

SPHN Data Coordination Centre - Seminar and Training Series

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"Harmonising the collection of health-related data and biospecimens in paediatric hospitals throughout Switzerland"

Background and Aims: Medical research in children is complicated because of data fragmentation, heterogeneity and scarcity. Children cannot be considered “small adults” when it comes to treatment. It is therefore critically important to improve the quality of medical data routinely collected in children’s hospitals to tailor high-quality paediatric research. This project is a first step towards the overall goal to develop an infrastructure capable to harness high-quality medical data, for every child in Switzerland. It aims to harmonize medical data collected in all Swiss children’s hospitals and to assess the feasibility of collecting additional patient-reported data.

Methods: We performed a scientific literature search and got in contact with national stakeholders to provide an overview of the paediatric medical data that are available for researchers in Switzerland. We are defining a Swiss Paediatric Standard Dataset that will include a general paediatric part and modules for each paediatric subspecialty. We will achieve this by leading a consensus finding process, involving more than 100 Swiss paediatricians including all paediatric hospitals and all subspecialties. We will also test the feasibility to collect patient-reported data on environmental, social and family-related factors in Swiss children’s hospitals.

Significance: This project will contribute to personalised health in paediatrics in Switzerland by setting nation-wide standards for the collection of health-related data and biosamples. It will lead to a major improvement of the quality of data collected from children during normal in- and outpatient care and greatly enhance their use for clinical research.

Date: Monday, 1 July, 2019

Time: 16:00 – 17:00

Room: Pharmazentrum, Hörsaal 2, Klingelbergstrasse 70, Basel

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