PEDSnet: A Pediatric Learning Health System

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Problem
It's hard to do efficient pediatric comparative effectiveness research:
Small samples • Low diversity • Multiple IRBs • Longitudinal follow-up
Privacy challenges • Enrollment goals • Data access • Start-up costs

Solution
PEDSnet, the clinical data research network
A pediatric network-of-networks composed of 8 children's hospitals and 3 specialty networks, representing 2.1 million patients. Data is collected from multiple sources and includes EHR records, biobanks, patient-reported outcomes, pharmacy, & medical claims. Information is pooled in a standardized format in a central location to create a secure, diverse library for researchers and clinicians. All participants have access to research findings, so that clinicians and patients can learn from the network, enabling informed decisions and increasing the effectiveness of care.

Evidence
Pooling data across multiple institutions can create a nationally representative sample
EHR data collected across multiple institutions closely resembles national data

Comparison of EHR and NHANES

Learning cycle model

Research studies conducted during normal course of clinical care
Biomedical Research
Knowledge Networks

Application of best available evidence for each patient

Clinicians
Point of Care

the learning engine

Patients

Vision
Adopt a national pediatric informatics network, enabling children's health systems around the country and internationally to pool data, in common terminology and standard format

Engage patients & their families in the design and oversight of studies as well as the prioritization of research questions

Create a national data sample characterized by geographic, economic, and racial/ethnic diversity

Enable research by mitigating regulatory, governance, & technical barriers

Encourage informed healthcare decisions by providing access to up-to-date effectiveness studies

Opportunities for collaboration with any institution that implements the data standards and interoperability compatible with PEDSnet data infrastructure

Participating Institutions: Children's Hospital of Philadelphia • Children's Hospital Colorado • Cincinnati Children's Hospital Medical Center • Nemours Children's Health System • Nationwide Children's Hospital • St. Louis Children's Hospital • Seattle Children's Hospital • Boston Children's Hospital • ImproveCareNow • NPC-QIC • ExpressScripts • IMS Health

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