Clinical data for paediatric research: the Swiss approach

Symposium, 5 and 6 December 2019, Sorell Hotel Ador, Bern

This symposium is supported by:

- **SwissPedNet** – Swiss Research Network of Clinical Pediatric Hubs (swisspednet.ch)
- **SPHN** – Swiss Personalised Health Network (sphn.ch)
- **SSP** – Swiss Society of Paediatrics (swiss-paediatrics.org)
- **Orphanet** – Portal for rare diseases and orphan drugs (orphanet.ch)

This symposium will describe the current situation, recent achievements, and emerging opportunities for using real world, standardized healthcare data in paediatric research.

Front-line clinicians, paediatric researchers, families, and healthcare system strategizers in Switzerland need immediate access to real world data from electronic health records so they can conduct high quality research that will answer emerging questions in paediatrics and then implement their findings to improve paediatric health care. **This symposium will:**

- Describe the standardized dataset for all paediatric clinics in Switzerland (results of the SPHN project "Harmonizing the collection of health-related data and biospecimens in paediatric hospitals throughout Switzerland")
- Describe available data sources for child health in Switzerland and explain how to link them to hospital datasets
- Share examples of successful initiatives from other countries that have improved paediatric research and care, and describe obstacles, pitfalls, solutions, and workarounds
- Raise pressing research questions in clinical paediatrics and generate short research sketches in interactive workshops

We will agree on a strategy for integrating observational paediatric health care data in Switzerland into research, generate and describe research ideas, and draft a sustainable plan for the future.

Target Audience
- The paediatric research community, including front-line clinicians, paediatric researchers, nurse practitioners, and interested healthcare professionals
- Health system leaders, patient organizations, and other research organizations

Organized by Prof. Claudia Kuehni and PD Ben Spycher, Research Group on Child and Adolescent Health, Institute of Social and Preventive Medicine, University of Bern.

Questions relating to the symposium can be addressed to coordinator Mr. Milenko Rakic (phone +41 31 631 59 64, e-mail: milenko.rakic@ispm.unibe.ch).

Program Thursday, December 5, 2019
Morning session: Building the infrastructure for real-time clinical research in Paediatrics

09:30	*Coffee and croissants*

10:00	**Welcome and Introduction**

10:15   **The Swiss Personalized Health Network (SPHN): opportunities for paediatric research**
Prof Urs Frey, *Basel, Chair of the SPHN steering board; Director, University Children's Clinic*
Aims: Give an overview of paediatric-relevant aspects within precision health

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11:00   **SwissPedNet**
Prof Posfay-Barbe, *Geneva, Chair, SwissPedNet*
Aims: Present the Swiss research network of clinical pediatric hubs

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11:20   **Harmonized dataset in Swiss Children's Clinics: where are we?**
Prof Claudia Kuehni, *Bern, Head, SwissPedReg and PI, Paediatric SPHN project*
Aims: Present the paediatric SPHN project, vision, achievements, and next steps

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11:55   *Break*

12:10   **PEDSnet: from concept to prototype to pilot to national scaling**
Prof Christopher Forrest, *Philadelphia, Principal Investigator of PEDSnet*
Aims: Present the history, organization, and governance of PEDSnet – a paediatric research network with longitudinal data from 6.5 million patients, which conducts patient-centered observational research and clinical trials across multiple children's hospitals and associated specialty networks in the USA. PEDSnet is based on the learning health system model championed by the US National Academy of Medicine

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12:50   **Lessons learned from multicentre online paediatric asthma management**
Dr Peter Merkus, Paediatric Pulmonologist, *Radboud University Medical Centre, Nijmegen the Netherlands*
Aims: Present an asthma database project, which includes online disease monitoring and direct communication between doctors and patients

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13:20   *Lunch*

Program Thursday, December 5, 2019
Afternoon session: Research with electronic health records

14:00	**PEDSnet research – presentation of specific research study use cases**
	Prof Christopher Forrest, *Philadelphia, Principal Investigator of PEDSnet*
	Aims: Present examples of recent and ongoing research projects that integrate the priorities of stakeholders into rapid cycle evidence generation. These research use cases will serve as a basis for the subsequent workshop.
14:30	**Using lab and clinical data from hospital data warehouses in Switzerland: experiences from ongoing research**
	PD Dr Alexander Leichtle, *Centre for laboratory medicine, Inselspital Bern*
	Aims: Discuss the current status of research data from university hospitals in Switzerland, with a focus on research with laboratory data
15:00	**Using the data for research**
	PD Dr Ben Spycher and Prof Claudia Kuehni, *PI SPHN project and SwissPedRegistry, ISPM Bern*
	Aims: Discuss different approaches to use the data for research – as an introduction for the following Workshops 1 and 2
15:30	***Break***
15:45	**Workshop I**
	Aims: Participants work in small groups, brainstorm research ideas, and sketch out future potential research projects based on routine hospital data in CH with or without international collaboration. Wild ideas are welcome at this stage.
16:45	**Plenum discussion**
	Aims: Discuss the short sketches developed in Workshop I. Choose topics to expand upon in Workshop II
17:30	**Orphanet as a research tool**
	Dr Loredana D'Amato Sizonenko, *Orphanet Switzerland Coordinator, University of Geneva*
	Aim: Present practical examples in the field of rare disease research with Orphanet
18:00	**Experiences from linking large data sets nationally (UK) and internationally**
	Dr Katie Harron, *Statistician, University College London*
	Aims: Learn more about the complexities of linking clinical hospital data, evaluating linkage quality, and nested clinical trials
18:30	**End of first day**

Program Friday, December 6, 2019
Morning session: The situation in Switzerland: Linkable routine data and ongoing projects in paediatric routine healthcare

09:00	*Welcome coffee*

09:30	**Routine administrative data and how they can be used for research** **Dr Adrian Spörri, PhD,** *Head, Swiss RDL (Registry and Data Linkage Center), ISPM Bern* Aims: Provide an overview of routinely collected health-relevant data in Switzerland (e.g., birth and cause of death statistics, census data and hospital episode statistics) and explain how they can be obtained, linked, and used for research

09:50	**FIRE: Electronic Documentation and Research in Family Medicine in Switzerland** **Prof Sven Streit,** *Institute of Primary Health Care (BIHAM), University of Bern* Aims: Present the FIRE project – a database for research in family medicine based on routine medical data from electronic medical records in Switzerland

10:10	**Swiss NeoNet: a learning health system for neonatology in Switzerland** **PD Dr Mark Adams and Prof Sven Schulzke,** *SwissNeonet, Universities of Zurich and Basel* Aims: Provide an overview of Neonet: how data are collected, analyzed, and used to provide optimal neonatal care in Switzerland and improve long-term outcomes

10:30	**Swissnoso: reducing infections in hospitals or long-term care facility in Switzerland** **PD Dr Rami Sommerstein,** *Head of Research & Development, Swissnoso* Aims: Present Swissnoso – the nationwide surveillance of postoperative wound infections (methods and ongoing research)

10:50	*Break*

11:20	**Workshop II** Aims: continue from Day 1. Choose promising ideas and develop them further. Consider real-world scenarios; i.e. take advantage of opportunities and circumvent limitations of paediatric clinical research in Switzerland.

12:20	**Plenary discussion of workshop results** Aims: Final remarks on workshop research projects and next steps (e.g., workshop proceedings)

12:40	*Lunch*

Program Friday, December 6, 2019
Afternoon session: Practical challenges and remedies

13:40 **Swiss SPHN data warehouse: standardized electronic health record data from Swiss University hospitals: current status and practical issues for using data**
Dr Katrin Crameri, *Director, Personalized Health Informatics Group, Basel*
Aims: Present the Swiss data warehouses and SPHN data center. Explain the process of harmonizing and processing data, data governance, obtaining data and using it for research

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14:00 **PEDSnet data network – common data model, system architecture, data flows, and data quality program**
Prof Christopher Forrest, *Philadelphia, Principal Investigator of PEDSnet*
Aims: Provide an overview of data network organization and architecture to support the pediatric national scale learning health system

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14:20 **SPAC: the Swiss Paediatric Airway Cohort: patient-reported and health record data from respiratory outpatient clinics in Switzerland**
Carmen de Jong*, PhD student, ISPM Bern*
Aims: Present the Swiss Paediatric Airway Cohort (SPAC) – a national, prospective study of children and adolescents referred to respiratory outpatient wards in Swiss Children's Clinics

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14:40 *Break*

15:00 **Legal aspects**
Philipp do Canto*, Public Sector Law, Zurich*
Aims: Legal and ethical aspects in Switzerland

15:20 **Outlook Panel discussion**
Various
Aims: Concluding panel discussion on paediatric research that uses clinical routine data

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16:20 **Closing remarks**

16:40 **Official end of the conference**