Information infrastructure for person-centred diabetes care

… state of the art of diabetes data sources in Europe …

EuBIROD NETWORK

University of Cyprus
21st September 2017

Welcome & Introduction

I. Štotl, U. Ljubljana

Main objective of the session

To produce a **collaborative scientific paper** authored by members of the EUBIROD Consortium, based on the document originally produced at the **Surrey Meeting in September 2015**.

1ˢᵗ EUBIROD Network General Assembly

24th-25th August 2015
Guildford, Surrey, UK

14 countries presented their national frameworks in a common document.

Extensive and very useful source of informations about the actual state of diabetes registries in Europe.
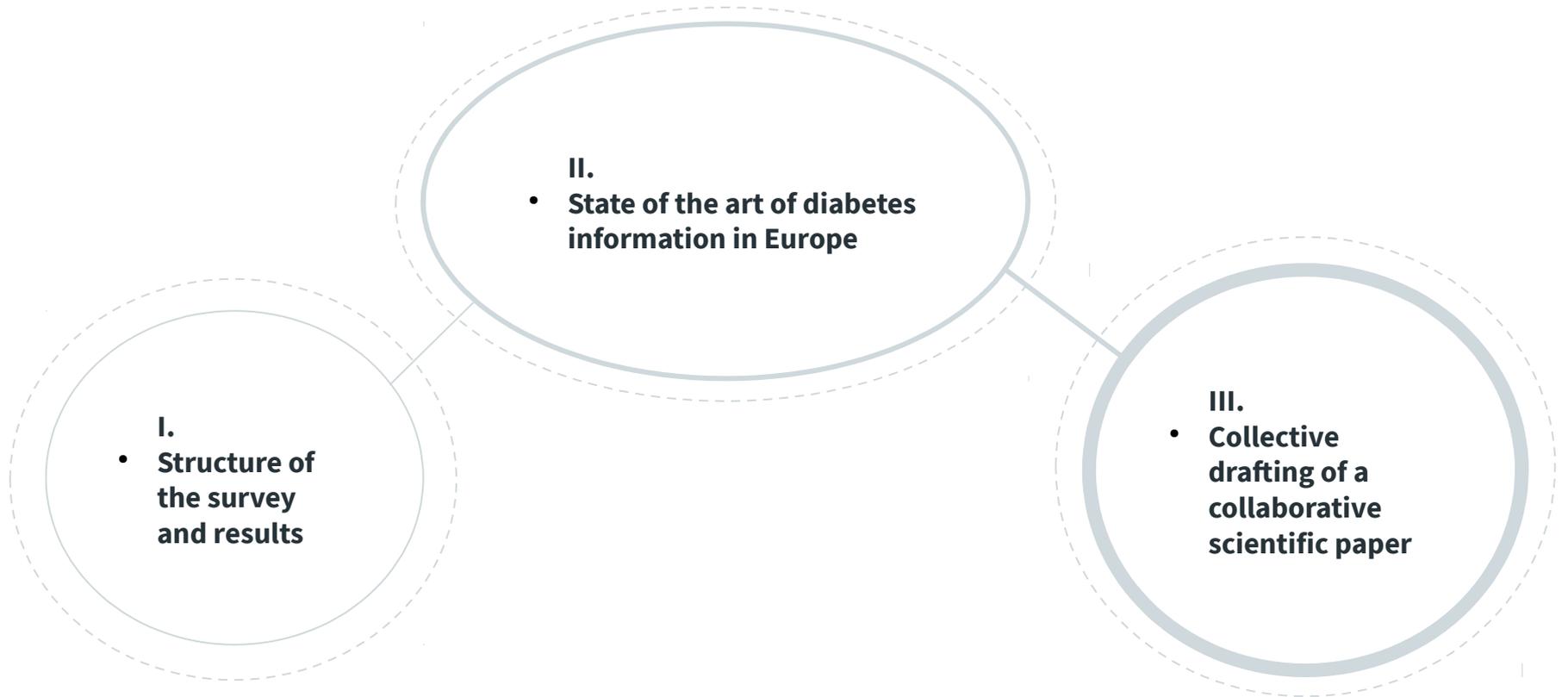
2nd BRIDGE HEALTH Meeting of the EUBIROD Network

Partners from **18 member** countries invited to enter/update information in the survey.

12 members finished the survey till now.

Steps in the session …

II.
- **State of the art of diabetes information in Europe**

I.
- **Structure of the survey and results**

III.
- **Collective drafting of a collaborative scientific paper**

State of the art of diabetes information in Europe

Part I (21.9.2017):
Different types and levels of data sources in Europe:

- Cyprus
- Hungary
- Israel
- Latvia
- Malta
- Poland
- Romania
- Slovenia

Part II (22.9.2017):
National audits, registers and surveillance systems:

- Belgium
- Croatia
- Germany
- Sweden
- UK-England
- UK-Scotland

Structure of the survey and results

(I. Štotl, U. Ljubljana, F. Carinci, U. Surrey)

Structure of survey

◎ **Introduction**
- Background, description of the activity

◎ **Scope of information**
- Research, Quality monitoring, Policy and Governance

◎ **Technical infrastructure**
- Data systems, IT solutions

◎ **Outputs**
- Dissemination strategies
- References (last five years)

Data collection

◎ REDCap open-source research server, hosted in Slovenia:
https://redcap2.ediabetes.si

◎ The REDCap Consortium has 2,521 active partners in 116 countries.

◎ Successful first test: only small glitches with survey, most of the time without problems ...

◎ Server avaliable for future research for EUBIROD group.

Some positive comments:

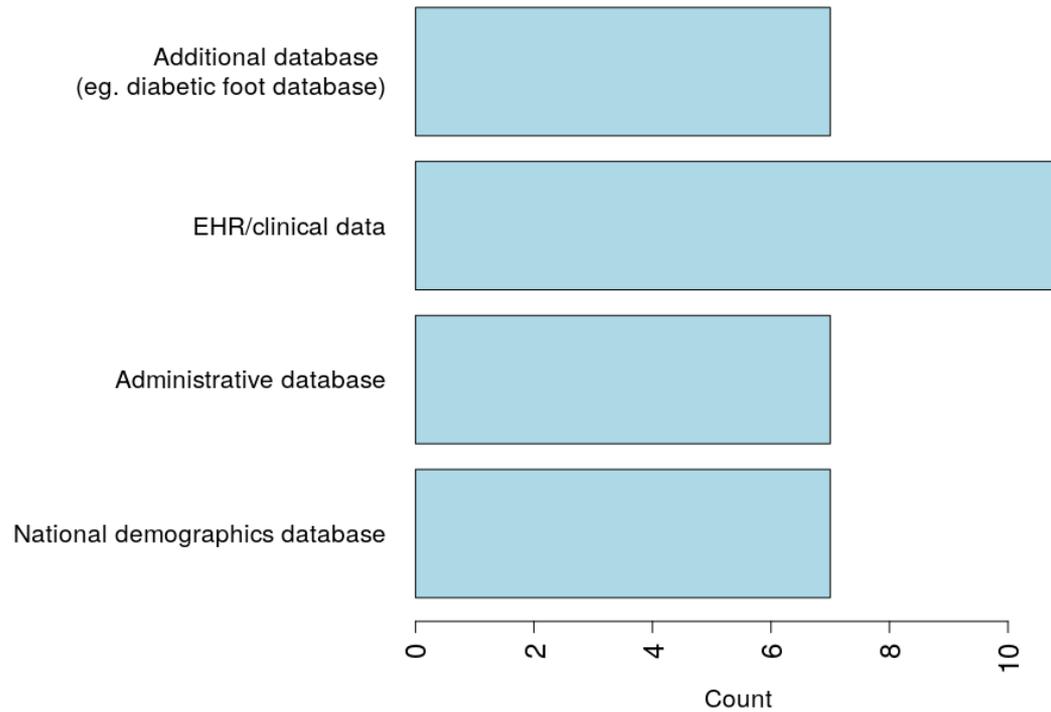"Thanks for facilitating the process by including the responses from last time! This was a great help!"
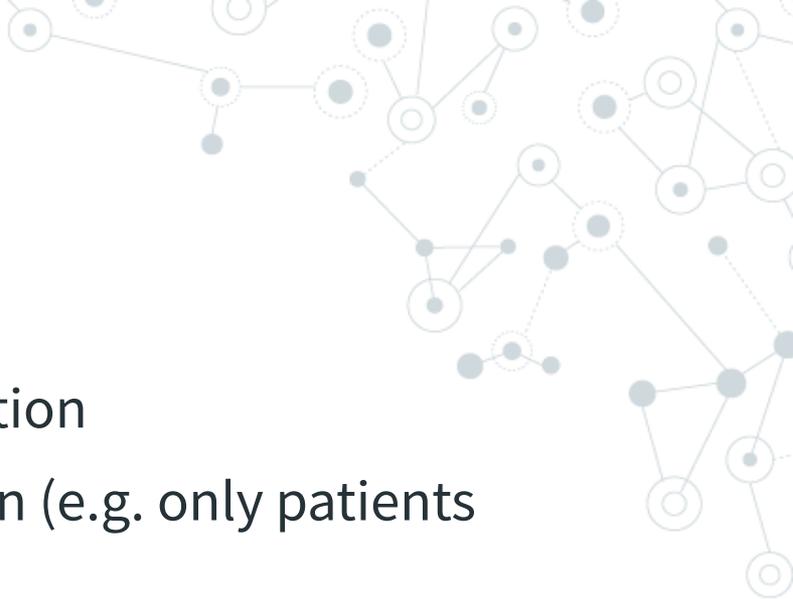
Participants **(n = 12)**

Record ID record_id	Country title	Complete? eubirod_network_diabetes_registries_survey_2017_complete
2	Belgium	Complete (2)
3	Croatia	Complete (2)
4	Cyprus	Complete (2)
5	Finland	Complete (2)
7	Israel	Complete (2)
19	Italy	Complete (2)
8	Latvia	Complete (2)
9	Malta	Complete (2)
10	Norway	Complete (2)
12	Romania	Complete (2)
1	Slovenia	Complete (2)
14	United Kingdom (Scotland)	Complete (2)

Type of reporting institution **(n = 12)**

- ◉ National public health institute **(33 %, 4)**

- ◉ University **(17 %, 2)**

- ◉ Public registry organization that formally includes different stakeholders **(17 %, 2)**

- ◉ Ministry of health **(17 %, 2)**

- ◉ Association of diabetologist **(8 %, 1)**

- ◉ Private subcontractor for public institution **(8 %, 1)**

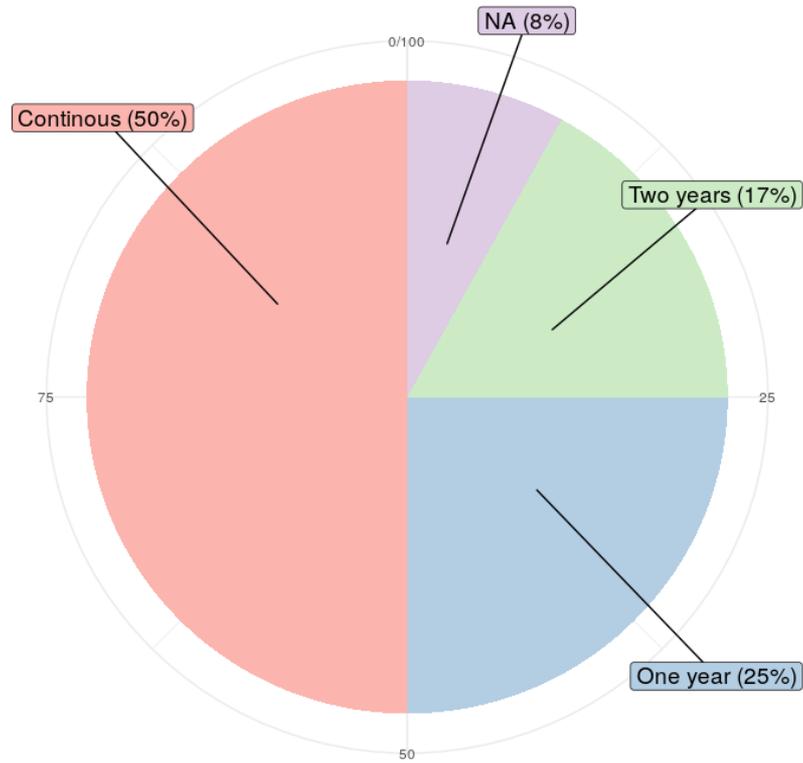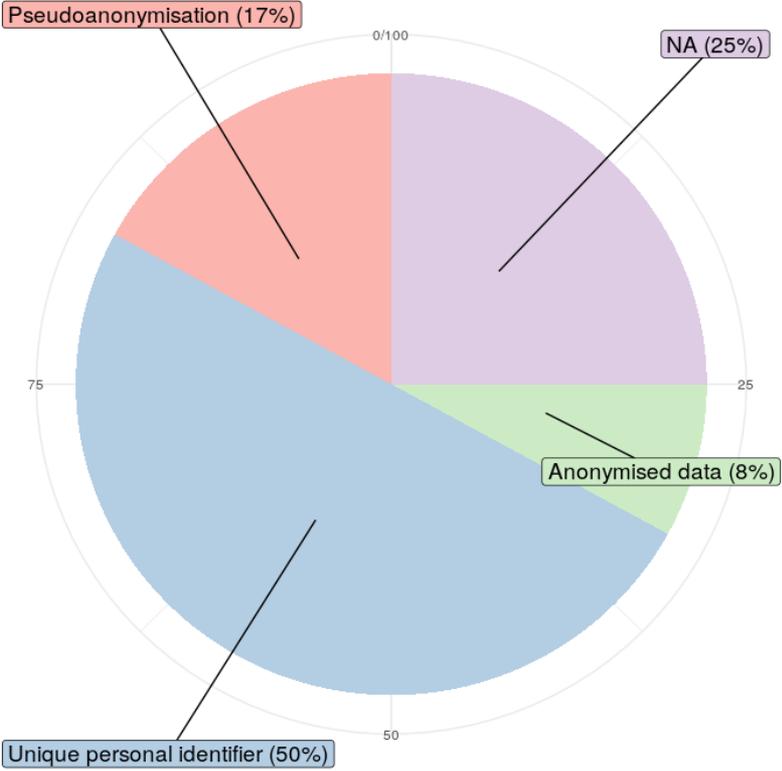# Data source **(n = 12;** data linkage in **66%)**
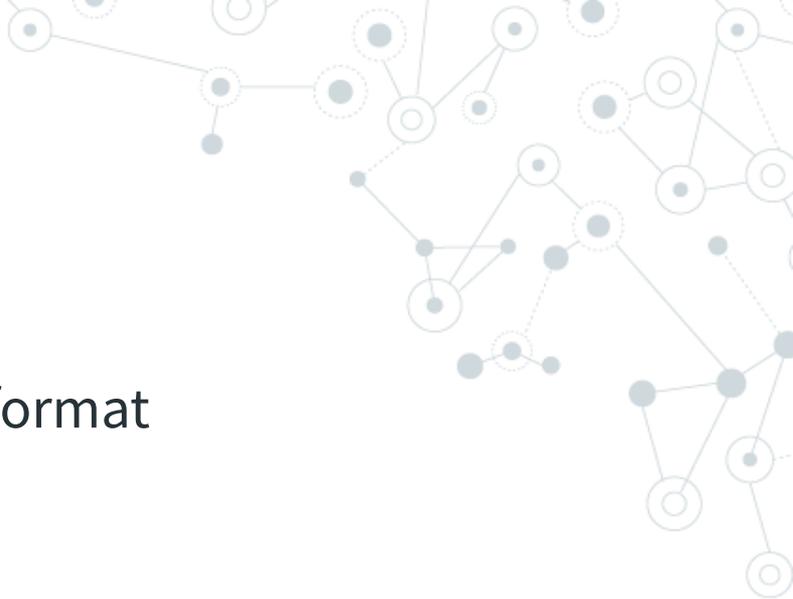
Geographic coverage **(n = 12)**

- ◎ **75 %** - national - complete population
- ◎ **17 %** - national – partial population (e.g. only patients taking insulin)
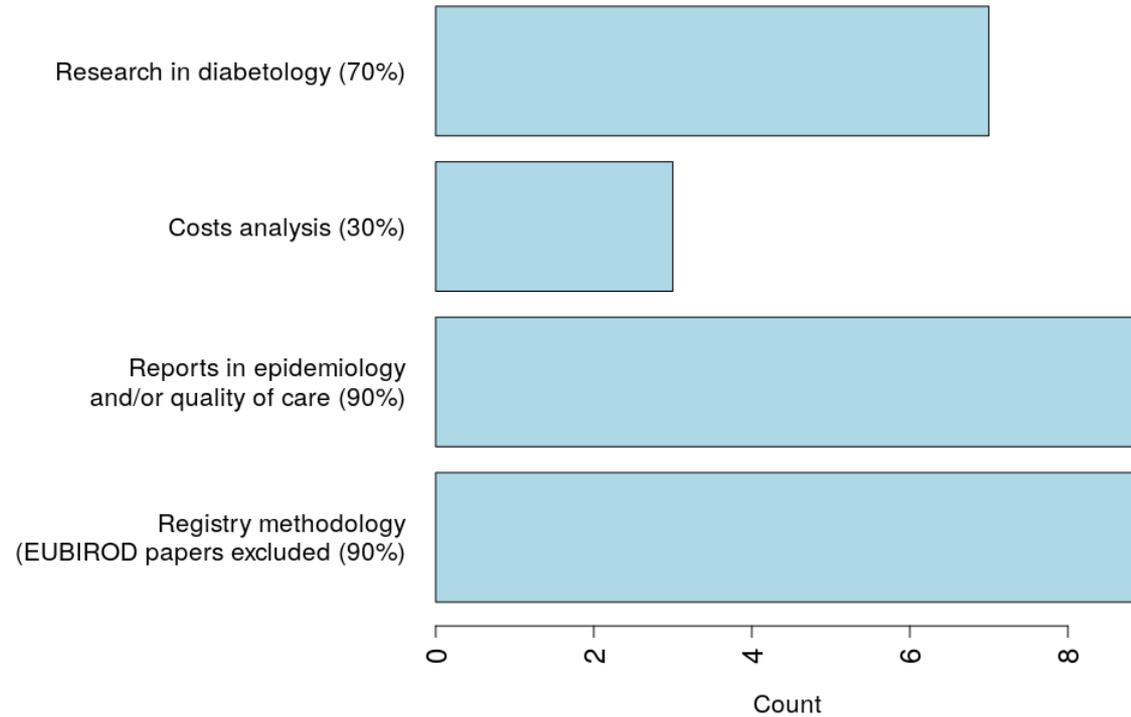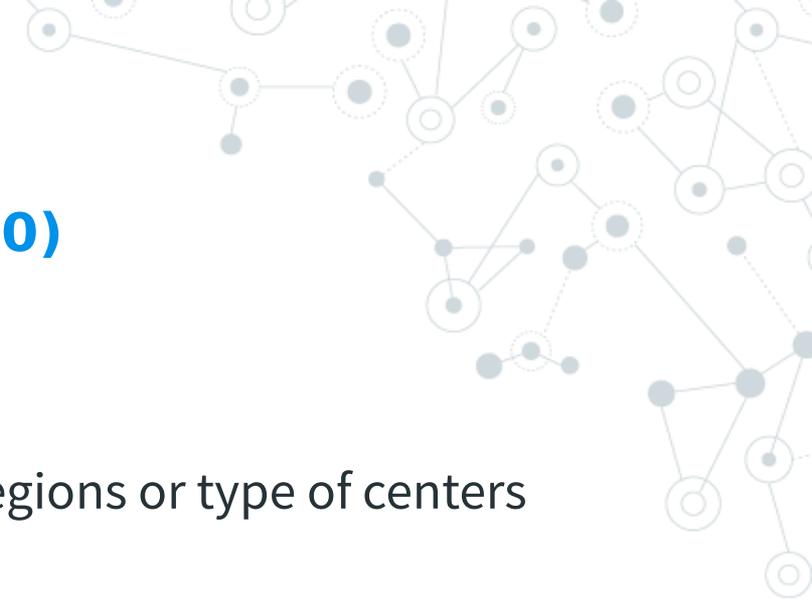- ◎ **8 %** - regional

Data collection

Identifier

Public dissemination **(n = 12)**

- ◎ **58 %** - public, regular in standard format
- ◎ **41 %** - on events or in papers
- ◎ **8%** - NA

Peer review papers **(n = 10 (85), median 7.0, SD 5.3)**

Active topic at the moment **(n = 10)**

30%

- Extension to other type of patients, regions or type of centers

- Legislation issues

- Migration of diabetes registry from pure clinical database into national health registry framework

- Integrating data about diabetes patients with efforts of fostering quality of prevention or care for people with other chronic diseases

Active topic at the moment **(n = 10)**

20%

◎ Data linkage

◎ Diabetic foot care monitoring

◎ Developing novel methods to capture data from data providers (E-health)

◎ Data science and machine learning

10%

◎ PROM's, record's access for patients, clinical action measures, semantic interoperability

Some other characteristics **(n = 12)**

- ◎ **75 %** of members participated in first BIRO analysis
- ◎ In **25 %** not clear if they include pediatric data (they probably do)
- ◎ In **58 %** legal obligation to send data

Only 6 technical reports.

⚠️

Conclusions (1)

◎ All registries in phase of active develoment

◎ Some registries are starting to implement new and complex technologies

◎ Majority is publishing about their activities

Conclusions (2)

◎ Data about registries in unstructured form at the moment, some data missing

◎ Standardised survey in the future for the purpose of benchmarking and better clarity ?

◎ Definitions for:

- standard modalities of registries

- progress stages in develoment of a registry

- list of secondary uses of diabetes registries

Conclusions (3)

◎ Extensive and very usefull source of informations about the actual state of diabetes registries in Europe

◎ Members that didn't manage to finish the survey are invited to do so to share their experience with others

◎ Dissemination of results after all responses collected

State of the art of diabetes information in Europe

Part I: Different types and levels of data sources