Annual Steering Board Meeting Summary

In January of 2017, the PEDSnet Steering Board convened for its annual in-person meeting to discuss the future state of the network. The Board expressed a vision for an integrated PEDSnet Learning Health System Consortium that focuses on improving outcomes. Importantly, the Board agreed to pursue the development of a business plan for a PEDSnet New Company, i.e., a multi-services company that reflects alignment/integration with networks. PEDSnet leadership is continuing to develop the business plan with sufficient detail to be able to present to the Steering Board for consideration.

In other noteworthy news related to sustainability, PCORnet has established a new non-profit organization committed to accelerating people-driven research known as the People-Centered Research Foundation (PCRF). Read more.

Research Updates

The Automating Quality and Safety Benchmarking for Children Study (PI: Walsh) has made great progress since notice of award. To date, in addition to the execution of the primary subcontract, the CCHMC protocol has been approved, and all participating PEDSnet sites have executed reliance agreements, therefore demonstrating the incremental gains in IRB efficiency that PEDSnet is beginning to make for multi-site studies.

PEDSnet Collaboration on NIH HCS Pragmatic Clinical Trial Proposals

PEDSnet recently reached out to investigators based at our eight institutions

Quick Links

PEDSnet Research
Access PEDSnet
PEDSnet Data
PEDSnet News
@pedsnet
PCORnet
PCORnet CRGs
PCRF

PEDSnet at AMIA 2017 Joint Summits on Translational Science

The PEDSnet Informatics team will be well represented at the 2017 American Medical Informatics Association Joint Summits on Translational Science in San Francisco at the end of this month. Poster presentations will include:

- Standardizing Clinical Diagnoses: Impact of Alternate Terminology Selection (Burrows, et al.)
- Understanding the Gaps Between Data Quality Checks and Research Capabilities in a Pediatric CDRN (Khare, et al.)
- Managing Science Query Traffic in a Large Pediatric Data Research Network (Razzaghi, et al.)
- Developing Computable Phenotypes for Pediatric Chronic Conditions in PEDSnet (Utidjian, et al.)

Welcome New Staff

Several new CHOP Research Institute hires will contribute to PEDSnet efforts.
with an invitation to collaborate on the NIH Health Care Systems Research Collaboratory-Demonstration Projects for Pragmatic Clinical Trials UG3/UH3 RFA. PEDSnet was specifically designed to support large-scale pragmatic clinical trials and is uniquely positioned to help investigators by providing access to a variety of tools and resources that will strengthen applications and streamline study implementation. We are excited that investigative teams from four of our eight institutions responded to this collaboration opportunity and are currently preparing to submit applications for the June 1 deadline.

PEDSnet Demonstration Project Co-PIs Receive U01 Sub-Award
PEDSnet would like to congratulate Nemours Investigators and PEDSnet Demonstration Project Co-PIs, Dr. Jim Franciosi and Dr. John Lima, who in collaboration with colleagues at the University of Florida were recently granted a U01 sub-award entitled, "Genomic Medicine Implementation: The Personalized Medicine Program" from the National Human Genome Research Institute to study a pharmacogenetic approach to optimizing proton pump inhibitor treatment in children. This project will coincide with the work being completed for the PEDSnet Demonstration Project, "Unanticipated Consequences of Proton Pump Inhibitor Use."

SMART IRB The NIH issued a final policy on the use of a Single IRB that will take effect September 25, 2017. The PCORnet Collaborative network of CDRNs and PPRNs is continuing to move sites toward fully executed joinder agreements for SMART IRB. Six of eight PEDSnet sites have executed SMART IRB agreements.

Communications Updates

Website User Authentication PEDSnet will soon enable "user authentication" on our website. This will allow for login access to appointed areas of the site in addition to the public-facing areas. We plan to establish logins for key groups in PEDSnet such as Leadership, Project Managers, Study Teams, and Stakeholders to start, but are unlimited as far as the creation of member-specific areas of the site and our ability to tailor access. With this flexibility in mind, we welcome suggestions on how best to utilize this new feature. Please stay tuned for the rollout announcement.

Please welcome:
- Heather Johnson, Administrative Director
- Rahul Darwar, Informatics Coordinator
- David Soler, RIA Programmer
- Susan Hague, RIA Programmer
- Harris Weinstein, Bioinformatics Engineer
- Shweta Chavan, Bioinformatics Engineer

PEDSnet Engagement Committee
We are pleased to announce that the PEDSnet Engagement Committee has now formed. Drs. Peter Margolis and Michael Seid will lead the committee, while RaeAnne Davis and Lisa Boerger of the PEDSnet Management Office will manage committee operations. The Committee is currently working out meeting schedule and other logistics, in addition to finalizing their Charter. The list of Engagement Committee members and their institutions follows:
- Katie Litterer, Boston Children's Hospital
- Alissa Scharpen, Children's Hospital Colorado
- Amy Kratchman, Children's Hospital of Philadelphia
- Jeannette Holiday, Cincinnati Children's Hospital Medical Center
- Sarah O'Brien, MD, Nationwide Children's Hospital
- Ana Maria Schwindt, DDS, Nemours Children's Health System
- Elizabeth Kruvand, St. Louis Children's Hospital
- Jen Faultner, Seattle Children's Hospital

Data Network Updates
Antibiotics & Obesity Study Investigators Respond to Provocative Article
Drs. Forrest, Block, and Bailey, representing the PCORnet Antibiotics and Obesity Study, submitted a commentary in response to a recent article in The Lancet Diabetes and Endocrinology from a research team based at Kaiser Permanente. The results of the KP team's observational study lead them to conclude that "infection, but not antibiotic use, during infancy is associated with risk of childhood obesity." The PCORnet team's response raises a number of questions about their conclusions and calls for future studies to replicate the findings before general acceptance of this claim. Information on accessing full text of both the original article (Li, et al.) and the commentary can be found here.

Send Us Your News!
We want to hear from you. Please email pmo@pedsnet.org with items you would like to see in our next newsletter.

Upcoming Events

Big Data for Patients (BD4P) Training Opportunity
Big Data for Patients (BD4P) is a data science training program that seeks to give patient advocates a basic understanding of the science of big data to enable them to participate more fully and effectively in big data initiatives. The program will serve to empower patients and advocates by enhancing data science literacy and critical appraisal skills. BD4P is currently accepting applications for the second BD4P Training Workshop on April 25-26, 2017.

March 24, 2017 Grand Rounds
John Spertus, MD, MPH, FACC, FAHA, Daniel Lauer/Missouri Endowed Chair and Professor at University of Missouri Kansas City will present "The Role of Patient-Reported Outcomes in Clinical Trials, Quality Assessment and Clinical Practice" at the 3/24 NIH Health Care Services Research Collaboratory and PCORnet Grand Rounds. Click for full information.

Be sure to visit our website and follow us on Twitter!