

# National Frameworks - Slovenia



**Iztok Štrotl**

**1st EUBIROD Network General Assembly**  
24th August 2015, University of Surrey, Guildford, Surrey, UK

univerzitetni  
klinični center ljubljana  
*University Medical Centre Ljubljana*



**EUBIROD**  
NETWORK

# Registry of Diabetes - Slovenia

- Slovenian National Registry of Childhood Diabetes
- Slovenian National Registry of Adult Patients with Diabetes
- Current additional databases:
  - National Hospital Health Care Statistics Database; e-DRG database
- Total prevalence of diabetic patients is currently calculated with the estimation from the number of persons with diabetes medications.

# Slovenian National Registry of Childhood Diabetes

- In Slovenia, all children and adolescents with newly diagnosed diabetes are referred to only one central institution:
  - Department of Pediatric Endocrinology, Diabetes and Metabolism (DPEDM) - University Medical Center - University Children's Hospital, Ljubljana
- Responsible for the Slovenian National Registry of Childhood Diabetes (SNRCD) since 1970.
- Active member of the original EUBIROD project with providing data and expertise for pediatric section.



# Registry of Childhood Diabetes - methodology

- Long and rich tradition in registry methodology and technology.
- In the last three years, they have further improved their database technology based on state of the art technology and industry standards such as:

- OpenEHR
- IHE
- HL7



*open***EHR**

- Pediatric clinic participates in international data collection and benchmarking within the Centre of Reference SWEET project

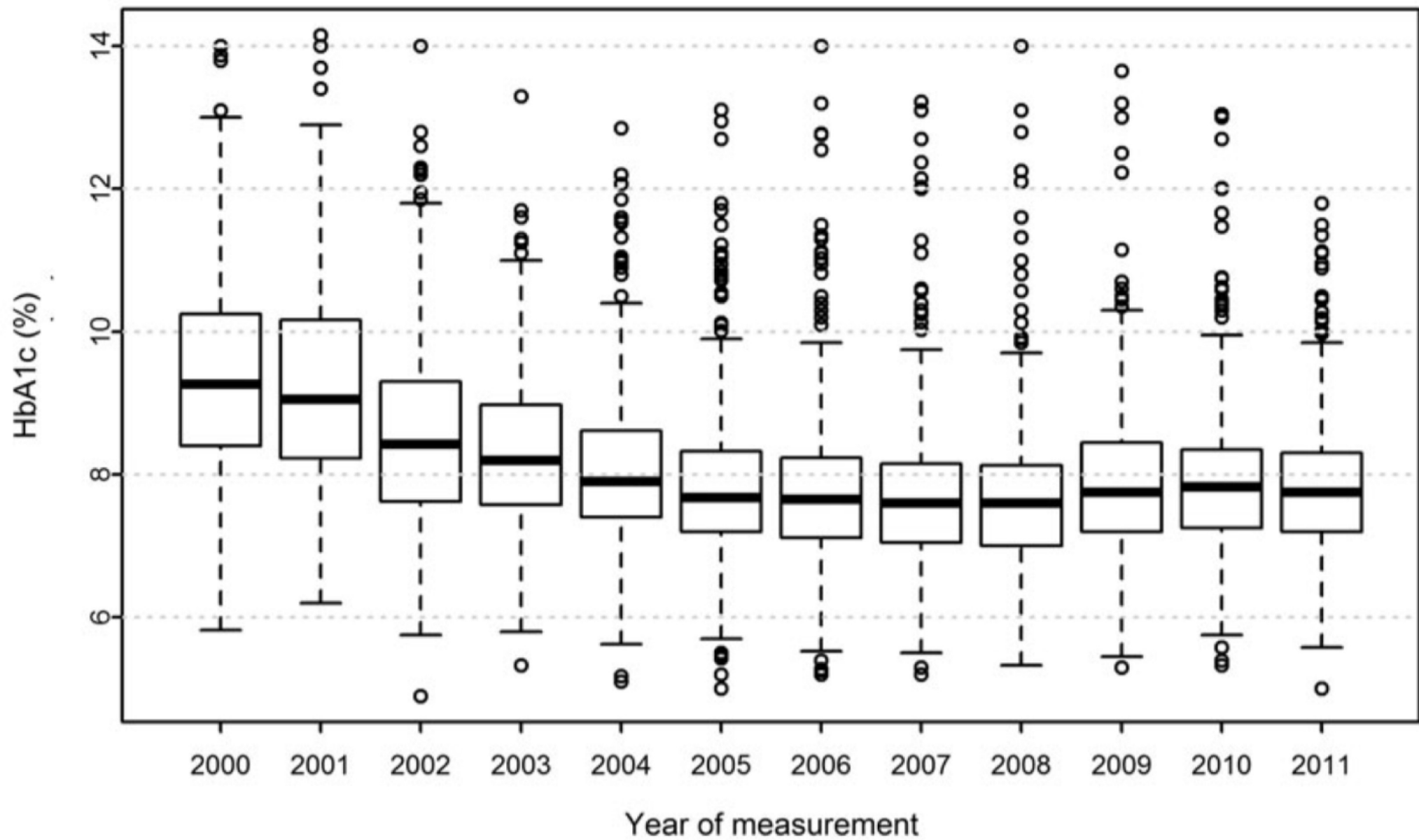


# Improved Metabolic Control in Pediatric Patients with Type 1 Diabetes: A Nationwide Prospective 12-Year Time Trends Analysis

Klemen Dovc, MD,<sup>1</sup> Sasa Starc Telic, MD,<sup>1</sup> Lara Lusa, PhD,<sup>2</sup> Nina Bratanic, MD,<sup>1</sup> Mojca Zerjav-Tansek, MD,<sup>1</sup> Primoz Kotnik, MD, PhD,<sup>1</sup> Magdalena Avbelj Stefanija, MD, PhD,<sup>1</sup> Tadej Battelino, MD, PhD,<sup>1,3</sup> and Natasa Bratina, MD, PhD<sup>1</sup>

- metabolic control over 12 years in a national cohort of childhood-onset type 1 diabetes.
- data from the prospective childhood-onset diabetes register
- the metabolic control of the entire nationwide pediatric type 1 diabetes population significantly improved during the 12-year observational period with a low rate of severe acute complications events.

Patients (N)=	286	334	378	401	432	443	452	471	492	482	526	513
CSII (%)=	0.3%	7.5%	52.6%	65.8%	81.2%	85.3%	90.7%	89.6%	94.1%	96.3%	90.9%	93.8%



# Slovenian National Registry of Adult Patients with Diabetes

- Department of Endocrinology, Diabetes and Metabolic Diseases (DEDMD), University Medical Centre Ljubljana, is responsible for Slovenian National Registry of Adult Patients with Diabetes.



- Data collection for this registry started in 1982.
- Only limited number of diabetic patients are included at the time.

# BIRO in adult population

- DEDMD was associated partner in original EUBIROD project
- didn't participate with data from adult patients in the original EUBIROD project.
- **2013 BIRO report:** DEDMD started to test BIRO on data from adult population with pilot survey of 100 patients.
- **2014 BIRO report:** Extended analysis to almost 2000 patients. Data was collected from local EHR in single diabetes center.



# Governance

- Governance for Slovenian National Registry of Diabetes in last years - evolving process.
- Slovenian parliament has approved a law in June 2015, that confirmed DEDMD as responsible for governance of SNRAD and DPEDM as responsible for SNRCD.

# Conclusions

- Advanced and modern database for pediatric registry with large majority of pediatric patients included
- Still a lot of work for adult population with diabetes
- EUBIROD network very important partner for future

