Parallel session PS2: Quality assessment, monitoring and evaluation of the networks

21st November 2018
4th Conference on ERNs (Brussels)

Ruben Diaz, MD, PhD
Secretary General
European Childrens Hospital's Organisation (ECHO)

Conflict of interest

I have no actual or potential conflict of interest in relation to this presentation

Mission

ECHO advocates for children's health and their access to the best quality care through the collaborative work of children's hospitals

Current Membership

Barcelona
> Sant Joan de Déu Barcelona Children's Hospital

Dublin
> Children's Hospital Group

Florence
> Meyer Children's Hospital

Helsinki
> HUS New Children's Hospital

London
> Great Ormond Street Hospital for Children

Munich
> Dr. von Hauner Children's Hospital

Paris
> Necker-Enfants Universitary Malades Hospital

Rotterdam
> Erasmus – MC Sophia Children's Hospital

Petach-Tikva
> Schneider Children's Hospital of Israel

Warsaw
> Children's Memorial Health Institute

Laying our foundations with data

Priority: We will create a data gathering and analysis infrastructure necessary to support current and future ECHO initiatives.

Objective: Provide high quality, relevant comparative data about the pediatric population ECHO's members serve, the characteristics and capacity of pediatric care facilities, the services they provide and the clinical results that they obtain.
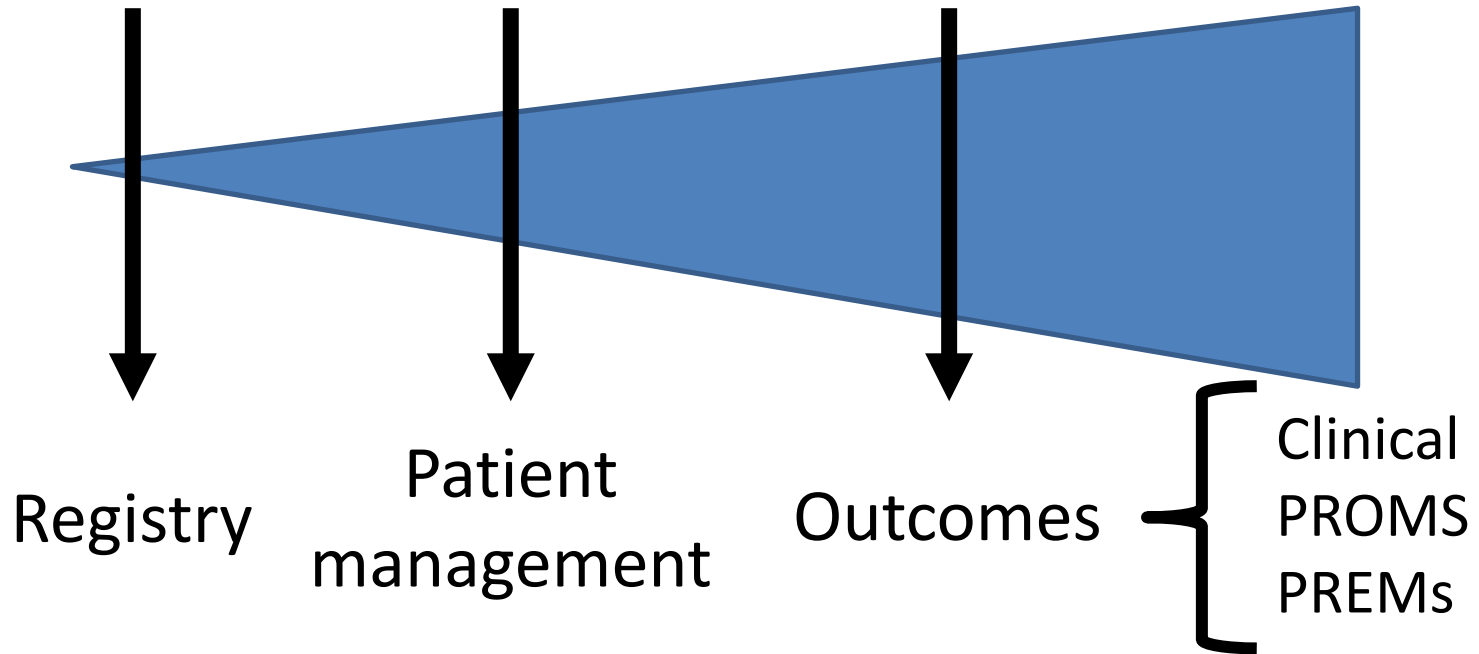
IMPROVING QUALITY AND SAFETY TO CREATE VALUE

Priority: We will measure quality, outcomes and value to improve the delivery of safe, effective and efficient care.

Objective: Foster collaborative initiatives that are aimed at measuring and benchmarking outcomes to reduce variability and improve performance in clinical care

ECHO
European Children's
Hospitals Organisation

Role of hospitals to support ERN networks' data collection

- Most clinical data is collected in hospital settings

- Comprehensive vs. focused data collection in the CPMS platform

- Role of data standardization to facilitate data sharing

- Support for continuous data acquisition to facilitate long term ERN network evaluation

ECHO
European Children's
Hospitals Organisation

Data Spectrum

Registry

Patient management

Outcomes

{ Clinical PROMS PREMs

ECHO
European Children's Hospitals Organisation

Challenges

- Core vs. ERN specific indicators
- Start small but grow steadily in capacity with a solid foundation
- Avoid duplication in efforts
- Clear visualization of resources needed
- Standardization of indicators under a common clinical documentation structure (HL7, FIHR)
- Hospital involvement should facilitate, not be a hindrance

Hospital collaborating together to establish platforms for standardized data sharing should be a valuable asset for ERN network development