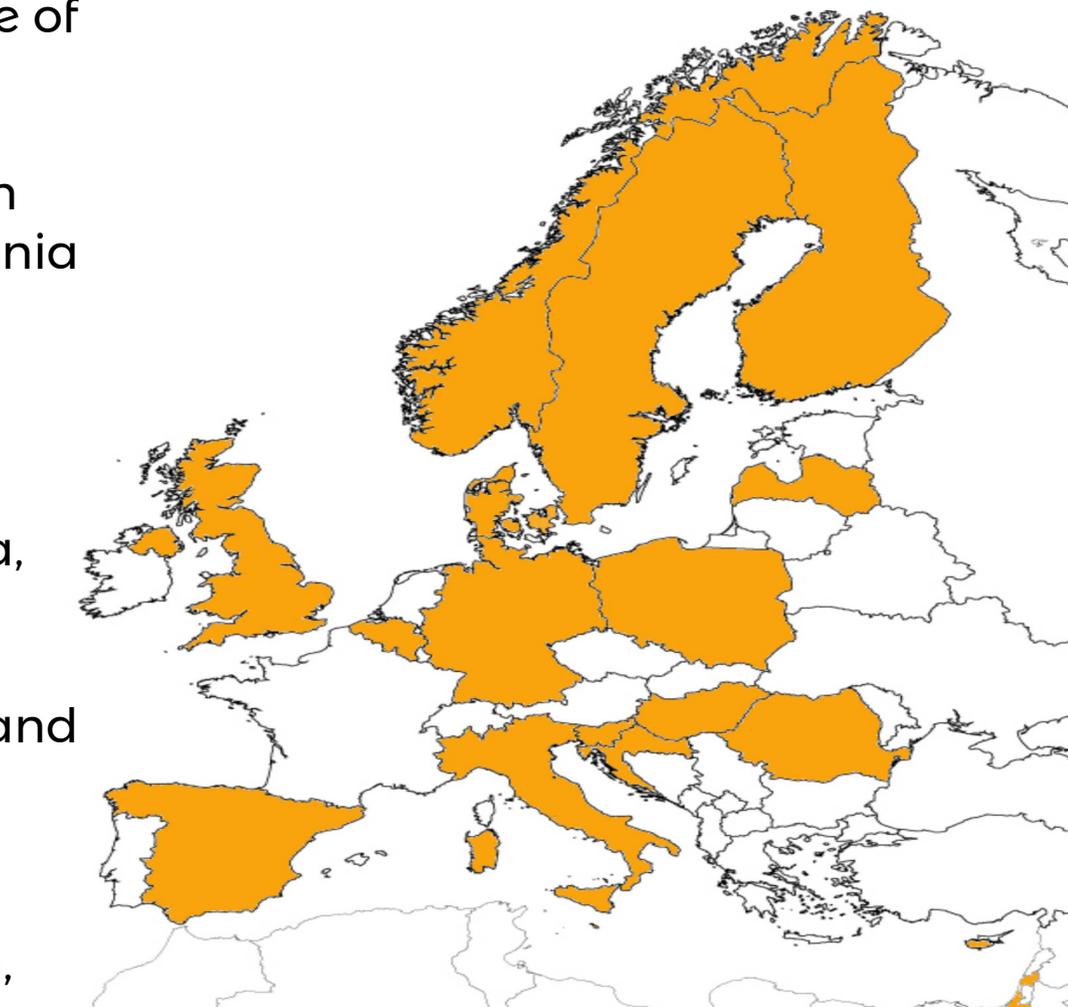
Preliminary Taxonomy

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



How to merge approaches?

Shared Evidence-based Diabetes Information System

ENABLER

Carinci et al, Diabetes registers and prevention strategies: towards an active use of health information, Diabetes Research and Clinical Practice 74 (2006) S215-S219



Available online at www.sciencedirect.com



Diabetes Research and Clinical Practice 74 (2006) S215-S219

DIABETES RESEARCH
AND
CLINICAL PRACTICE

www.elsevier.com/locate/diabres

Diabetes registers and prevention strategies: towards an active use of health information

Fabrizio Carinci^{1,*}, Marco Orsini Federici², Massimo Massi Benedetti²

¹Health Systems Research, Pescara, Italy

²Dipartimento di Medicina Interna, Università di Perugia, Perugia, Italy

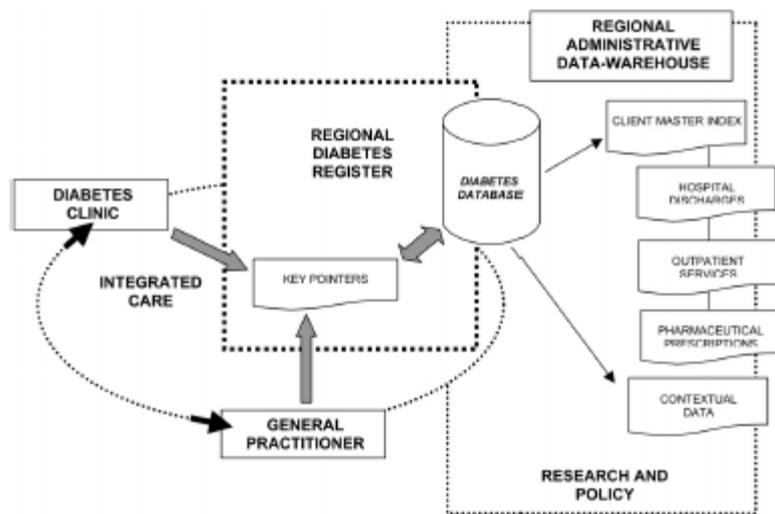


Fig. 1. Architecture of the integrated Diabetes Register.

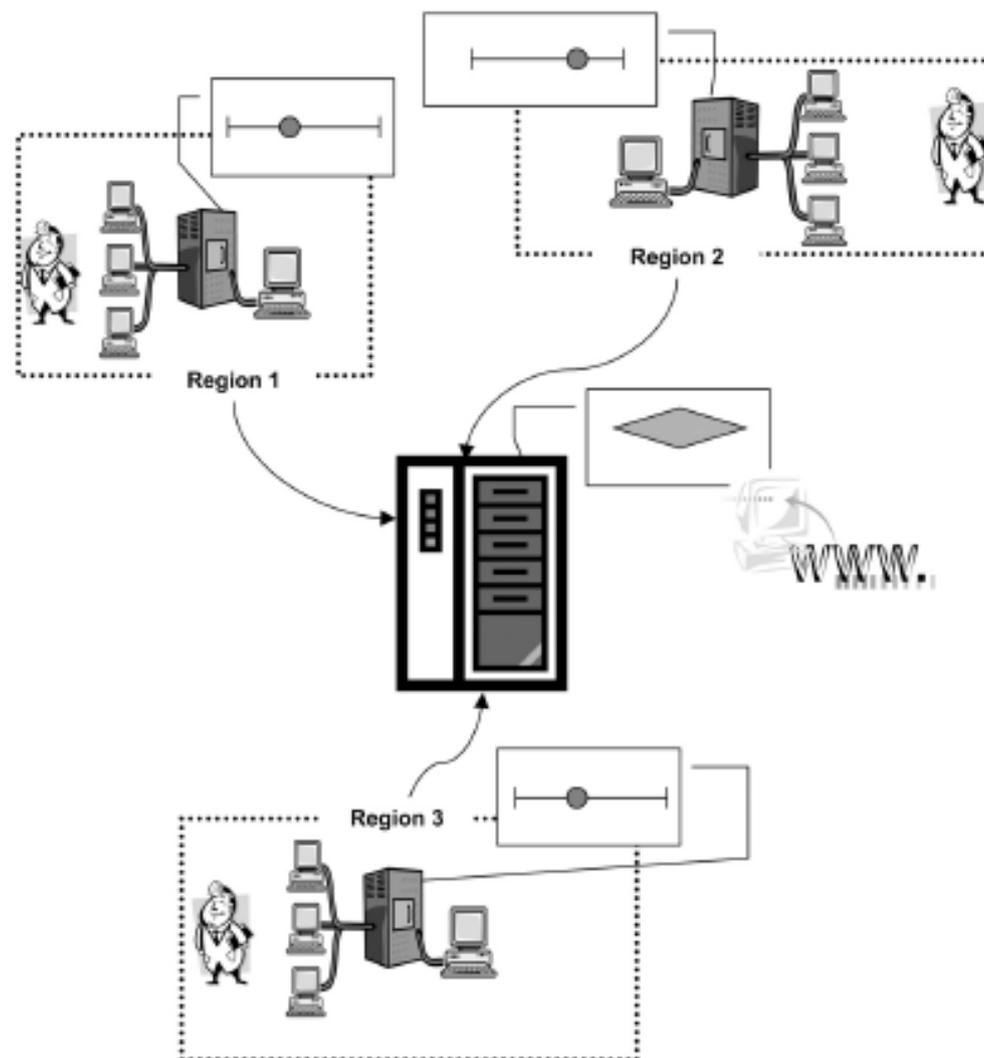


Fig. 2. Shared evidence-based Diabetes Information System.

EU BIRO and EUBIROD projects

EU DG-SANCO co-funded public health projects

BIRO project (2005-2009)

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

EUBIROD project (2008-2012)

“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”

BRIDGE-HEALTH (2015-2017)

Task 8.2: “to provide 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.”

A lasting coalition for
brainstorming, debate,
research and development
projects!

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, Denmark
University of Debrecen, Hungary
Ministry of Health, Israel
Sereatrix, 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



HIRS

HUB FOR
INTERNATIONAL
HEALTH
RESEARCH

- **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

BIRO glossary

...the foundations developed
together

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*

The BIRO approach



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>

ENABLER

BIRO = Best Information through Regional Outcomes

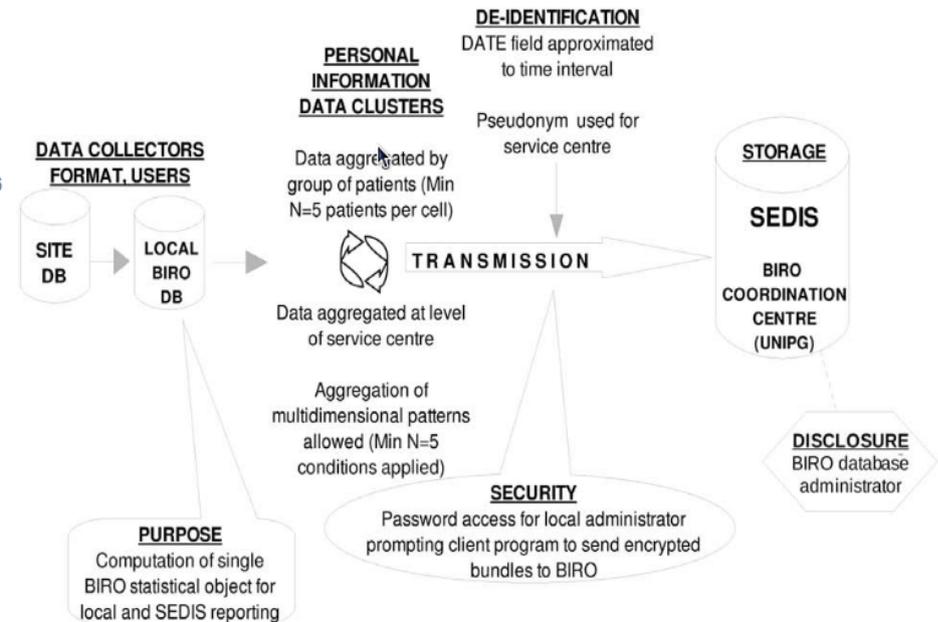
Designed and implemented to report on quality of care and outcomes in diabetes in Europe

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

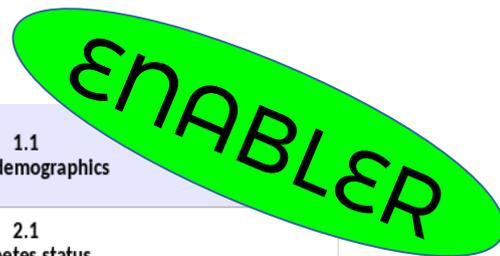
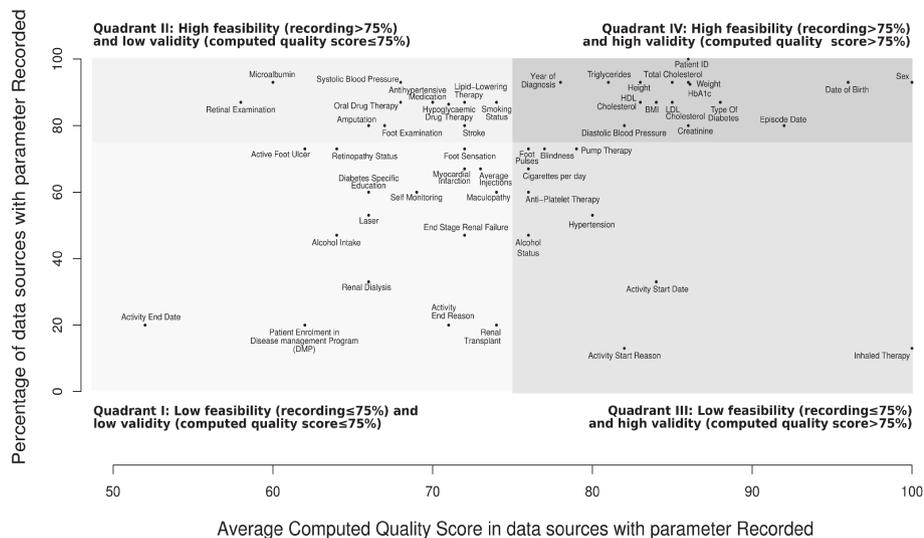


Core Standards of the EUBIROD Project*

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

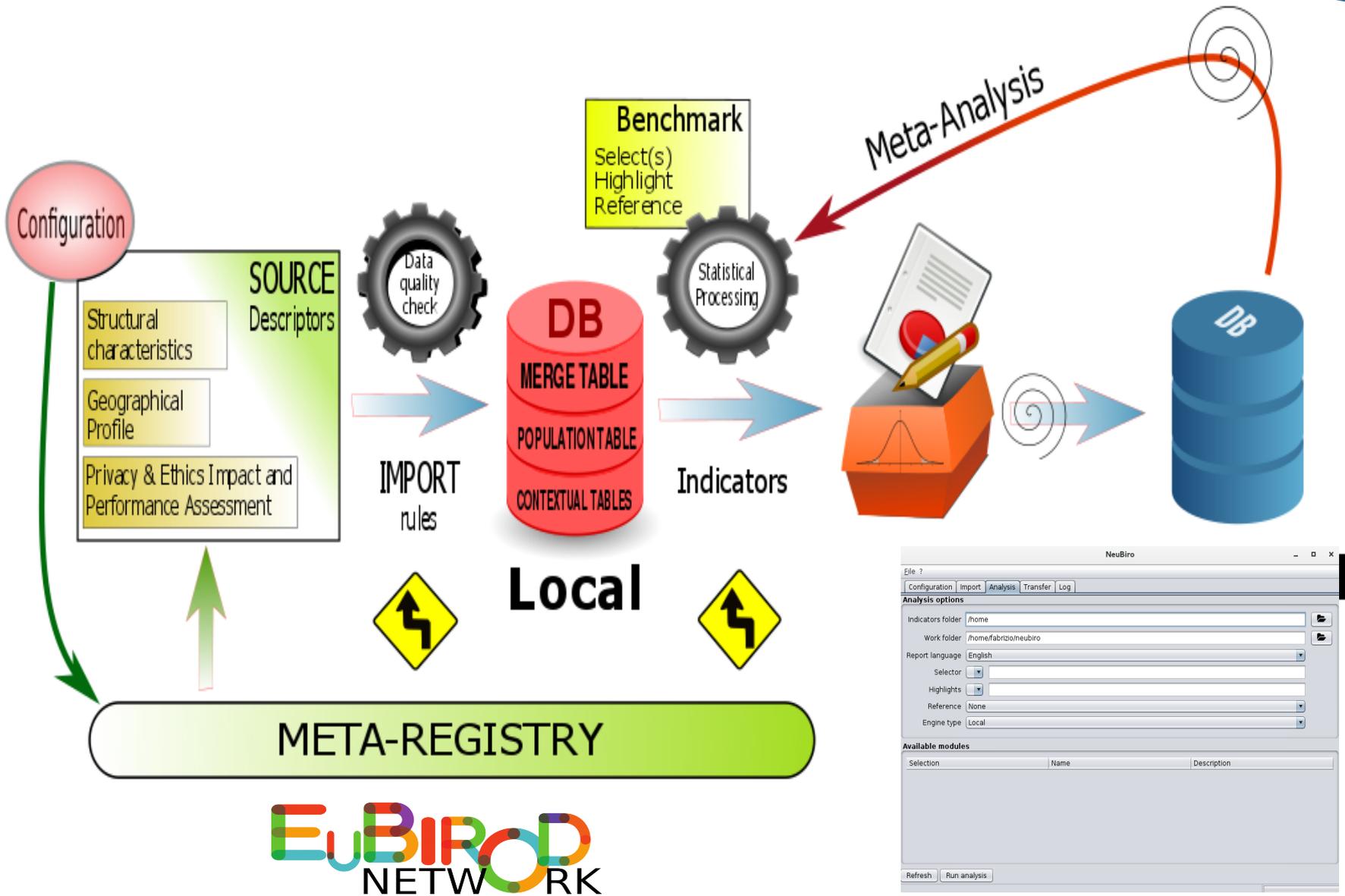
¹University of Dundee, Scotland; ²Hub for International Health Research, Italy; ³University of Surrey, United Kingdom; ⁴University of Malta, Malta; ⁵Joanneum Research, Austria; ⁶University Children's Hospital Ljubljana, Slovenia; ⁷Centre Hospitalier de Luxembourg, Luxembourg; ⁸Scientific Institute of 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 CLINICAL CHARACTERISTICS	2.1 Diabetes status
	2.2 Risk factors for diabetes complications
	2.3 Diabetes complications
3 HEALTH SYSTEM	3.1 Structure (provider level)
	3.2 Structural quality
	3.3 Processes
	3.3.1 Foot examinat on
	3.3.2 Eye examinat on
4 POPULATION	3.3.3 Measurement done (in the last 12 months)
	3.3.4 Treatment (at least one prescript on in the last 12 months)
5 RISK ADJUSTED INDICATORS	3.3.5 Management
	4.1 Area level
	5.1 Epidemiology
	5.2 Process quality (in adults with diabetes in the last 12 months)
	5.3 Outcome Quality: Intermediate outcomes (in adults with diabetes in the last 12 months)
	5.4 Outcome Quality: Terminal outcomes (in the last 12 months)

General Software for Federated Analysis

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EuBIROD NETWORK

Successful Road Test EUBIROD Report (2012)

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8/2/2012: New BIRO Release 2.1.12

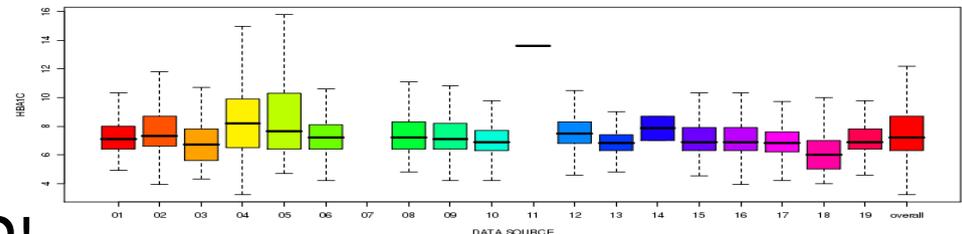
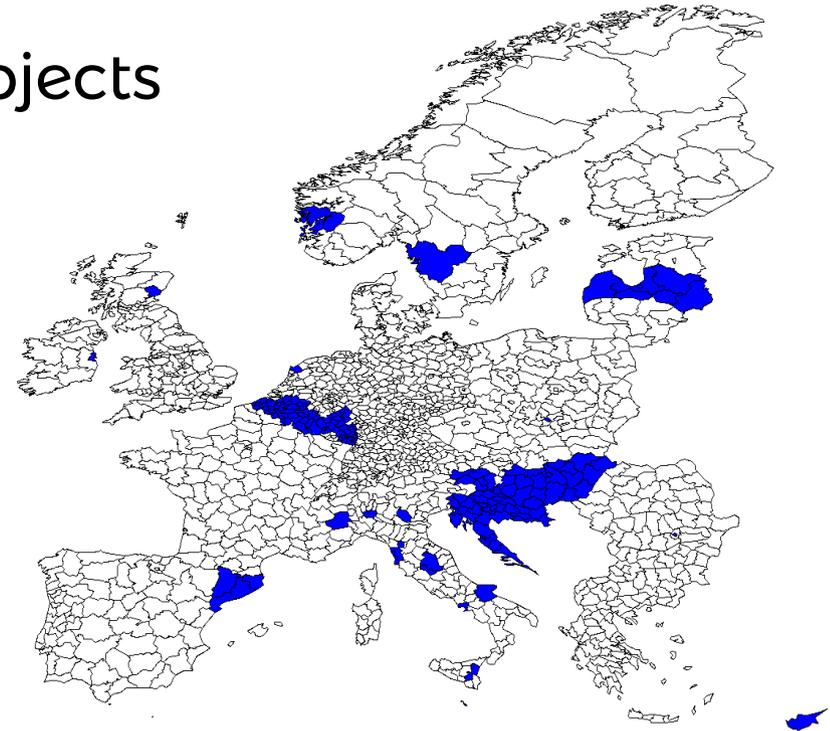
15/2/2012: Collection of statistical objects

21/2/2012: EU Draft Report from 18 countries (N=79 indicators)

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

1/3/2012 Project Ends

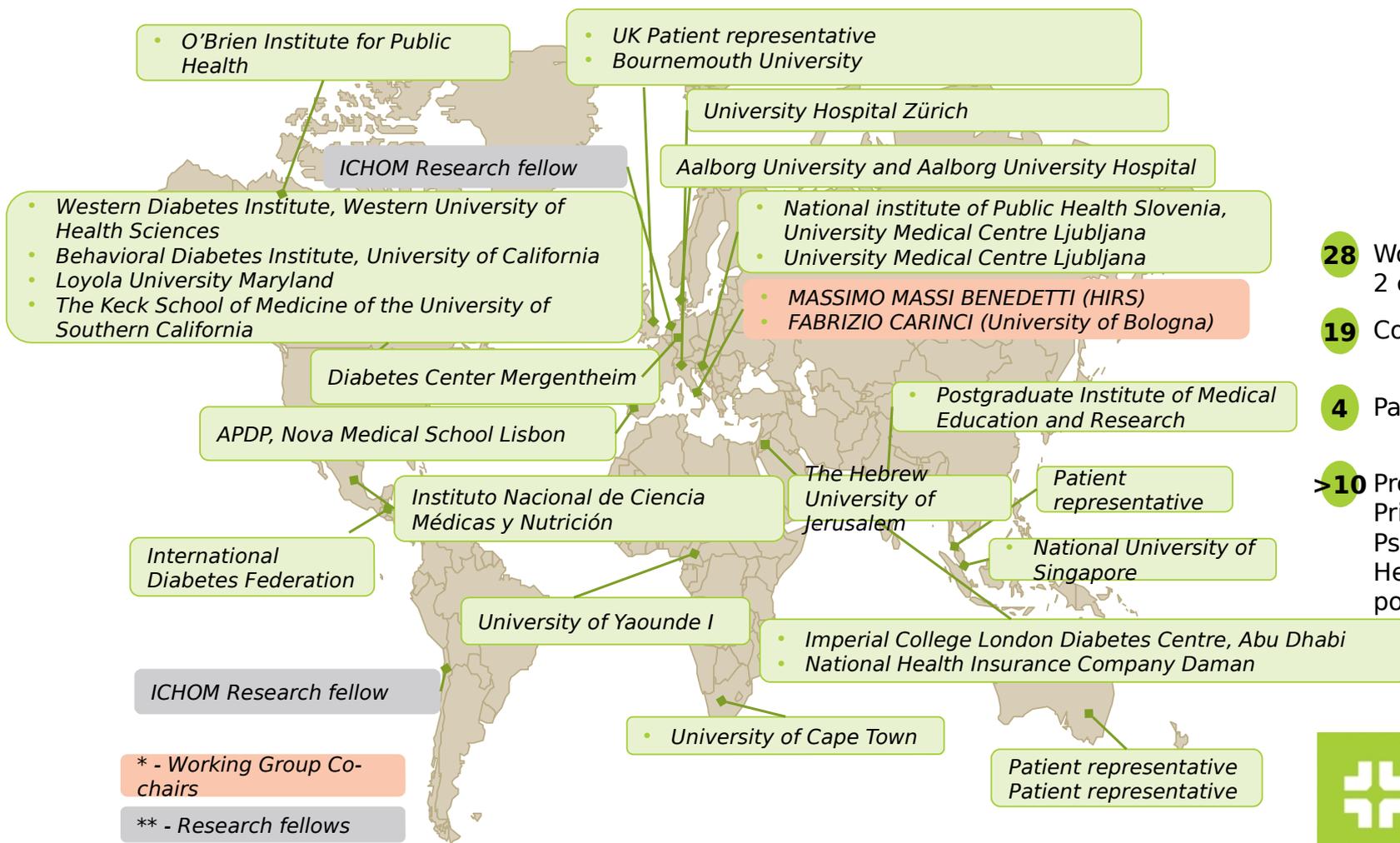
SUSTAINABILITY:
DIABETES INFORMATION
NOT INCLUDED AS A TOPIC
IN EU PROGRAMS SINCE THEN!



Standard Set on Diabetes

ICHOM 2017-2018

ENABLER



- 28** Working Group members led by 2 co-chairs
- 19** Countries represented
- 4** Patients across 3 continents
- >10** Profiles: Patient advocacy, Primary care, Endocrinology, Psychology, Nursing, Public Health, Insurance, Health policy, Biostatistics



Scope of the set

Patient population	Management approach	Disease stage
<p>Adults (aged ≥ 18 years)</p> <ul style="list-style-type: none">• Type 1 diabetes mellitus• Type 2 diabetes mellitus	<p>Education and lifestyle</p> <ul style="list-style-type: none">• Weight management• Diet• Exercise <p>Pharmacological</p> <ul style="list-style-type: none">• Oral• Parenteral <p>Psychosocial care</p> <ul style="list-style-type: none">• Mental health	<p>Early uncomplicated disease</p> <p>Diabetes with co-morbid disease e.g. Diabetes and obesity</p> <p>Diabetes with complications e.g. Diabetes with neuropathy</p>

The Working Group specifically excluded certain populations from the set, as they have distinct needs that would be best addressed in a separate project. Excluded from the set are:

- Paediatric and neonatal populations (aged <18 years)
- Gestational diabetes
- Secondary diabetes

Agreed specifications for routine monitoring: the ICHOM Diabetes Data Dictionary

SAMPLE
ITEMS

Variable ID: SYSBP
Variable: Blood Pressure
Systolic reading
Definition: What is the person with diabetes' most recent systolic blood pressure from the past 12 months
Supporting Definition: Systolic and diastolic blood pressure readings are used to determine the presence of hypertension and whether blood pressure is controlled if on blood pressure lowering medication. Control will be defined depending on the most relevant hypertension guidelines
Inclusion Criteria: All patients
Timing: Baseline
Annually
Data Source: Clinician /Healthcare provider
Type: Numerical
Response Options: Numerical systolic BP in mmHg

Variable ID: DIABP
Variable: Blood pressure
Diastolic reading
Definition: What is the person with diabetes' most recent diastolic blood pressure from the past 12 months
Supporting Definition: Systolic and diastolic blood pressure readings are used to determine the presence of hypertension and whether blood pressure is controlled if on blood pressure lowering medication. Control will be defined depending on the most relevant hypertension guidelines
Inclusion Criteria: All patients
Timing: Baseline
Annually
Data Source: Clinician /Healthcare provider
Type: Numerical
Response Options: Numerical diastolic BP in mmHg

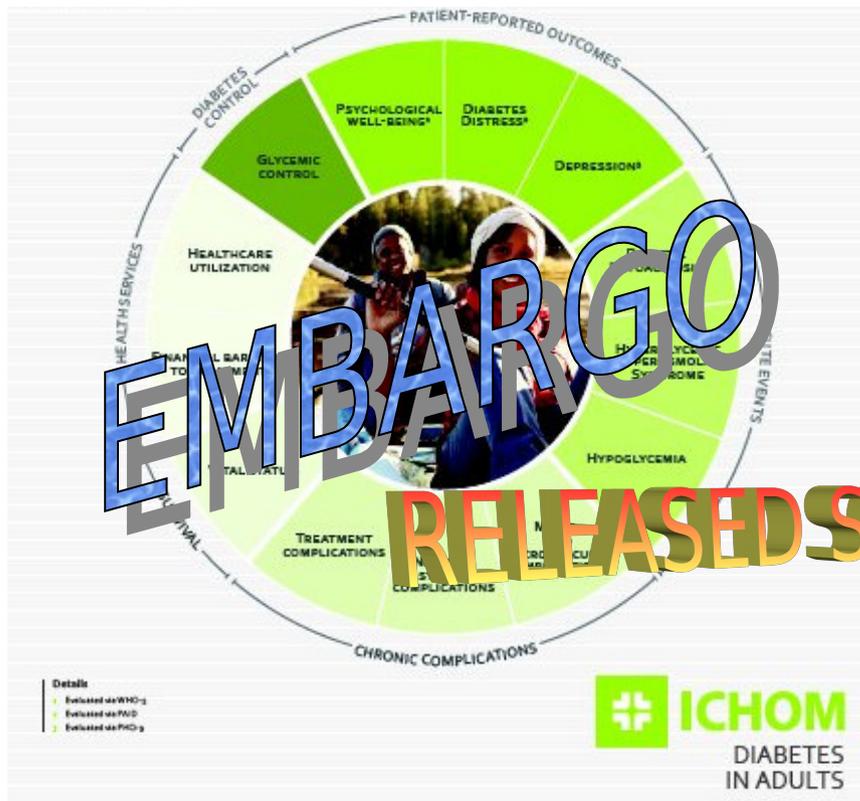


RELEASED SOON

Overview of the contents of the set

Category	Outcomes included	Reporting source
Patient-reported outcomes	Psychological Wellbeing	Patient-reported outcome measure
	Diabetes Distress	
	Depression	
Diabetes Control	Glycaemic control	Provider
Acute Events	Diabetic Ketoacidosis	Provider and Patients
	Hyperglycaemic Hyperosmolar Syndrome	
	Hypoglycaemia	
Chronic Complications	Micro- and Macrovascular complications	Provider and Patients
	Nervous System Complications	
	Treatment Complications	
Health Services	Financial barriers to treatment	Provider and Patients
	Healthcare Utilisation	
Survival	Vital Status	Provider

Delivering the final product: the ICHOM Standard Set on Diabetes



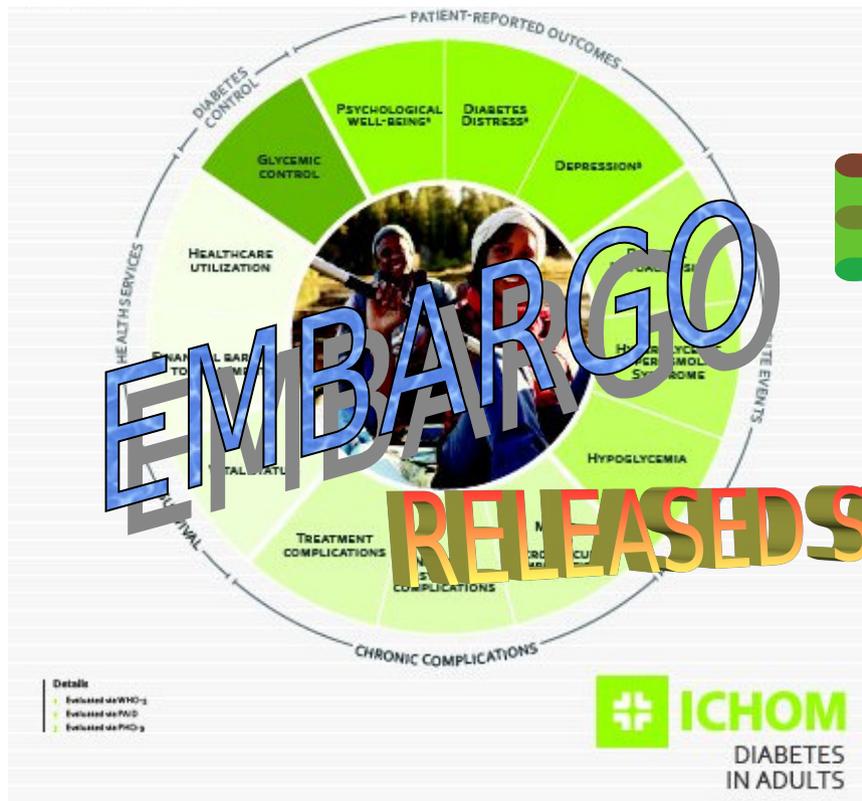
Follow-Up Algorithm

The following algorithm illustrates when Standard Set variables should be collected from patients and clinicians.



<http://www.ichom.org/medical-conditions/diabetes/>

Time to progress together now?



EUBIROD
NETWORK

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

EMBARGO
RELEASED SOON
BARRIER
ENABLER
BARRIER
ENABLER
ENABLER

Conclusions

- Diabetes registers are increasingly recognized by EU Member States as a necessary solution to monitor and improve outcomes across Europe. However, there is still a lack of coordination for international comparisons
- Novel approaches for privacy enhanced rigorous data collection have been successfully trialled in the BIRO and EUBIROD projects. Meanwhile, the federated architecture has been recognized as a viable and effective general solution by other EU projects.
- The release of the ICHOM standard set for diabetes underpins the creation of a **pan-European diabetes register** that can use standardized information for multiple stakeholders wishing to apply value-based health care
- The sustainability of the register is paramount to match key goals with the actual capacity of measuring targets on a routine basis, in the interest of people with diabetes