EuBIROD NETWORK

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

2018 EAPM MILAN

2nd European Alliance for Personalised Medicine Congress
Forward as One: Integrating Innovation into
Europe's Healthcare Systems

26 - 28 November 2018 - Milan Italy

Overview of outcomes measurement in diabetes and reflections on diabetes registry research

Fabrizio Carinci

Technical Coordinator of the EUBIROD Network
Adjunct Professor of Biostatistics, University of Bologna, Italy
Visiting Professor, University of Surrey, UK
fabrizio.carinci@unibo.it

Why do we need standardised health information?

- To provide broader and faster access to an ever increasing amount of data of critical importance to **improve health systems in the public interest**

- To **support research** and make **policy makers accountable** for the results obtained through their National legislation, policies and plans

- 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 same criteria and methods for fair comparisons**

- To avoid drawing conclusions from **random fluctuations**, which can be critical when data is incomplete or not sufficiently reliable

OECD Health at a Glance 2017

Publications are useful, but late and not detailed enough to support policy decisions and personal choices

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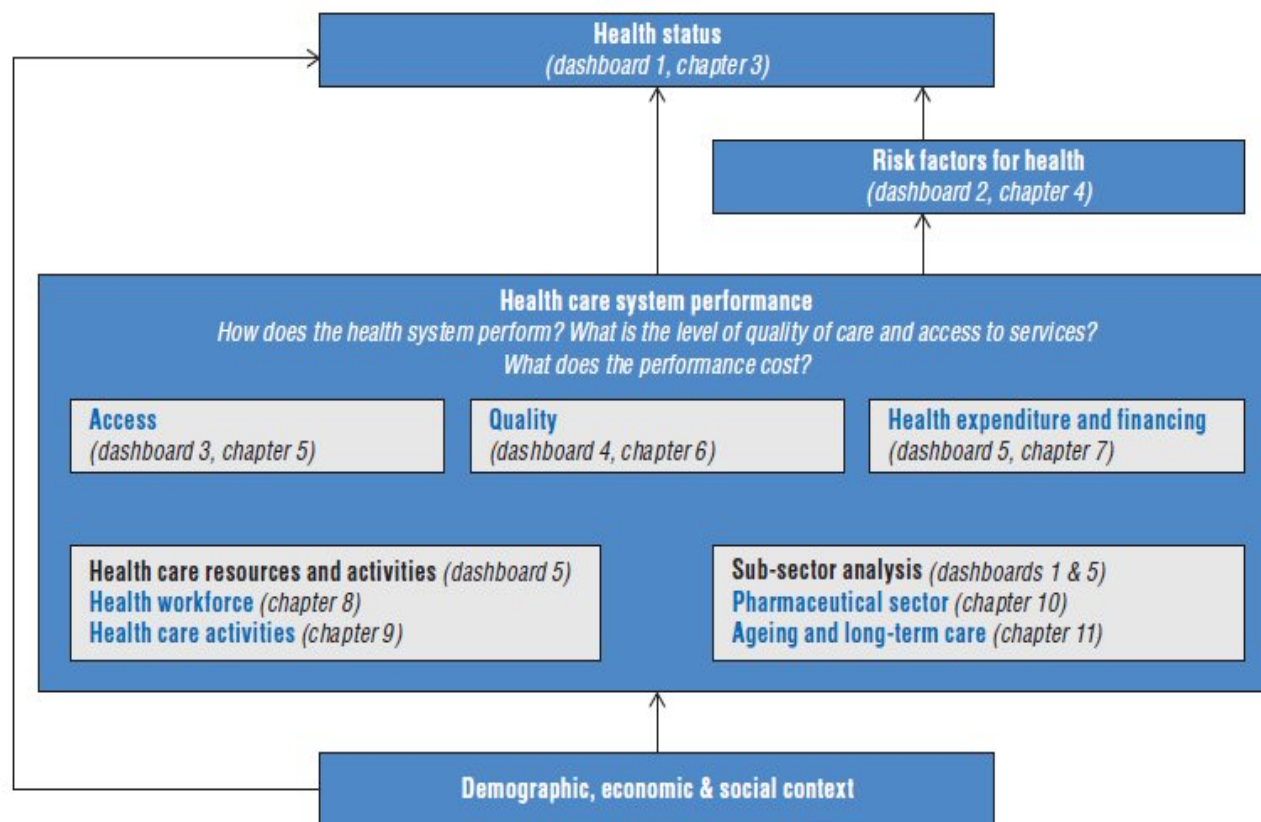
Source: Adapted from Carinci, F. et al. (2015), "Towards Actionable International Comparisons of Health System Performance: Expert Revision of the OECD Framework and Quality Indicators", *International Journal for Quality in Health Care*, Vol. 27, No. 2, pp. 137-146.

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

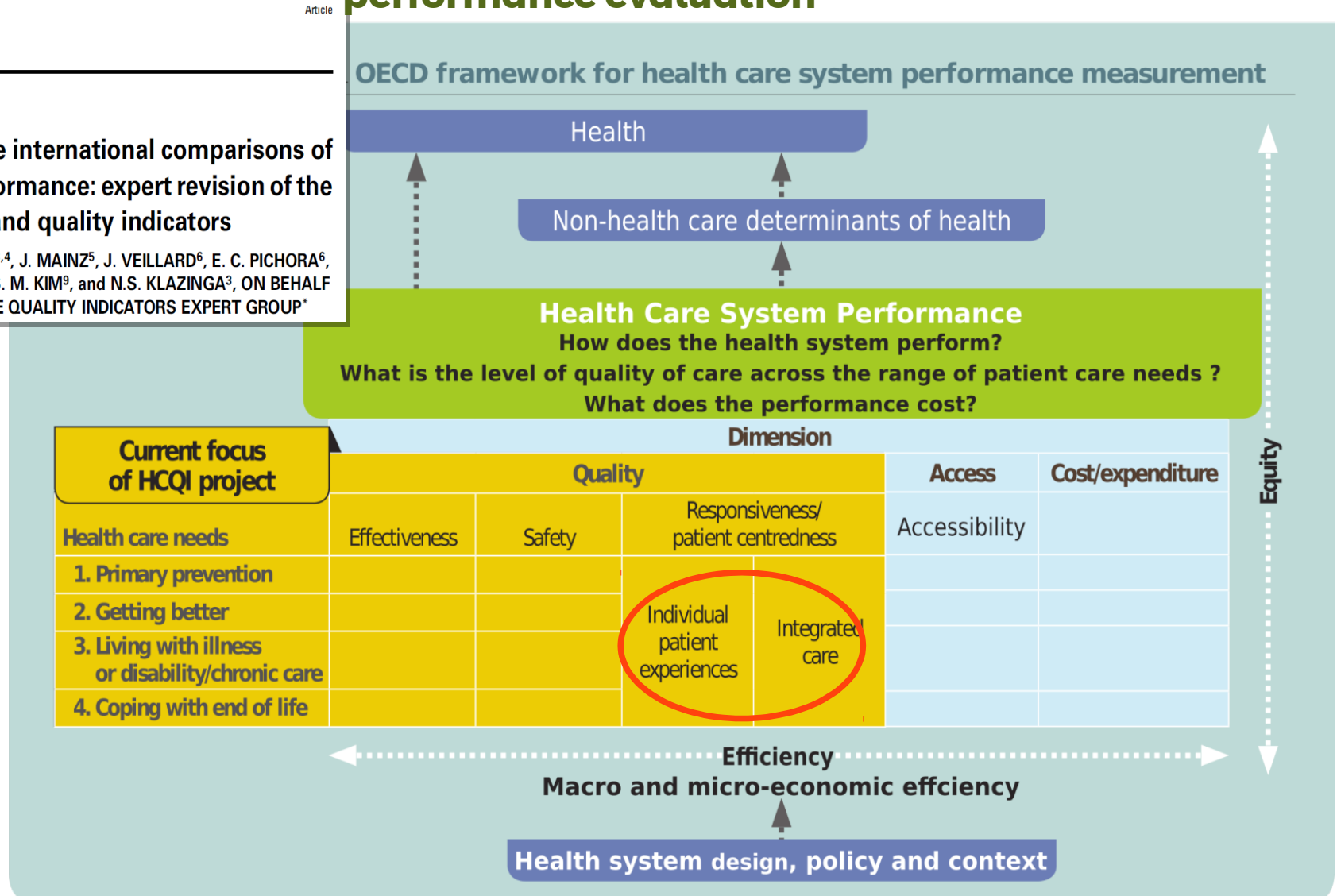# OECD Health System Performance Framework 2015

Global standards are essential to share common principles for performance evaluation

ISQua®

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. MAINZ[5], J. VEILLARD[6], E. C. PICHORA[6], J. M. JANUEL[7], I. ARISPE[8], S. M. KIM[9], and N.S. KLAZINGA[3], ON BEHALF OF THE OECD HEALTH CARE QUALITY INDICATORS EXPERT GROUP*

OECD framework for health care system performance measurement

Health

Non-health care determinants of health

Health Care System Performance
How does the health system perform?
What is the level of quality of care across the range of patient care needs ?
What does the performance cost?

Current focus of HCQI project	Dimension				
	Quality			Access	Cost/expenditure
Health care needs	Effectiveness	Safety	Responsiveness/ patient centredness	Accessibility	
1. Primary prevention					
2. Getting better					
3. Living with illness or disability/chronic care		Individual patient experiences	Integrated care		
4. Coping with end of life					

Equity

Efficiency
Macro and micro-economic efficiency

Health system design, policy and context

How well are we doing?
Outcomes should refer to comparable, well defined populations!

- **At a population-level**, all segments of the population should be taken into account: missing those "hard to reach" will lead to "biased" results (e.g. blind not going to visits, etc)

- **At a personal level,** measurements should cover all relevant levels of care (from prevention to primary, specialist and acute care)

- Databases maintained by regions/countries may not include all people with diabetes in the denominator (e.g. undiagnosed or not recognised as person with diabetes)

- Databases maintained by single providers may report results only for specific patients (selection bias) and for catchment areas (geographical location) that cannot be compared to the population

How well are we doing?
Measures should cover all relevant aspects and be regularly monitored

- Epidemiological studies provide essential references, but do not represent a permanent source of information to understand **how well are we doing on a permanent basis**

- We need more detail that currently have to compare quality and outcomes at a global level. Even countries that are more evolved in diabetes reporting, **cannot compare systematically without robust global standards.**

- Which indicators are available today?

- General data on **diabetes prevalence** (IDF ATLAS, 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)

Deaths due to diabetes mellitus

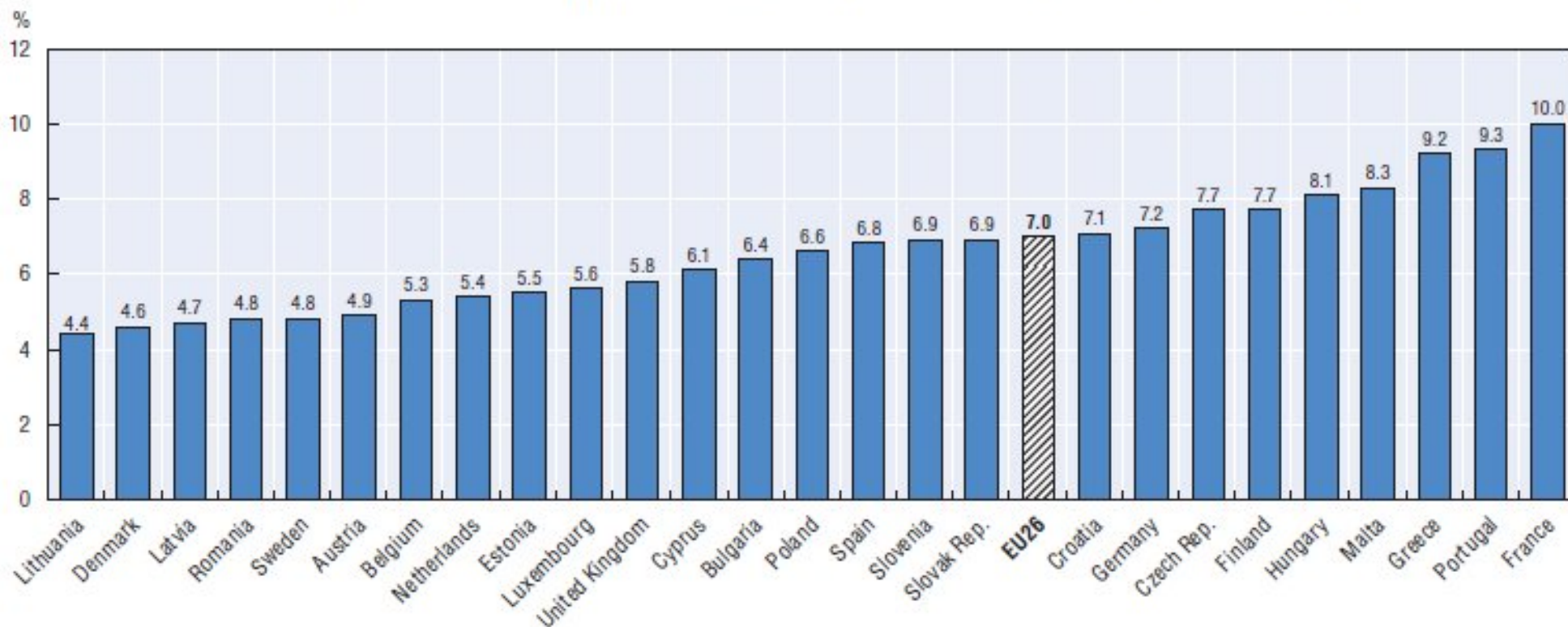Standardized death rate by 100 000 inhabitants, Year 2014

Source: Eurostat
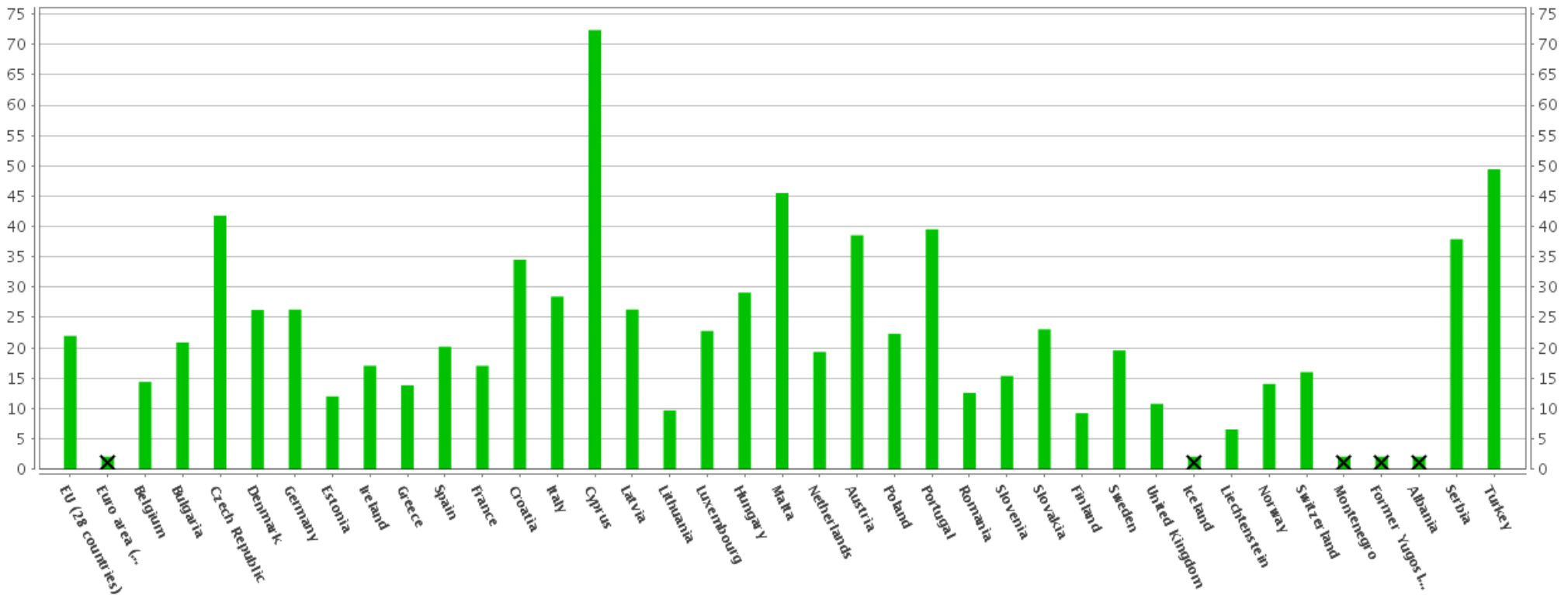
Diabetes Prevalence

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)

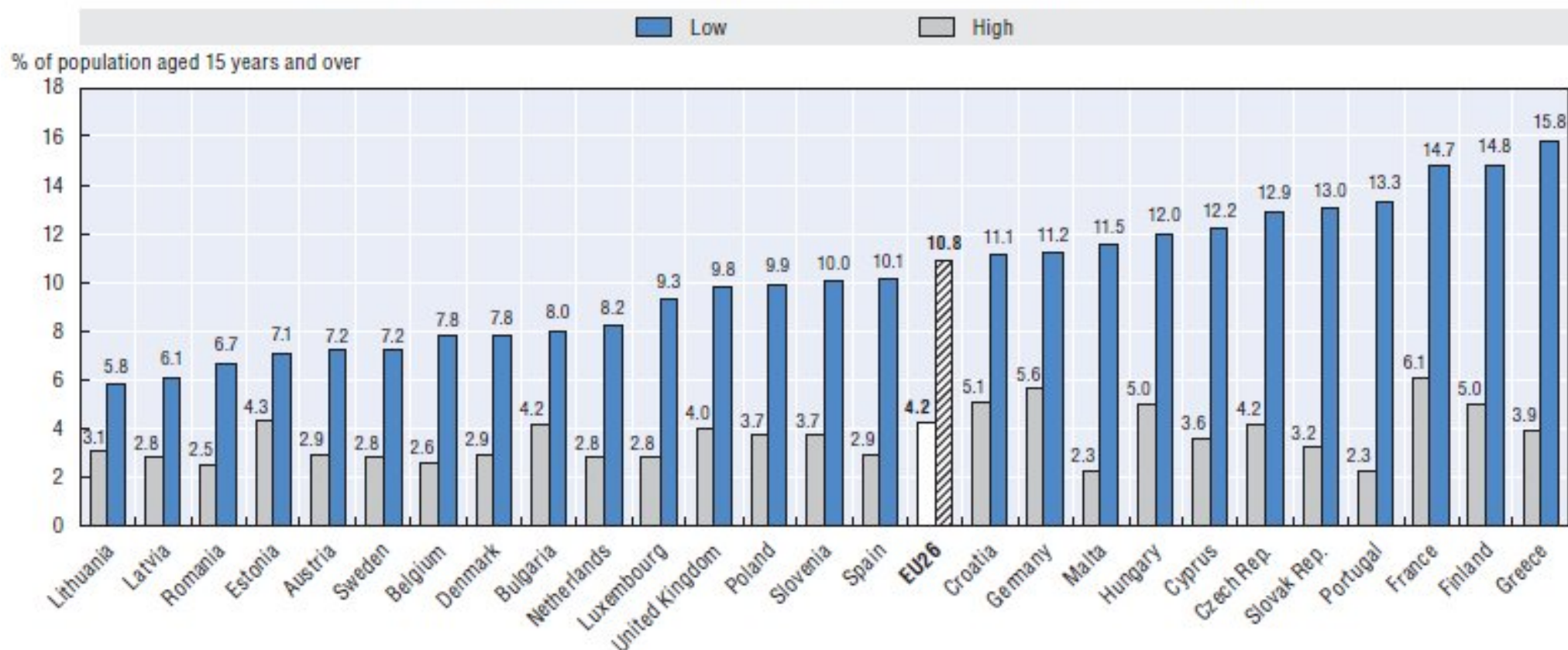Source: Eurostat Database, based on Health Interview Surveys.

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

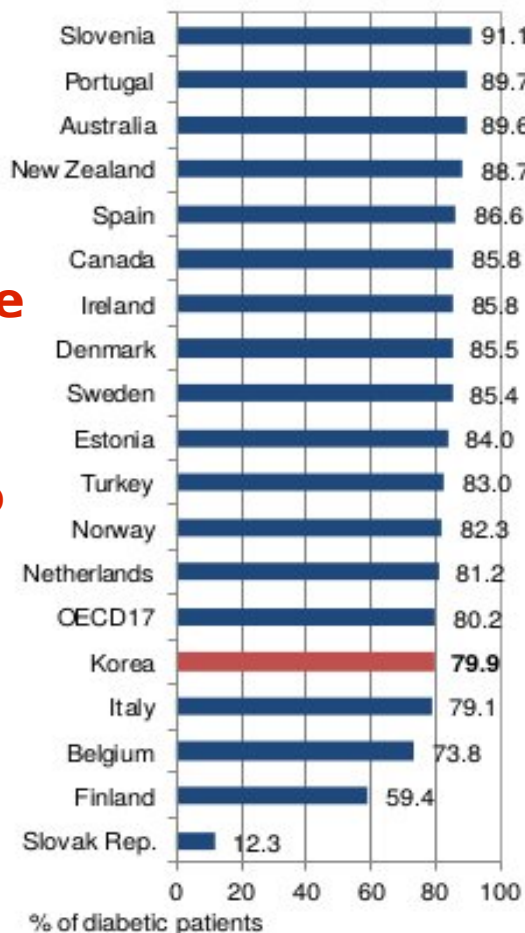6.11. **Diabetes hospital admission in adults, 2010 and 2015 (or nearest years)**

Age-sex standardised rates per 100 000 population

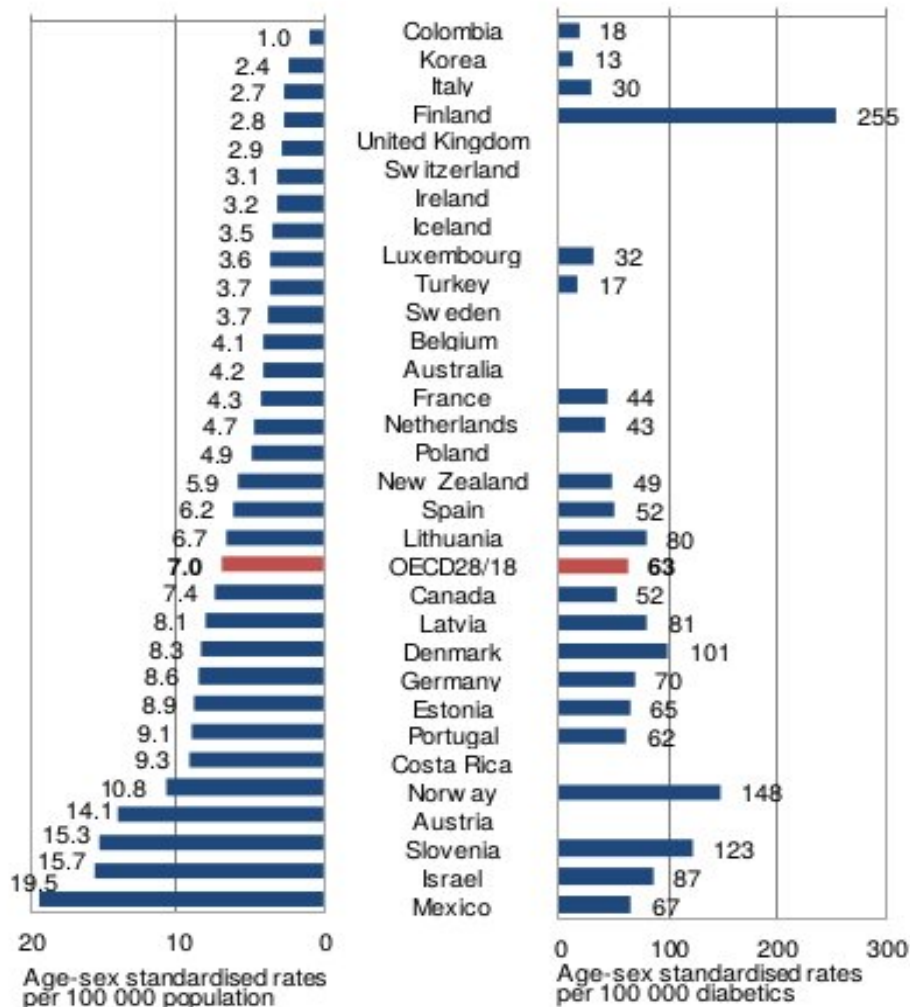● 2010 ● 2015
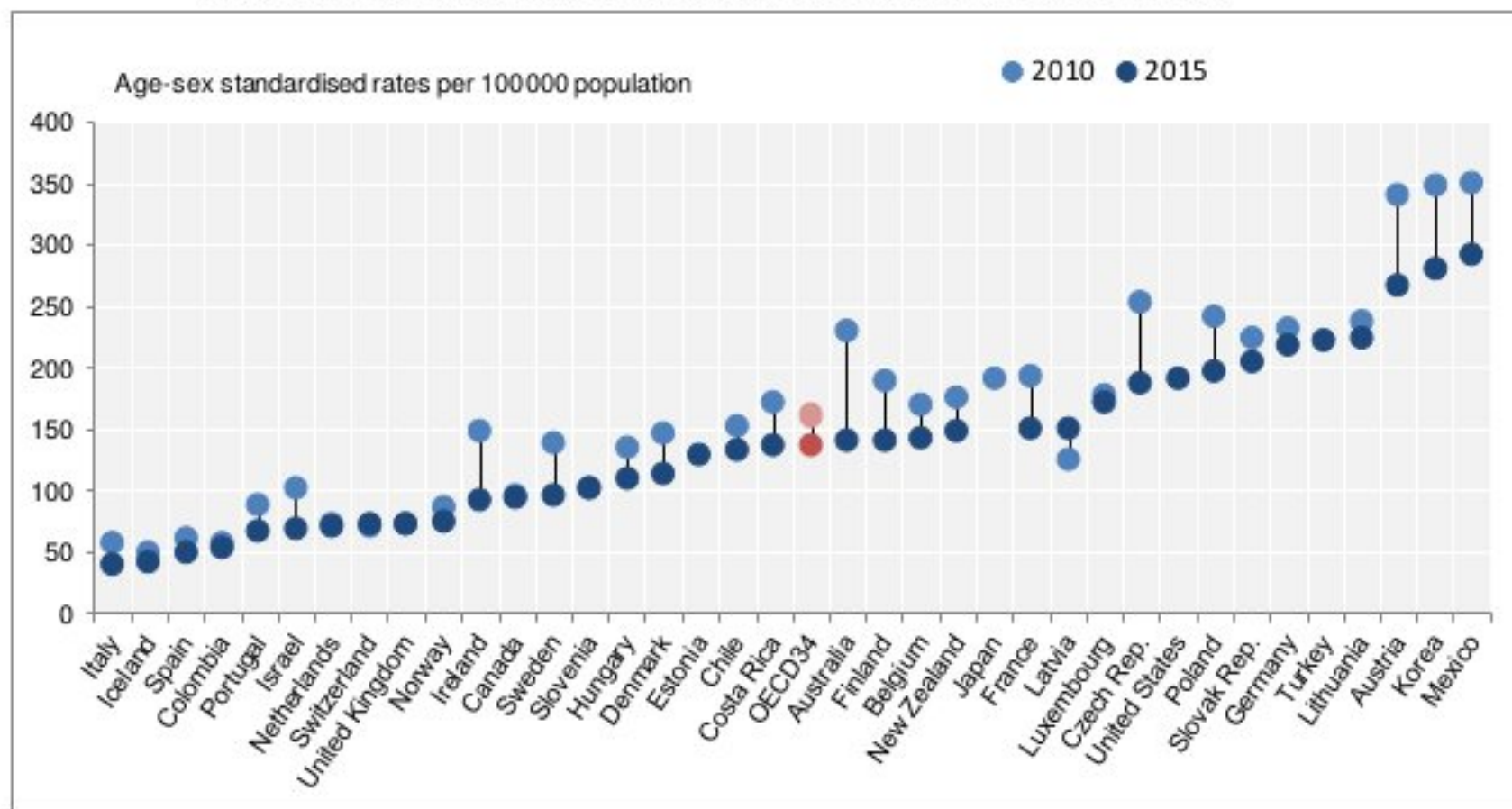
Note: Three-year average for Iceland and Luxembourg.
Source: OECD Health Statistics 2017.

Examples: Prescription of hypertensive and Lower extremity amputations in diabetes, 2015

Recent attempts to strengthen the information base: useful, but difficult to compile and interpret

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

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

% of diabetic patients

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

Country	Age-sex standardised rates per 100 000 population	Age-sex standardised rates per 100 000 diabetics
Colombia	1.0	18
Korea	2.4	13
Italy	2.7	30
Finland	2.8	255
United Kingdom	2.9	
Switzerland	3.1	
Ireland	3.2	
Iceland	3.5	
Luxembourg	3.6	32
Turkey	3.7	17
Sweden	3.7	
Belgium	4.1	
Australia	4.2	
France	4.3	44
Netherlands	4.7	43
Poland	4.9	
New Zealand	5.9	49
Spain	6.2	52
Lithuania	6.7	80
OECD28/18	**7.0**	**63**
Canada	7.4	52
Latvia	8.1	81
Denmark	8.3	101
Germany	8.6	70
Estonia	8.9	65
Portugal	9.1	62
Costa Rica	9.3	
Norway	10.8	148
Austria	14.1	
Slovenia	15.3	123
Israel	15.7	87
Mexico	19.5	67

Note: Three-year average for Iceland and Luxembourg.

Source: OECD Health Statistics 2017.

Source: OECD Health at a Glance 2017

From local to global:
Relevance of a new standard set in diabetes

- A global standard set in diabetes will help monitoring actions and plans in a comparable way, **Using more granular data of clinical relevance: same approach from single provider to countries and international organizations**

- **A complete set of measurement will allow exploring aspects that cannot be covered today:** integrated care, patient experiences and personal choices, etc.

- **A multidimensional approach can represent a valid model for all non communicable diseases**

- **The standard set will help connecting information stored in different silos (networks) and/or dispersed at the national/sub-national level**

Example: diabetes registers in Europe

HIGH QUALITY INFORMATION ... but...

- Heterogeneous
- Fragmented/Difficult to connect
- Regulated by different policy mechanisms
- Not based on standardised measures
- Lacking solid international comparisons
- Different principles for data sharing
- Regularly available only in national language

DATA

STATISTICAL OUTPUT

POPULATION-BASED DISEASE REGISTER

People with DISEASE

OUTCOMES

Total Population (Region)

INDICATOR

Numerator

Denominator
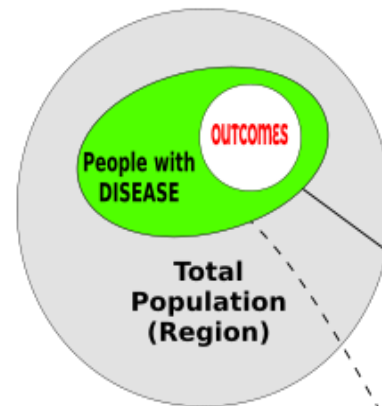
METHODOLOGY IS CRUCIAL IN THE CONSTRUCTION AND USE OF DISEASE REGISTERS
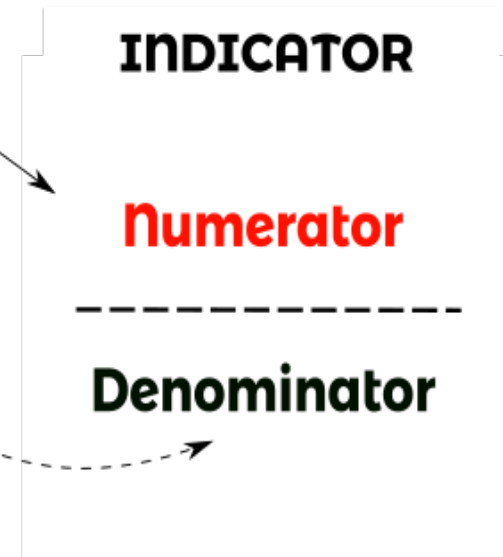
Different types of models for data collection may bias the results...

DATA

STATISTICAL OUTPUT

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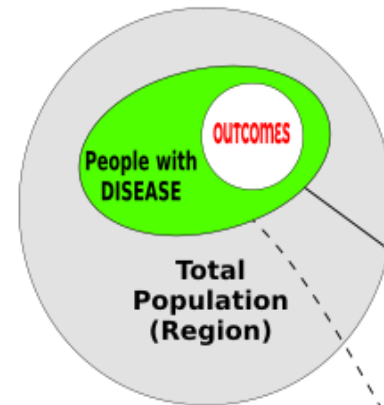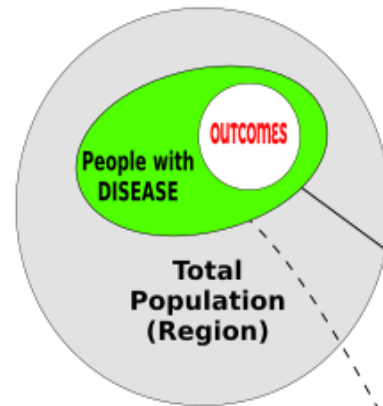
POPULATION-BASED
DISEASE REGISTER
LINKED TO A
PROVIDER SOURCE

OUTCOMES
People with DISEASE
Total Population (Region)

Provider Database
OUTCOMES
People with DISEASE
Total Population (Region)

INDICATOR

$$\frac{\text{Numerator}}{\text{Denominator}}$$

Different data sources may lead to very different results...
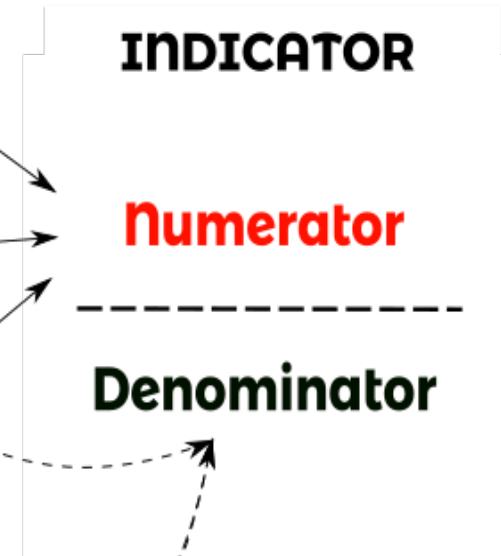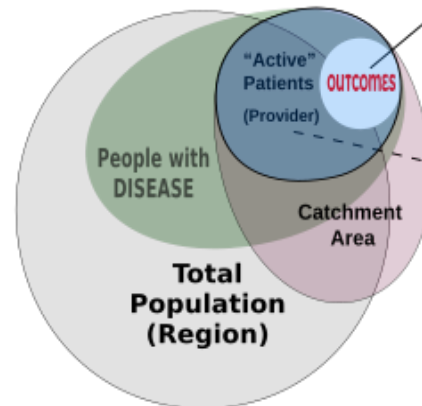
Structure of a population-based disease register

Allows collecting a range of measures in a rigorous manner!
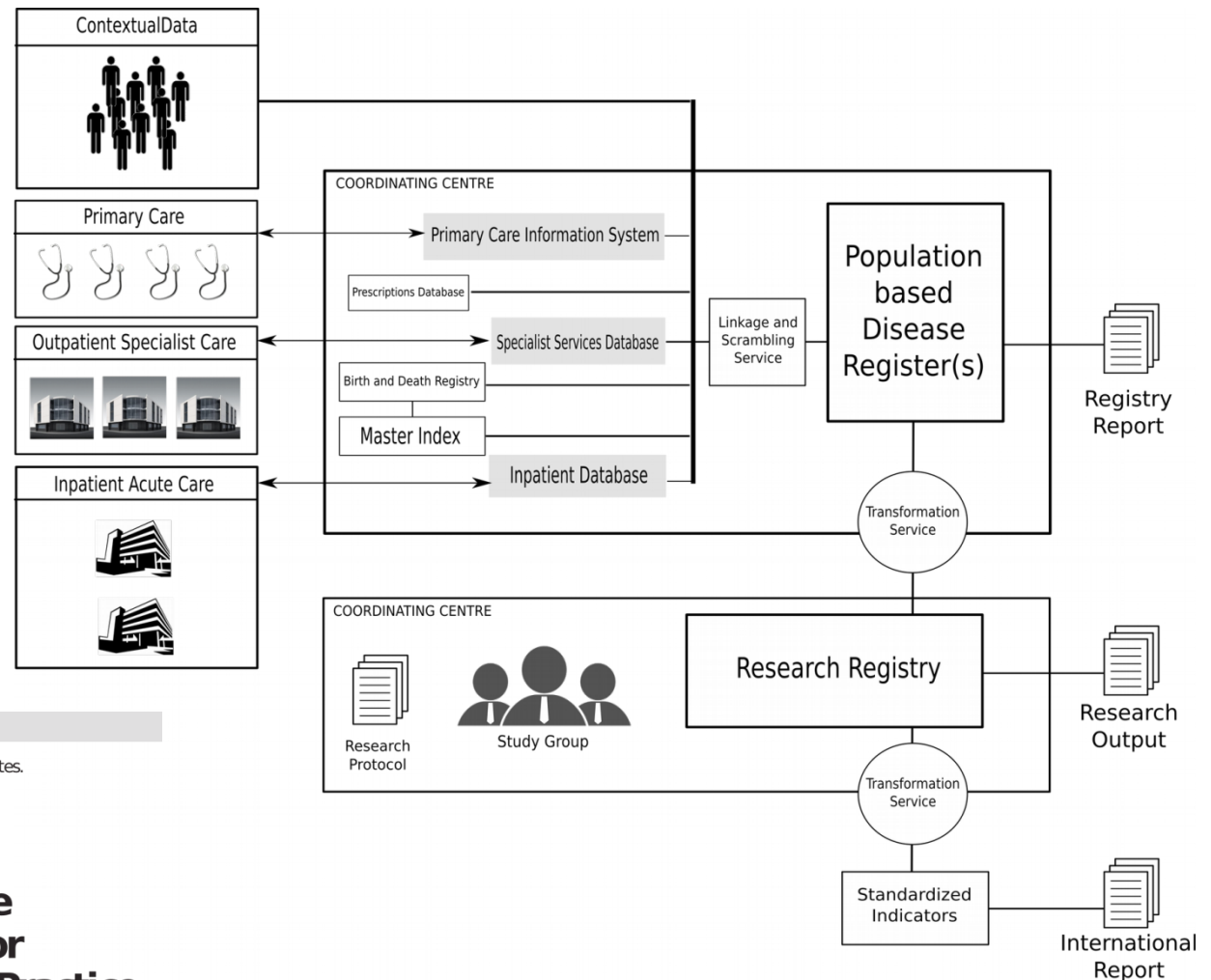
Standardized Information Exchange in Diabetes: Integrated Registries for Governance, Research, and Clinical Practice

F. Carinci[a] · C.T. Di Iorio[a] · M. Massi Benedetti[b]

[a]Serectrix snc, Pescara, [b]Hub for International Health Research, Perugia, Italy

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
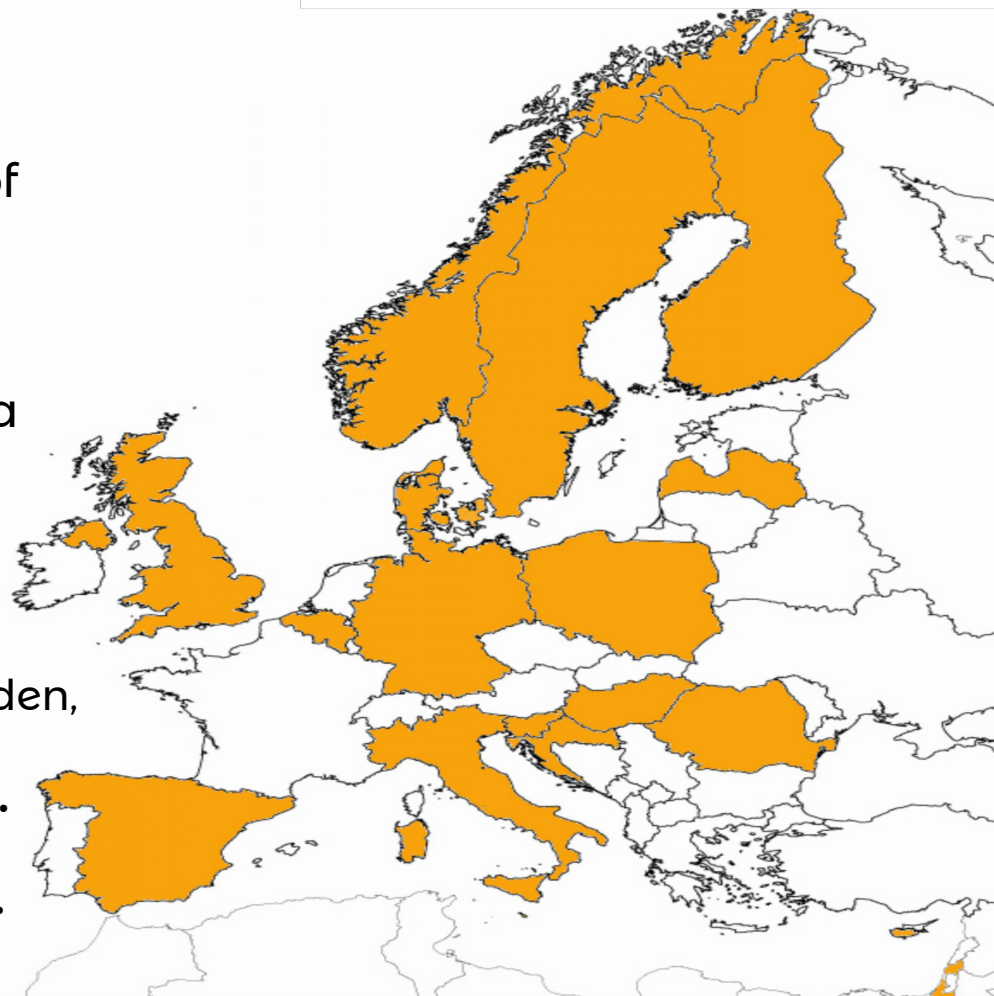
Timeframe: August-September 2017

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?

EU BIRO and EUBIROD projects

EU DG-SANCO co-funded public health projects

BIRO project (2005-2009)

EUBIROD project (2008-2012)

BRIDGE-HEALTH (2015-2017)

Law, ethics and medicine

Privacy impact assessment in the design of transnational public health information systems: the BIRO project

C T Di Iorio,[1] F Carinci,[1] J Azzopardi,[2] V Baglioni,[3] P Beck,[4] S Cunningham,[5] A Evripidou,[6] G Leese,[7] K F Loevaas,[8] G Olympios,[6] M Orsini Federici,[3] S Pruna,[9] P Palladino,[10] S Skeie,[8] P Taverner,[8] V Traynor,[6] M Massi Benedetti[3]

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

European Journal of Public Health, 000–000
© The Author 2012. Published by Oxford University Press on behalf of the European Public Health Association. All rights reserved.
doi:10.1093/eurpub/cks043

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

Concetta Tania Di Iorio[1], Fabrizio Carinci[1], Massimo Brillante[2], Joseph Azzopardi[3], Peter Beck[4], Natasa Bratina[5], Scott G. Cunningham[2], Carine De Beaufort[6], Noemi Debacker[7], Przemyslawa Jarosz-Chobot[8], Michael Jecht[9], Ulf Lindblad[10], Tony Moulton[11], Želiko Metelko[12], Attila Nagy[13], George Olympios[14], Simion Pruna[15], Michael Røder[16], Svein Skeie[17], Fred Storms[18], Massimo Massi Benedetti[19]

Original Articles

Core Standards of the EUBIROD Project*

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

S. G. Cunningham[1]; F. Carinci[2,3]; M. Brillante[1]; G. P. Leese1[1]; R. R. McAlpine1[1]; J. Azzopardi[4]; P. Beck[5]; N. Bratina[6]; V. Boucquet[7]; K. Doggen[8]; P. K. Jarosz-Chobot[9]; M. Jecht[10]; U. Lindblad[11]; T. Moulton[12]; Ž. Metelko[13]; A. Nagy[14]; G. Olympios[15]; S. Pruna[16]; S. Skeie[17]; F. Storms[18]; C. T. Di Iorio[19]; M. Massi Benedetti[2]

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

Contents lists available at ScienceDirect

HEALTH POLICY

Health Policy

ELSEVIER   journal homepage: www.elsevier.com/locate/healthpol

Essential levels of health information in Europe: An action plan for a coherent and sustainable infrastructure

Fabrizio Carinci[a,b,*]

[a] EUBIROD Network, Hub for International health ReSearch (HIRS), Perugia, Italy
[b] Serectrix snc, Pescara, Italy

Successful Road Test EUBIROD Report (2012)
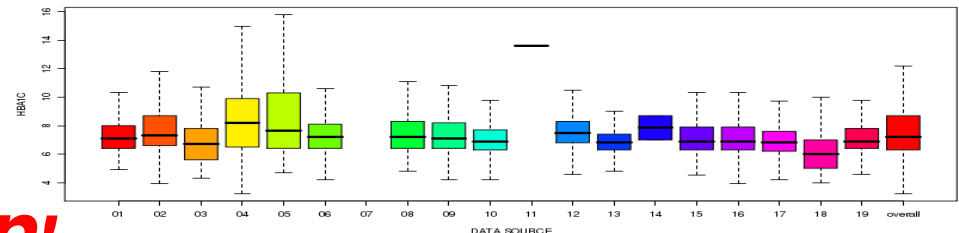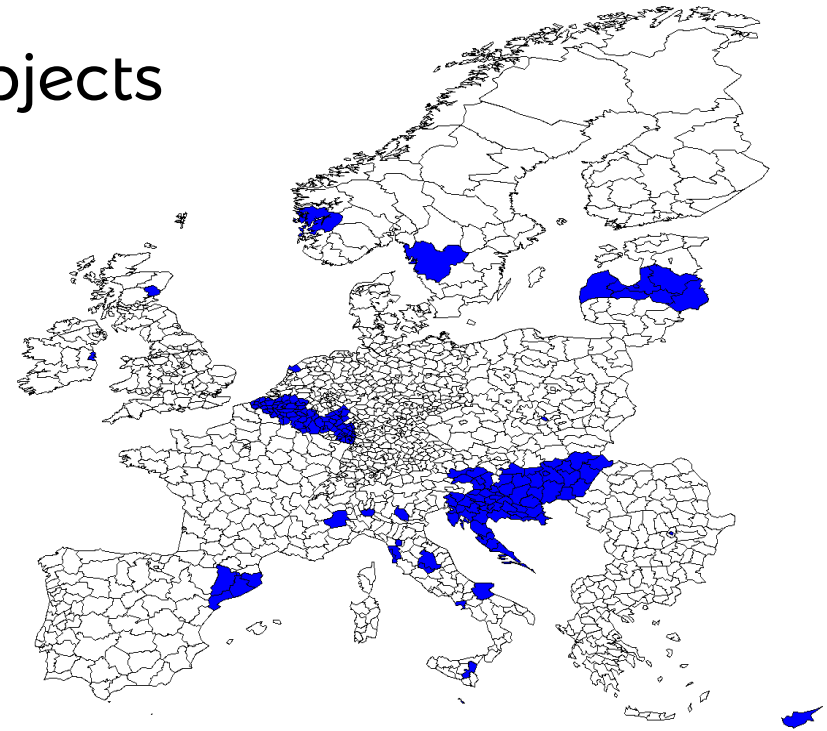
8/2/2012: New BIRO Release 2.1.12
15/2/2012: Collection of statistical objects
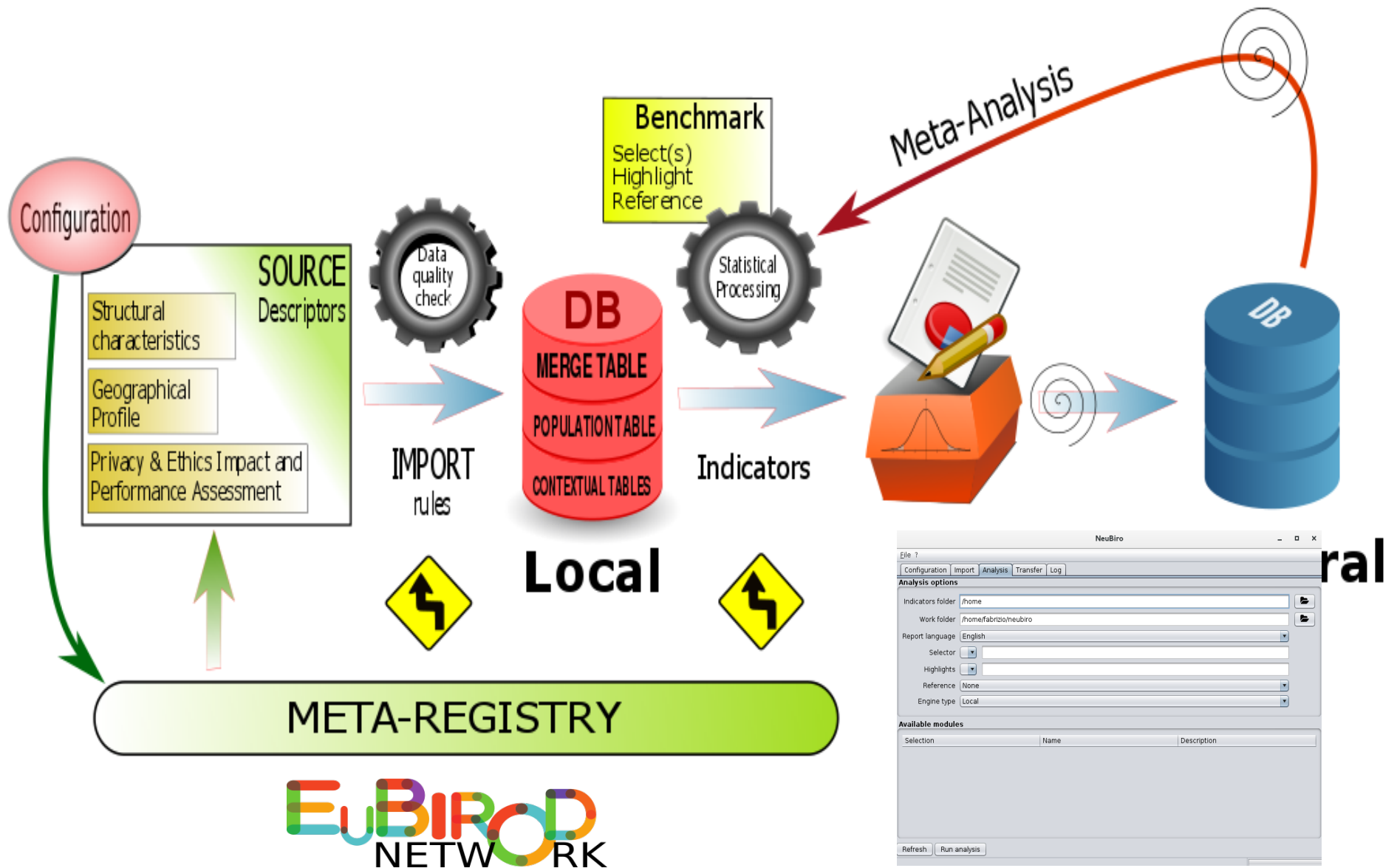**21/2/2012: EU Draft Report from 18 countries (N=79 indicators)**

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!

General Software for Federated Analysis

EuBIROD NETWORK

Linking registers through common information standards: "federated" model

- 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
- 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

Partnerships are essential to implement common standards in the public interest

Coordinating Centre

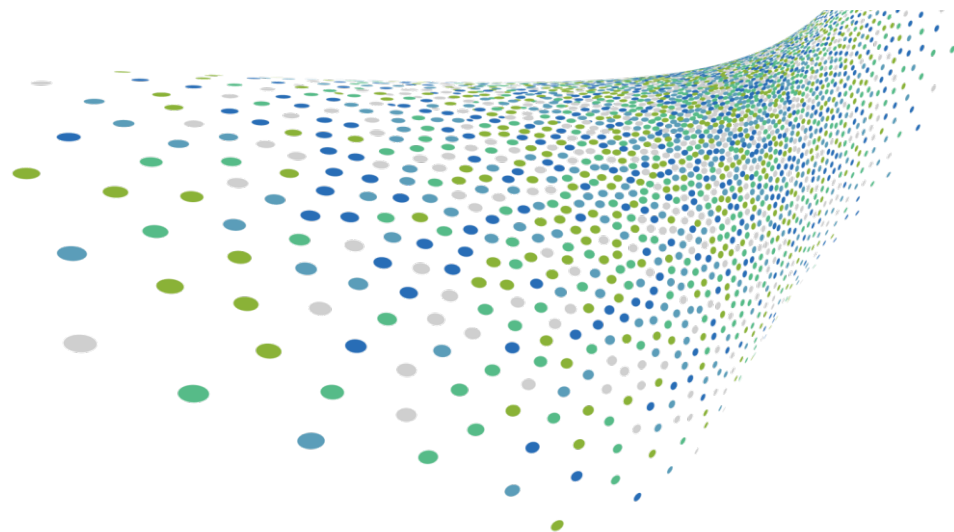HIRS HUB FOR INTERNATIONAL HEALTH RESEARCH

- **Sharing:**
  - Information
  - Best practices
  - Tools
  - Methods
- **Creating Opportunities for:**
  - Targeted Research Partnerships
  - Direct Involvement with EU/International Organizations
- **Building together:**
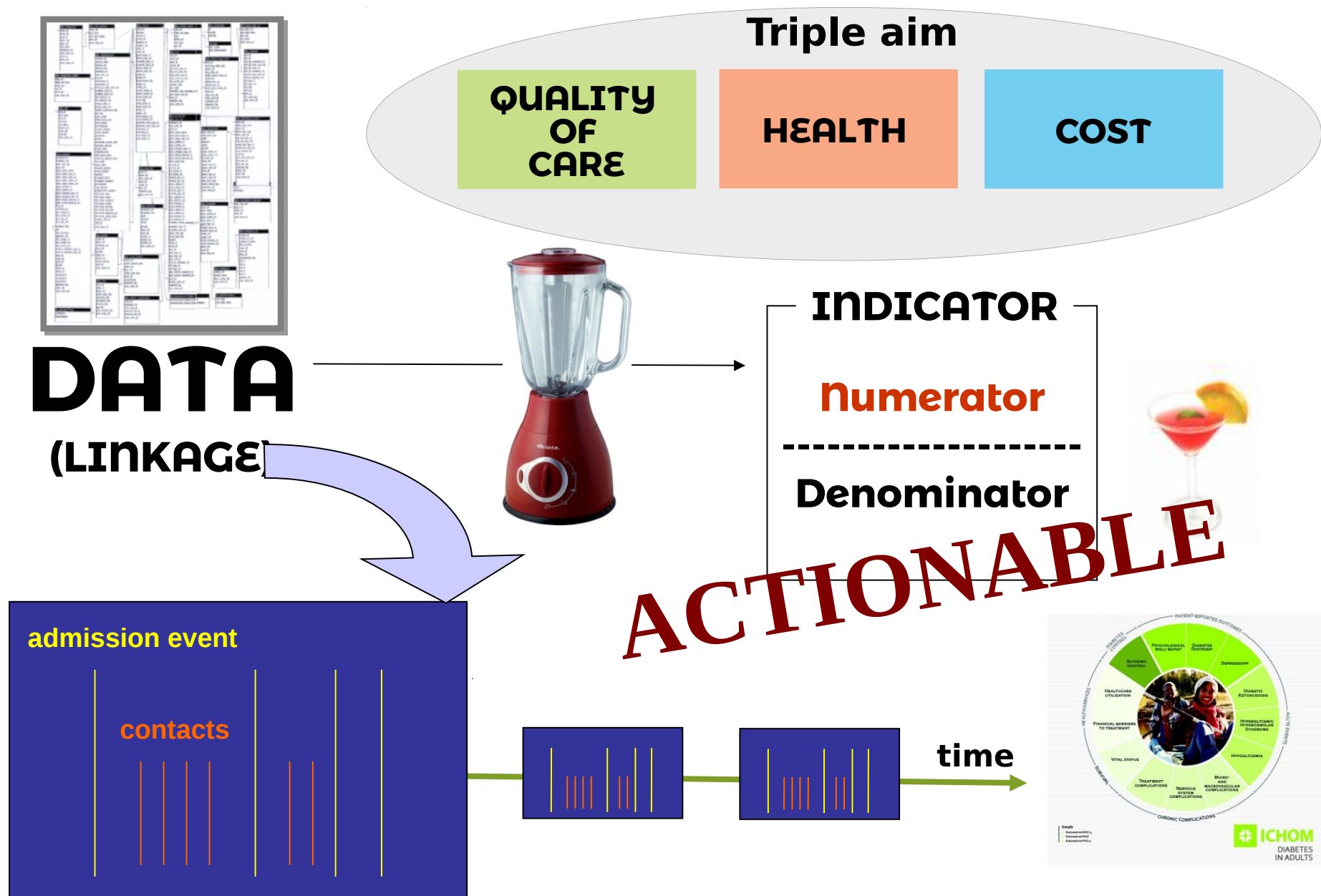 - Global platform for diabetes monitoring

Person-centred health systems

...a wind of change?

At the OECD Health Ministerial 2017, Health Ministers from around the globe:
- committed to realise person-centred 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)

A data model for person-centred health care

Triple aim

| QUALITY OF CARE | HEALTH | COST |

DATA (LINKAGE)

INDICATOR

Numerator

Denominator

ACTIONABLE

admission event

contacts

time

Time to make progress together?