



**International
Diabetes Federation
Europe**



Improving the well-being of people with diabetes and those at risk

Organised by IDF Europe, under the auspices of the Finnish Presidency

14 November 2019, 12.30-15.00

Lunch event, European Parliament, Brussels, MEP Salon

Transforming diabetes outcomes: the role of diabetes registries

Prof Massimo Massi-Benedetti, Coordinator, EUBIROD

Different registries for different

Targets

- Research
- Epidemiology
- Administrative purposes
- Quality of care improvement

Beneficiaries

- People affected by diabetes
- Policy makers
- Health care decision makers
- Health care administrators
- Health professionals
- Research institutions
- Industry
- The general population

European Parliament Resolution of 14 March 2012 addressing the EU diabetes epidemic (2011/2911 RSP)

“The European Parliament,

- ***Calls on the Commission to draw up common, standardised criteria and methods for data collection on diabetes, and, in collaboration with the Member States, to coordinate, collect, register, monitor and manage comprehensive epidemiological data on diabetes, and economic data on the direct and indirect costs of diabetes prevention and management”***

Until now
the EU Commission
has not satisfied
the call on European Diabetes Registry
of the EU Parliament

Status of the art of National Diabetes Registries in European countries

- **Very few European countries have fully working National Diabetes Registries**
- **In some countries local or regional Diabetes Registries are routinely used**
- **In other countries, already implemented registries have been terminated or put in hold due to difficulties of various type**
- **The vast majority of European countries do not have any local/national Diabetes Registry**

DIABETES EVIDENCE INITIATIVE CENTRAL EUROPE (DEICE)

AN EXPERT DECLARATION

Leveraging evidence-based practices to improve diabetes in Central Europe



WORKING GROUP 1: Development of registries

The need for registries to measure, share and improve data based on (better) practices. Considerations for establishing national/regional registries, including matters related to data privacy.

MEMBERS:

Prof Gabriela Roman (Romania), co-chair,
Prof Zdravko Kamenov, (Bulgaria), co-chair,
Dr. Zsolt Gaál (Hungary),
Prof Nebojša M. Lalić (Serbia),
Prof Jan Škrha (Czech Republic).

KEY FINDINGS: THE STATE OF AFFAIRS OF DIABETES REGISTRIES IN CENTRAL EUROPE

Countries in DEICE survey
with functional registries:
ZERO

MoH
is the key stakeholder

Low priority for **MoH** No/limited **Resources**

DATA ON SPECIFIC CONDITIONS AND FOR DIFFERENT PURPOSES ARE BEING COLLECTED BY SOME INTERNATIONAL ORGANIZATIONS SUCH AS THE

- ***JDRF REGISTRY FOR TYPE 1 DIABETES***
- ***OECD DATA COLLECTION ON LOWER LIMBS AMPUTATIONS IN PEOPLE WITH DIABETES***
- ***.....***

Some of the main problems for the realization of diabetes registries

- **Source(s) for data collection**
- **Standardization of data from different sources**
- **Regulatory issues**
- **Privacy**
- **Maintenance**
- **System updating**
- **Data processing**
- **Timely availability of outcomes**
- **Tailoring of information according to various constituencies**

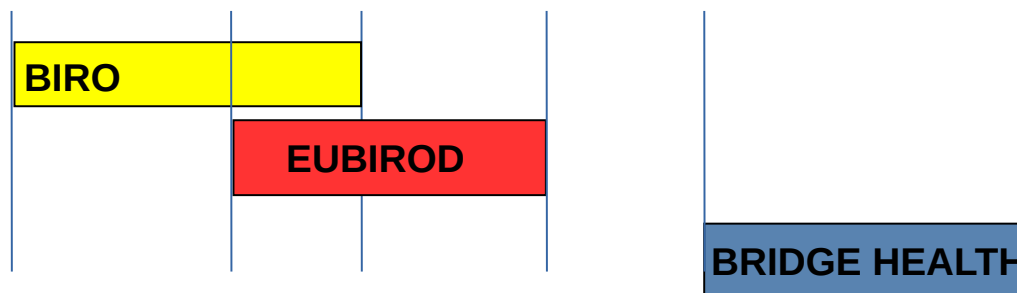
A European Network of Diabetes Data Sources: EUROPEAN BEST INFORMATION THROUGH REGIONAL OUTCOMES IN DIABETES

1. University of Perugia (I)
2. Serectrix snc (I)
3. University of Dundee (GB)
4. Joanneum Research (A)
5. NOKLUS (N)
6. Paulescu Institute (RO)
7. University of Malta (M)
8. Republic of Cyprus (CY)
9. Sahlgrenska Institute (SE)
10. University of Debrecen (H)
11. Institute of Public Health (B)
12. IDF (B)
13. Adelaide Meath Hospital (IRL)
14. CBO (NL)
15. Centre Hospitalier (LUX)
16. University of Ljubljana (SLO)
17. IMABIS Foundation (E)
18. Medical University Silesia (PL)
19. Havelhoe Hospital (D)
20. Hillerod University Hospital (DK)
21. Vuk Vrhovak University (HR)
22. University of Surrey (UK)
23. University Tor Vergata (I)

EU PROJECTS CONSORTIA



11/2005 9/2008 5/2009 3/2012 5/2015 11/2017



Collaborating Institutions:

24. Foundation for Care Information (NL)
25. Ministry of Health, Latvia
26. IDIBAPS, Spain
27. Dasman Diabetes Centre, Kuwait
28. Ministry of Health of Israel
29. National Diabetes Register of Sweden (SE)
30. German Diabetes Surveillance System (D)
31. National Diabetes Register of Denmark (DK)
32. THL (FI)

Some of the main problems for the realization of diabetes registries

As approached through the EUBIROD EU Project

- Source for data collection (*clinical, administrative, research, etc. databases*)
- Standardization of data from different sources (*data dictionary*)
- Regulatory issues (*compatibility with laws of all participating countries*)
- Privacy (*privacy by design*)
- Maintenance (*negligible work load, minimal cost*)
- System updating (*open source*)
- Data processing (*advanced statistical engines*)
- Timely availability of outcomes (*real time information*)
- Tailoring of information according to various constituencies (*patients, policy makers, administrators, HC professionals, general population*)

PROJECT PROPOSAL

THE EUROPEAN DIABETES REGISTER

A SHARED PLATFORM LINKING REGIONAL AND NATIONAL DIABETES DATA SOURCES USING A STANDARD SET TO MONITOR AND IMPROVE QUALITY OF CARE AND OUTCOMES OF PEOPLE WITH DIABETES

The **general objective** of the project is:

“to create an official European public website where all major diabetes indicators will be made routinely available on a regular basis (6/12/x months), using a standard set shared across public and private organizations to contribute towards a common repository to be used by decision makers, health professionals and single individuals to collectively improve quality of care and outcomes in the interest of people with diabetes”

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The **specific objectives** of the project are to secure a:

- **European shared governance structure**
- **Management structure**
- **Information infrastructure**
- **Sustainable funding mechanism**
- **Location of the Central Web Portal**

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Partners

- **IDF Europe (Coordination)**
- **IDF Europe interested members**
- **Members of the EUBIROD Network**
- **Any other interested public or private entity (tbd)**

Funding

- **EU sources as appropriate**

Definitive location of the registry

- **An EU infrastructure (tentatively the Joint Research Centre)**

In order to make the today's event not only a most laudable initiative for Diabetes awareness, it would be extraordinary if it could represent the starting point for a concrete collaboration between the European Diabetes "Universe" here represented by IDF Europe and the EU authorities for the realization of a European Diabetes Registry based on EU already highly successful investments