# Diabetes information in Europe

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# Why do we need diabetes 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

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# What do we actually know routinely?

- Not much

- 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)

EuBIROD NETWORK

# 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; R. R. McAlpine1; 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]

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| 1 DEMOGRAPHIC CHARACTERISTICS | | 1.1 Basic demographics | |
|---|---|---|---|
| 2 CLINICAL CHARACTERISTICS | | 2.1 Diabetes status | |
| | 2.2 Risk factors for diabetes complications | 2.2.1 Obesity and Growth (most recent value in the last 12 months) | |
| | | 2.2.2 Lifestyle | |
| | | 2.2.3 Clinical measurements (most recent value in the last 12 months) | |
| | | 2.3 Diabetes complications | |
| 3 HEALTH SYSTEM | | 3.1 Structure (provider level) | |
| | | 3.2 Structural quality | |
| | 3.3 Processes | 3.3.1 Foot examination | |
| | | 3.3.2 Eye examination | |
| | | 3.3.3 Measurement done (in the last 12 months) | |
| | | 3.3.4 Treatment (at least one prescription in the last 12 months) | |
| | | 3.3.5 Management | |
| 4 POPULATION | | 4.1 Area level | |
| 5 RISK ADJUSTED INDICATORS | | 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) | |

….but the data available are already enough to seriously worry…

…and urge countries to deliver <u>and use</u> more information on diabetes!

# Deaths due to diabetes mellitus

Standardized death rate by 100 000 inhabitants, Year 2014

Source: Eurostat
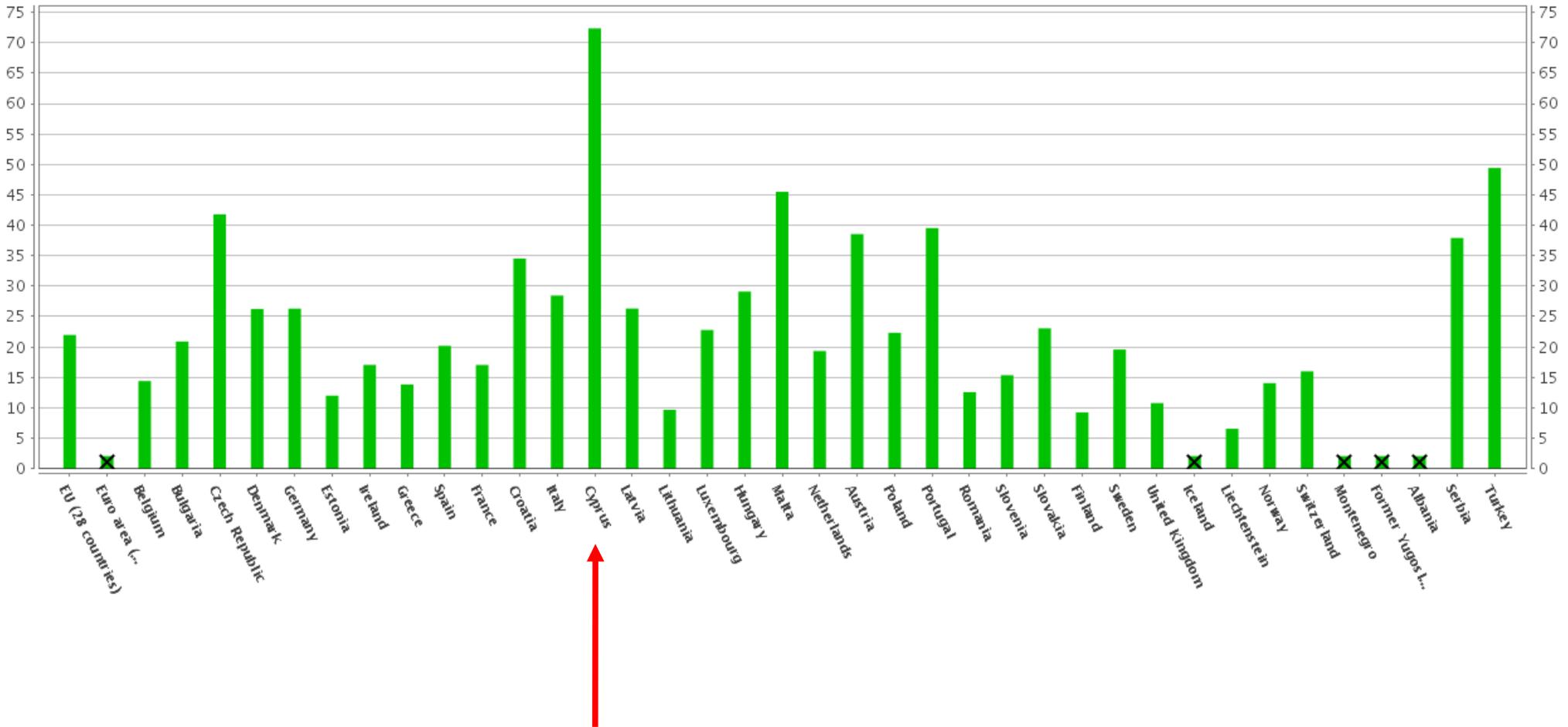
# Diabetes Prevalence

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)
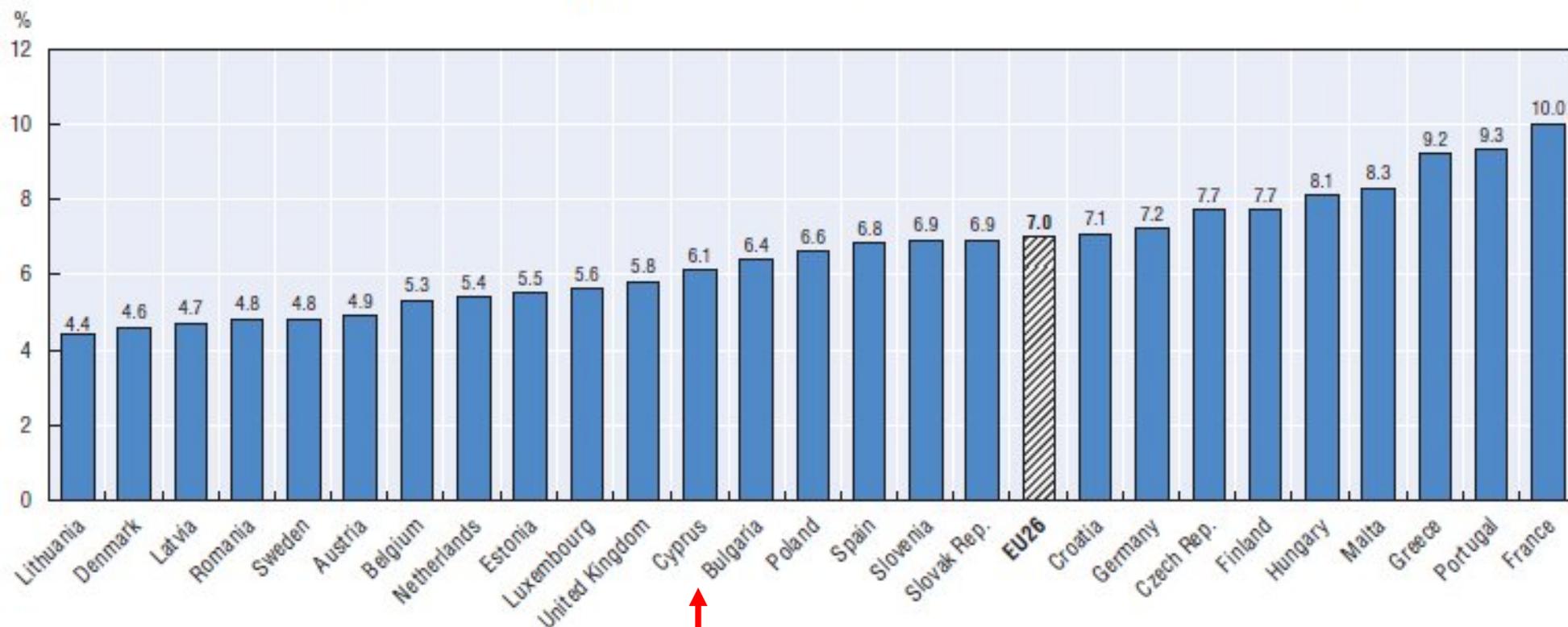
Source: Eurostat Database, based on Health Interview Surveys.

# 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)**

Legend: Low / High

% of population aged 15 years and over

| Country | Low | High |
|---|---|---|
| Lithuania | 5.8 | 3.1 |
| Latvia | 6.1 | 2.8 |
| Romania | 6.7 | 2.5 |
| Estonia | 7.1 | 4.3 |
| Austria | 7.2 | 2.9 |
| Sweden | 7.2 | 2.8 |
| Belgium | 7.8 | 2.6 |
| Denmark | 7.8 | 2.9 |
| Bulgaria | 8.0 | 4.2 |
| Netherlands | 8.2 | 2.8 |
| Luxembourg | 9.3 | 2.8 |
| United Kingdom | 9.8 | 4.0 |
| Poland | 9.9 | 3.7 |
| Slovenia | 10.0 | 3.7 |
| Spain | 10.1 | 2.9 |
| EU26 | 10.8 | 4.2 |
| Croatia | 11.1 | 5.1 |
| Germany | 11.2 | 5.6 |
| Malta | 11.5 | 2.3 |
| Hungary | 12.0 | 5.0 |
| Cyprus | 12.2 | 3.6 |
| Czech Rep. | 12.9 | 4.2 |
| Slovak Rep. | 13.0 | 3.2 |
| Portugal | 13.3 | 2.3 |
| France | 14.7 | 6.1 |
| Finland | 14.8 | 5.0 |
| Greece | 15.8 | 3.9 |

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)**
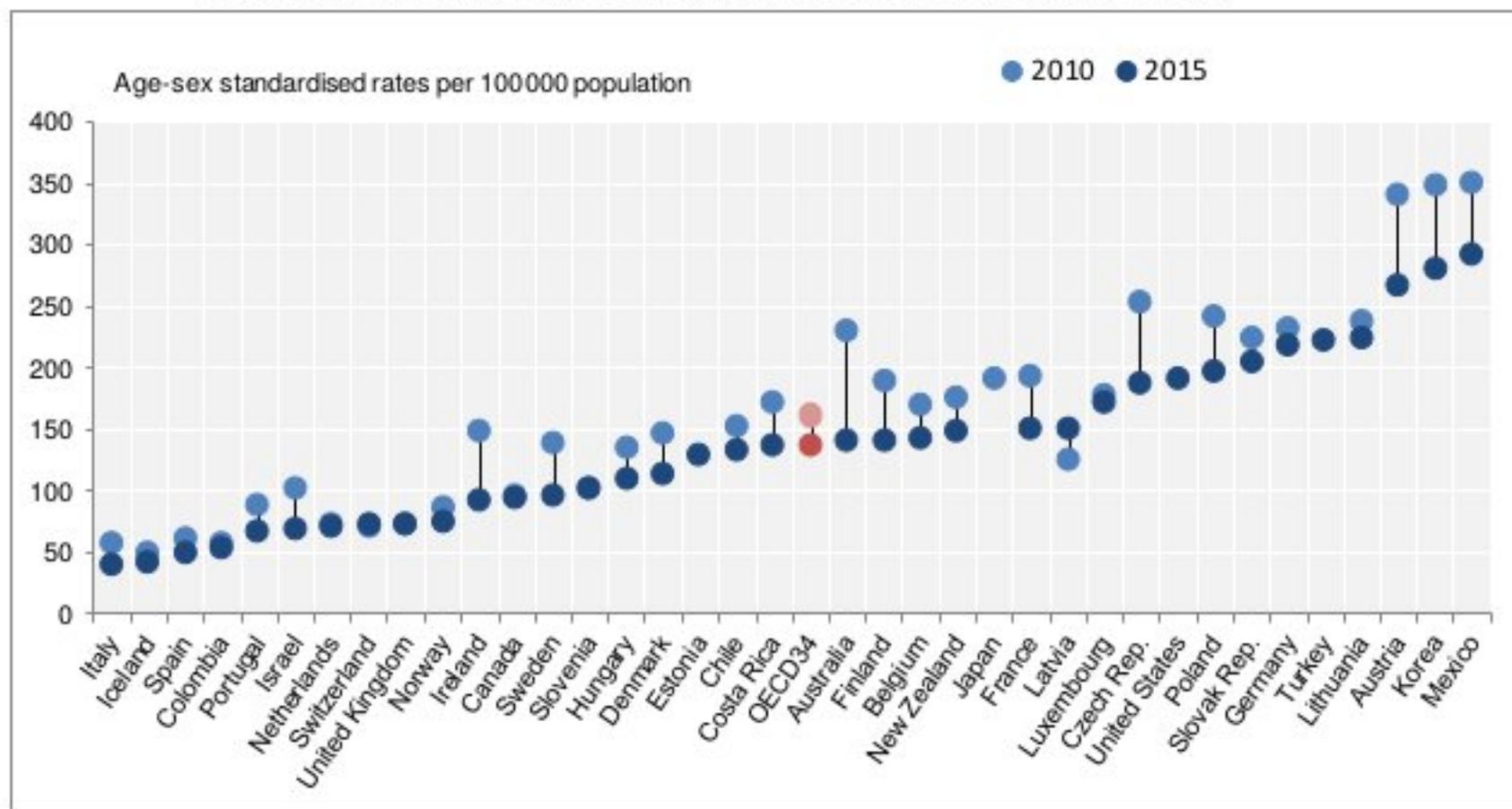
Note: Three-year average for Iceland and Luxembourg.

Source: OECD Health Statistics 2017.

# Prescription of hypertensive 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)**

| 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

*Source: OECD Health Statistics 2017.*
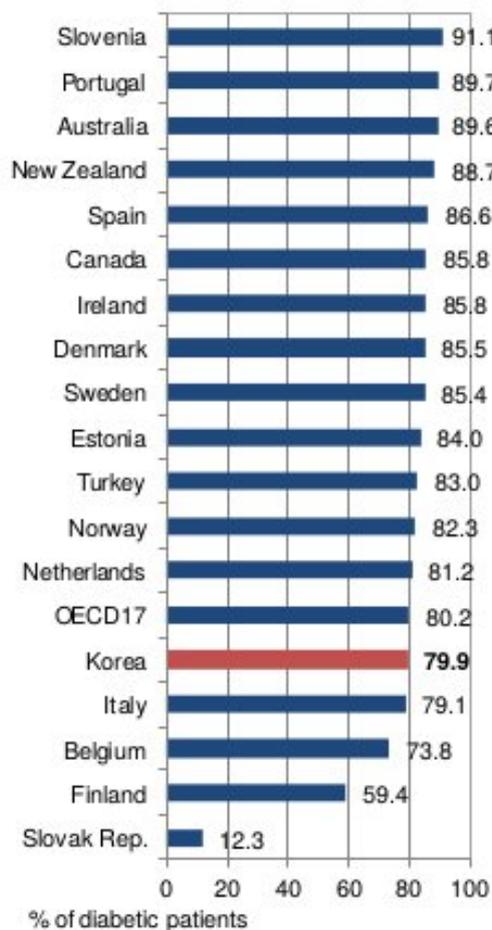
**6.13. Major lower extremity amputation in adults with diabetes, 2015 (or nearest year)**

| 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.*

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

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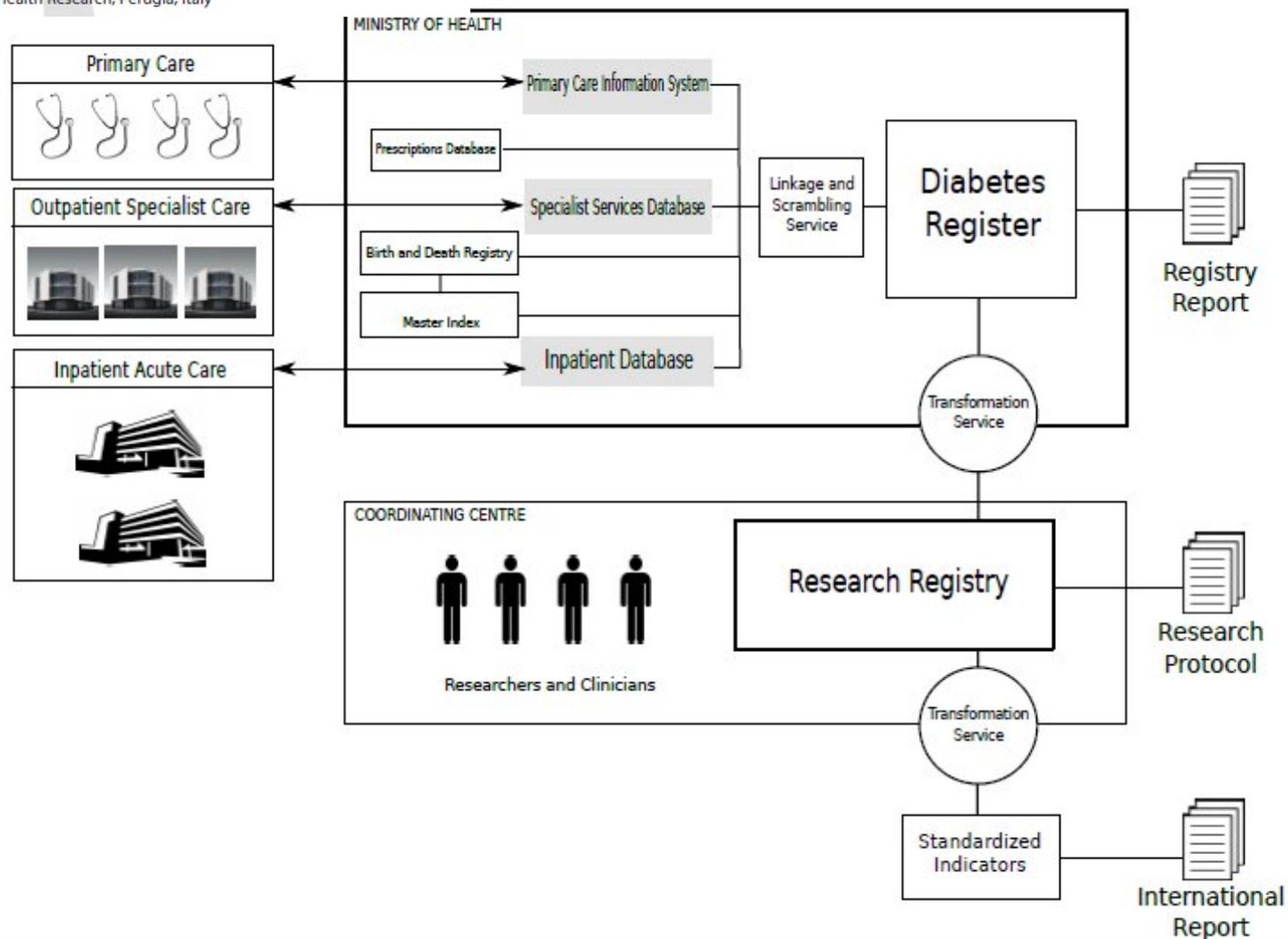
# General characteristics and number of indicators delivered by Diabetes Registers contributing to the EUBIROD Report 2012

| Diabetes Register | ID | Site type | No. Indicators Delivered |
|---|---|---|---|
| Healthgate, Styria, Austria | AT | Regional Shared-data Register | 67 |
| IPH Survey, Belgium | BE | National Data – Complete | 64 |
| Larnaca Region, Cyprus | CY | Regional Shared-data Register | 73 |
| Rheinland-Pfalz, Germany | DE | Regional Shared-data Register | 73 |
| IDIBAPS Diabetes Clinical Data Collection, Spain | ES | Sample Regional Data | 21 |
| National Diabetes Register, Croatia | HR | National Data – Complete | 75 |
| GPMSSP Database, Hungary | HU | GP | 51 |
| Tallaght, Ireland | IE | Hospital Clinic (Diabetes) | 57 |
| Umbria Region and SID National Network, Italy | IT | Hospital Clinics (Diabetes, Internal Medicine) | 78 |
| Pediatric Registry, Luxembourg | LU | Hospital Clinic (Diabetes) | 21 |
| National Diabetes Registry Database, Latvia | LV | National Data – Complete | 58 |
| Mater Dei Hospital, Malta | MT | Disease Management Programme | 30 |
| West Friesland Region, Netherlands | NL | Regional Shared-data Register | 52 |
| National Diabetes Register, Norway | NO | National Data – Sample | 57 |
| Paediatric Diabetes Register of Silesia, Poland | PL | Regional Shared-data Register | 70 |
| Bucharest Diabetes Database, Romania | RO | Hospital Clinic (Diabetes) | 41 |
| Skaraborg Primary Care Diabetes Database, Sweden | SE | Regional Primary Care Project | 63 |
| Type 1 Childhood Diabetes Register, Slovenia | SI | National Data – Complete | 38 |
| DARTS, Tayside, Scotland, United Kingdom | UK | Regional Shared-data Register | 68 |

# General characteristics and number of indicators delivered by Diabetes Registers contributing to the EUBIROD Report 2012

| Select whole table | Type 1 | | | | | | | | | Type 2 | | | | | | | | | Other Type |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | Age % | | | Duration of Diabetes % | | | | | | Age % | | | | Duration of Diabetes % | | | | |
| ID | Males % | <15 | 15-25 | 25-65 | ≥65 | <10 | 10-20 | ≥20 | N | Males % | <50 | 50-65 | 65-80 | ≥80 | <10 | 10-20 | ≥20 | N | N |
| AT | 49.2 | - | 8.6 | 46.5 | 44.9 | 17.8 | 37.8 | 44.3 | 185 | 48.4 | 8.4 | 25.1 | 43.6 | 22.9 | 56.4 | 29.1 | 14.5 | 1,191 | - |
| BE | 57.7 | - | 8.0 | 50.1 | 41.9 | 28.6 | 30.2 | 41.2 | 3,359 | 48.9 | 6.6 | 31.2 | 46.1 | 16.0 | 30.8 | 41.8 | 27.4 | 7,304 | - |
| CY | 56.6 | - | 17.0 | 60.4 | 22.6 | 28.3 | 30.2 | 41.5 | 53 | 54.2 | 6.7 | 40.1 | 46.7 | 6.4 | 55.2 | 29.8 | 15.0 | 745 | - |
| DE | 56.9 | 4.8 | 12.1 | 38.4 | 44.7 | 34.6 | 30.1 | 35.3 | 1,800 | 49.2 | 8.7 | 26.8 | 47.5 | 16.9 | 54.0 | 32.0 | 14.0 | 12,569 | 354 |
| ES | 42.1 | - | 14.0 | 64.0 | 21.9 | 16.7 | 35.1 | 48.2 | 114 | 40.7 | 18.5 | 50.9 | 26.9 | 3.7 | 51.9 | 25.9 | 22.2 | 108 | - |
| HR | 50.3 | 0.7 | 8.6 | 55.9 | 34.8 | 32.1 | 30.5 | 37.4 | 1,818 | 52.1 | 8.6 | 40.3 | 44.4 | 6.7 | 51.2 | 33.1 | 15.7 | 22,810 | 427 |
| HU | - | - | - | - | - | - | - | - | - | 48.7 | 7.2 | 38.9 | 45.3 | 8.6 | 66.1 | 28.7 | 5.2 | 1,306 | - |
| IE | 54.6 | 17.7 | 24.0 | 39.9 | 18.3 | 80.1 | 8.8 | 11.1 | 879 | 59.4 | 13.9 | 41.5 | 35.0 | 9.5 | 91.7 | 6.9 | 1.3 | 3,782 | 388 |
| IT | 51.6 | 1.4 | 13.5 | 56.3 | 28.8 | 25.6 | 30.5 | 43.9 | 4,391 | 55.1 | 5.9 | 30.7 | 49.4 | 14.0 | 47.7 | 29.9 | 22.3 | 37,068 | 1,500 |
| LU | 42.5 | 46.2 | 47.5 | 6.2 | 0.0 | 83.1 | 15.0 | 1.9 | 160 | - | - | - | - | - | - | - | - | - | - |
| LV | 55.3 | 7.1 | 13.6 | 44.7 | 34.6 | 40.4 | 26.7 | 32.9 | 2,831 | 32.8 | 6.4 | 33.6 | 47.8 | 12.2 | 75.6 | 18.1 | 6.3 | 50,933 | 300 |
| MT | 58.6 | 2.9 | 30.0 | 48.6 | 18.6 | 50.0 | 24.3 | 25.7 | 70 | 56.7 | 10.4 | 40.7 | 40.0 | 8.9 | 77.4 | 16.0 | 6.6 | 2,712 | 55 |
| NL | - | - | - | - | - | - | - | - | - | 53.0 | 8.9 | 36.3 | 43.5 | 11.2 | 68.6 | 26.0 | 5.5 | 4,884 | - |
| NO | 53.5 | - | 13.9 | 54.9 | 31.2 | 23.0 | 27.5 | 49.5 | 2,049 | 56.8 | 13.5 | 34.3 | 39.2 | 12.9 | 61.4 | 30.1 | 8.5 | 2,860 | - |
| PL | 53.1 | 68.7 | 31.3 | 0.0 | 0.0 | 95.3 | 4.7 | - | 467 | - | - | - | - | - | - | - | - | - | - |
| RO | - | - | - | - | - | - | - | - | - | 49.7 | 19.3 | 51.0 | 27.2 | 2.5 | 100.0 | 0.0 | 0.0 | 1,767 | - |
| SE | 59.7 | - | 0.8 | 23.9 | 75.3 | 42.0 | 58.0 | - | 243 | 55.4 | 5.6 | 27.3 | 49.4 | 17.7 | 73.3 | 26.7 | 0.0 | 7,475 | 749 |
| SI | 52.3 | 34.3 | 60.2 | 5.5 | 0.0 | 68.4 | 28.2 | 3.4 | 440 | - | - | - | - | - | - | - | - | - | - |
| UK | 54.4 | 6.8 | 15.9 | 45.1 | 32.2 | 32.5 | 26.1 | 41.4 | 1,803 | 54.4 | 9.0 | 30.9 | 42.5 | 17.6 | 70.3 | 23.7 | 6.0 | 17,832 | - |
| Overall | 54.0 | 5.7 | 14.3 | 47.1 | 32.8 | 35.2 | 27.9 | 36.9 | 20,662 | 47.4 | 7.6 | 33.3 | 46.2 | 12.9 | 62.4 | 25.6 | 12.0 | 175,346 | 3,773 |

# Objectives of the Cyprus meeting

- To share best practices on the management and use of diabetes information in support of national strategies in Cyprus

- To review adherence to privacy and ethics principles in complex health databases, in the framework of new EU regulations and OECD recommendations

- To report on the state of the art of diabetes data sources in Europe

- To review and finalize blueprints and new software for secure international data collection of diabetes indicators from the existing databases

- To revise our future collective strategies and plan the EUBIROD data collection 2017

# EUBIROD in Cyprus: growing together



23-26th May 2007, Larnaca

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]
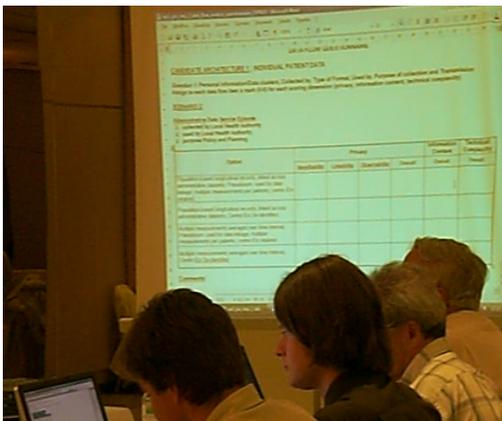
EUBIROD Final Meeting - Larnaca, 24-25th February 2012

**Diabetes Information for European Citizens**

Realized with the generous support of:

The Cyprus Diabetes Association          Cyprus Ministry of Health

Session 1. Diabetes Information in Cyprus

• **The role of the Cyprus Diabetes Association**
  (Stavros Michael, President, Cyprus Diabetes Association)

→ EUBIROD Diabetes Report

BRIDGEHEALTH
BRidging Information and Data Generation for Evidence-based Health Policy and Research

EuBIROD NETWORK
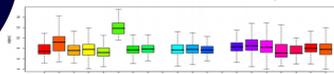
Nicosia, 20-23rd September 2017

User

Technical