

BORIS i världen – hur står sig BORIS internationellt?

En genomgång av barnfetmaregister i världen:
symposium på ECO-ICO sept 2020

Claude Marcus



1

Overview of Established Pediatric Obesity Registries



United States



Germany/Austria

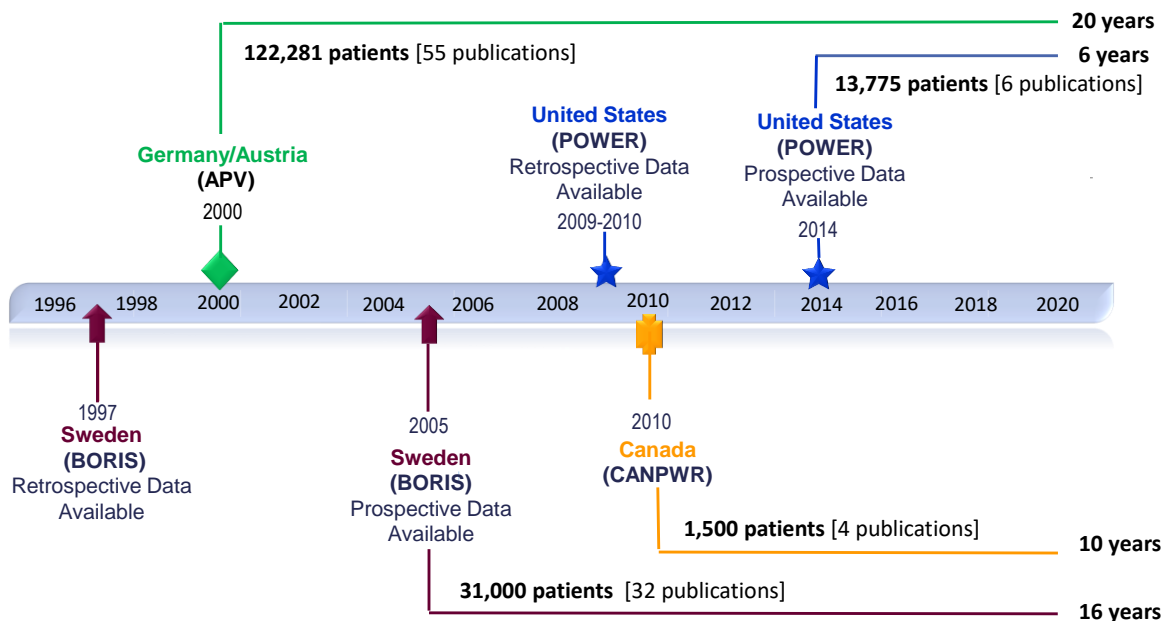


Canada



Sweden

2



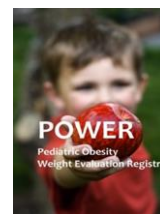
Pediatric Obesity Registry – Timeline /Patients Enrolled

3

Registry Goals

United States

- Better understand and **improve health outcomes** of youth with overweight and obesity participating in pediatric weight management programs.
- Identify patient and program characteristics, and evaluate their association with health outcomes and care delivery
- Help standardize and **improve quality of care** for youth with obesity
- **Promote collaborative research** (QI projects and multi-center clinical trials) to test innovative and promising treatment options for youth with obesity.



Germany/Austria

- **Improve the outcome of obesity care**



4

Registry Goals

Sweden

- **Optimize treatment outcomes** on the national level
- Compare patient recruitment and treatment outcomes at different hospitals
- Provide registry data for local quality evaluation and improvement



Canada

Address key questions in this observational study:

- **Individual, family and clinic characteristics related to improvements in multiple health outcomes** up to 3 years after enrollment in a pediatric weight management program
- **Individual, family and clinic characteristics related to attrition rates** in families after entrance to a pediatric weight management program



5

Funding Sources

United States

Site enrollment fee for each 2-year cycle: \$5,000-\$6,000

2020: Received funding from Rhythm Pharmaceuticals

- Discounted enrollment fee for Cycle 4 by \$1,000/site
- Provided \$1,000/site to support data entry and data management at site level



Germany/Austria

European Union consortium SOPHIA (Stratification of Obese Phenotype to Optimize Obesity Therapy)

German Competence Network Obesity

German Federal Centre for Health Education



6

Funding Sources

Canada

Fully funded on research dollars

- Canadian Institutes of Health Research
- Population Health Research Institute, McMaster Children's Hospital and McMaster University

Research study nearing completion – discussions underway for “next steps”



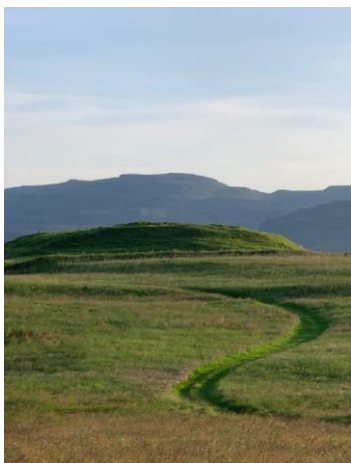
Sweden

Government support - It is “free of charge” to use the registry and centers have no economic incentives for their participation



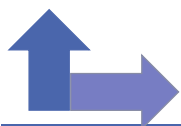
7

Can we find a path forward?



What metrics are important to patients and their families?

Is it feasible for registries to collect this data?



8

Next Steps

Explore opportunities to conduct research involving the established pediatric obesity registries

Serve as resource to assist others interested in establishing a registry in their respective country



9

BORIS står sig väl internationellt!

- Ett av de största registren i världen
- Samma problem som andra register med dropouts
- Samarbete med andra register kommer att ge mycket ny information
- Samarbete planeras mellan registergruppen och "hälsoekonomgruppen" för att öka kunskapen om fetma och fetmabehandlingens betydelse för samhället



10