

PEDSnet Scholars Program Description and Syllabus 2022-2024

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Training Program Description

The PEDSnet Scholars program prepares promising faculty to conduct learning health system (LHS) science that improves care delivery and outcomes for children and the systems that serve them. It builds upon decades of faculty experience in research mentorship and the resources of nationally renowned pediatric academic medical centers that collaborate in the PEDSnet clinical research network. Scholars use methods that leverage modern data systems and test interventions in pragmatic child/family-centered outcomes research studies, embedded in diverse delivery systems and communities. In so doing, they provide the evidence base for shared clinical decisions and effective delivery system interventions that bring us closer to the goal of improved health for individual children and populations.

The program aims are to:

1. **Community:** Create a national community of faculty who become leaders in their institutions and the nation in Learning Health System science for children;
2. **Research:** Support scholars in the conduct of patient-centered outcomes research in the context of their local Learning Health System;
3. **Curriculum:** Deliver a curriculum that builds core competencies in Learning Health System science; and,
4. **Mentorship:** Provide research, health system, and life course mentorship.

The program leverages the network and institutional resources of PEDSnet to provide mentorship and learning experiences that allow each scholar to become proficient in the AHRQ learning health system researcher training competencies and become well-versed in the application of relevant PCORI methodology standards. Each scholar's mentorship team will include a local research scientist, a senior health system executive, and a PEDSnet mentor drawn from other PEDSnet institutions. Scholars will conduct learning health system science designed to improve pediatric healthcare delivery and/or health outcomes for children, that is driven by stakeholder engagement.

Background

As defined by a 2013 Institute of Medicine report, a Learning Health System (LHS) can be any type of healthcare delivery system that combines research, data science, and quality improvement, yielding knowledge as a by-product of the patient clinician interaction. In addition to their interactions with clinicians, there is much to be learned about how patients manage their health outside of medical settings, interact with community-based programs, and the effects of public health interventions on population health. An essential and distinguishing attribute of a LHS is co-production of healthcare: patients, clinicians, family members, and health system leaders working together as partners, sharing expertise and know-how.^{1, 2} There have been calls to create a national LHS,³ to align academic medical centers around the vision of the LHS,⁴ and to develop specialty-specific networks that promote learning across institutions.^{5, 6} *For any of these to succeed, a cadre of leaders will be needed to build the evidence base and study innovations in implementation of these practices in healthcare organizations.*

¹ IOM (Institute of Medicine). *Best care at lower cost: The path to continuously learning health care in America*. Washington, DC: The National Academies Press; 2013.

² Berwick DM. What 'patient-centered' should mean: confessions of an extremist. *Health Aff (Millwood)*. 2009;28(4):w555-565.

³ Friedman CP, Wong AK, Blumenthal D. Achieving a nationwide learning health system. *Science translational medicine*. 2010;2(57):57cm29.

⁴ Grumbach K, Lucey CR, Johnston SC. Transforming from centers of learning to learning health systems: the challenge for academic health centers. *JAMA*. 2014;311(11):1109-1110.

⁵ Kwon S, Florence M, Grigas P, et al. Creating a learning healthcare system in surgery: Washington State's Surgical Care and Outcomes Assessment Program (SCOAP) at 5 years. *Surgery*. 2012;151(2):146-152.

⁶ Forrest CB, Margolis PA, Bailey LC, et al. PEDSnet: a National Pediatric Learning Health System. *J Am Med Inform Assoc*. 2014;21(4):602-606.

Opportunities to improve care for children abound. Children in the US have a 70% increased risk of death compared with counterparts who grow up in Europe.⁷ Since 1960, rates of children living with disability increased from 2% to 8%.⁸ Current care quality and population-level outcomes for children remain woefully deficient by objective measures^{9, 10} particularly for those from low-income families or racial and ethnic minority groups.^{11, 12, 13, 14} There continues to be slow and imperfect translation of the best evidence-based prevention and clinical care practices to the children who will benefit.^{15, 16, 17} Optimal healthcare delivery, including the roles of generalist and specialty providers, may be different for children with chronic illness compared with adults.¹⁸ Childhood obesity, which affects 17% of the nation's youth,¹⁹ is an epidemic with inimical health effects for the nation well into the future. Pediatric healthcare in the 21st century must attend to the unique needs of children--what we have called the 4D's of childhood²⁰: rapid development of biological, behavioral, and socio-emotional health assets that have critical periods that render children particularly vulnerable to the effects of the intrauterine, chemical, physical, and social environments; dependency on adults such as parents, teachers, and healthcare providers for helping them to manage and promote their health; demographic trends that expose far too many children to unstable housing, poverty, and food insecurity - fully 40% of children live in families whose income is insufficient to cover basic expenses²¹; and, disease patterns that differ markedly from adult counterparts. Children's health services are not only addressing acute and chronic medical conditions, they are also transforming into community-based systems of care that optimize health-development across the early years to promote acquisition of assets that enhance children's adaptability and enable their flourishing as adults.²²

Thus, pediatric LHS researchers must address care received in clinical settings and the home, school, and social environments and community systems that affect child and family health and well-being. It will also require researchers, focused specifically on child health, whose work is more directly aligned with the needs of patients, providers, pediatric health systems, and the communities in which they live. *The preparation of the next generation of leaders of this work is the overarching goal of the PEDSnet Scholars mentored career development program.*

⁷ Thakrar AP, Forrest AD, Maltenfort MG, Forrest CB. Child mortality in the US and 19 OECD comparator nations: a 50 year time trend analysis. *Health Aff (Millwood)* 2018;37:140-9.

⁸ Halfon N, Houtrow A, Larson K, Newacheck PW. The changing landscape of disability in childhood. *Future Child*. 2012;22(1):13-42.

⁹ Mangione-Smith R, DeCristofaro AH, Setodji CM, et al. The quality of ambulatory care delivered to children in the United States. *N Engl J Med*. 2007;357(15):1515-1523.

¹⁰ Perrin JM, Homer CJ. The quality of children's health care matters--time to pay attention. *New England Journal of Medicine*. 2007;357(15):1549-1551.

¹¹ Thakrar.

¹² Schuster MA, Elliott MN, Kanouse DE, et al. Racial and ethnic health disparities among fifth-graders in three cities. *N Engl J Med*. 2012;367(8):735-745.

¹³ Flores G. Technical report--racial and ethnic disparities in the health and health care of children. *Pediatrics*. 2010;125(4):e979-e1020.

¹⁴ Berdahl TA, Friedman BS, McCormick MC, Simpson L. Annual report on health care for children and youth in the United States: trends in racial/ethnic, income, and insurance disparities over time, 2002-2009. *Acad Pediatr*. 2013;13(3).

¹⁵ Mangione-Smith

¹⁶ Dougherty D, Conway PH. The "3T's" road map to transform US health care: the "how" of high-quality care. *Journal of the American Medical Association*. 2008;299(19):2319-2321.

¹⁷ Szilagyi PG. Translational research and pediatrics. *Acad Pediatr*. 2009;9(2):71-80.

¹⁸ Perrin JM, Kuhlthau KA, Gortmaker SL, Beal AC, Ferris TG. Generalist and subspecialist care for children with chronic conditions. *Ambul Pediatr*. 2002;2(6):462-469.

¹⁹ Ogden CL, Carroll MD, Fryar CD, Flegal KM. *Prevalence of obesity among adults and youth: United States, 2011-2014*. Hyattsville, MD: National Center for Health Statistics;2015.

²⁰ Forrest CB, Simpson L, Clancy C. Child health services research. Challenges and opportunities. *JAMA*. 1997;277(22):1787-1793.

²¹ National Center for Children in Poverty (NCCPP). Child Poverty. 2017; <http://www.nccp.org/topics/childpoverty.html>. Accessed December 21, 2017.

²² Perrin JM, Bloom SR, Gortmaker SL. The increase of childhood chronic conditions in the United States. *Journal of the American Medical Association*. 2007;297(24):2755-2759.

Career Pathways of a Learning Health System Scientist

The type of career pathways that will be pursued by an LHS scientist are emerging and not pre-determined given the nascent nature of the field. LHS scientists may seek independent investigator status or may focus on advancing outcomes of the health system through the use of improvement and research tools in clinical operations. A LHS scientist could also pursue a mix of funded research and clinical operations or a career as an independent researcher. One of the exciting aspects of the program and field, is the ability to define a career trajectory.

Core Competencies

Upon successful completion of this course, scholars will have gained core competencies in the following seven learning health systems research domains. Please refer to the [Forrest et al. \(2018\). Development of the Learning Health System Researcher Core Competencies. Health Services Research, 53\(4\), 2615- 2632](#) for a complete list of competencies.

1. Systems science;
2. Formulating meaningful and stakeholder-informed research questions;
3. Research methods;
4. Informatics;
5. Ethics of research and implementation in health systems;
6. Improvement and implementation science; and,
7. Engagement, leadership, and research management.
8. New: Health justice and equity

Scholars will also be introduced to relevant PCORI methodology standards. The Scholar program aims to underscore three standards that are foundational to Learning Health System science. These include standards for:

1. Patient Centeredness;
2. Mixed Methods Research; and
3. Studies of Complex Interventions.

Please refer to [“The PCORI Methodology Standards” PCORI \(Patient-Centered Outcomes Research Institute\) Methodology Committee. Feb 2019](#) for a complete list of methodology domains and competencies.

Program components

The scholars program is built around the following primary components:

1. Improvement/Implementation Science or Research project **proposal** (required as part of the scholar application); and Improvement/Implementation Science or Research **project**;
2. Semi-monthly learning sessions and works-in-progress;
3. Self-guided, online learning modules;
4. Personal quality improvement project;
5. Scholar career development plan;
6. Mentoring; including institutional experiences in health system operations, improvement, and strategy;
7. PEDSnet Quality and Safety leaders panel; and
8. Annual In-person workshops, rotating at PEDSnet institutions (as circumstances permit).

As a national program, interactive learning activities will primarily leverage remote education modalities, such as video and web conferencing platforms.

Description of components

1. *Research or improvement/implementation science proposal and project*
 - As part of the scholar application, candidates must submit a written project proposal of 7 pages that includes specific aims, a well-referenced background section that articulates the state of current knowledge, a methods section with some detail regarding potential data sources, stakeholder engagement approach (a unique and required section of the application), and analysis plans, and a brief section on the significance and innovation of the proposed work. The purpose of the proposal is to assess the promise of each applicant in research or improvement/implementation science, their understanding of child/family-centered outcomes research, the relevance of the project to address an issue of importance to the strategic aims of the organization, and their ability to express scientific ideas in writing.
 - Upon admission to the program, it is expected that the project proposed will be more fully developed during the program as scholars learn new methods and receive input from their mentor teams. Scholars are required to produce a final capstone presentation as a deliverable, as well as submit the results for peer-reviewed publication.
2. *Semi-monthly learning and works-in-progress sessions*
 - One hour learning sessions are held no less frequently than twice a month. The learning sessions are facilitated by faculty and cover curriculum content addressing AHRQ LHS competencies and PCORI methodology standards. Learning sessions may also focus on a discussion of timely or classic journal articles, provide scholars a platform to present progress on their LHS projects. Learning sessions may have required video recordings, readings or homework assignments to be completed in advance.
3. *Self-guided, online learning modules*
 - The Scholars program leverages existing multimedia resources to supplement curriculum on topics such as patient-centered care, improvement, safety, leadership and implementation science. The curriculum includes the completion of four online trainings/courses that support the Engagement, Quality Improvement Science, Data Science, Implementation Science, and Pragmatic Trials modules of the curriculum. Please refer to syllabus table for course details.
4. *Personal Quality Improvement project*
 - Over 10-12 weeks, scholars will use improvement methodology, tools, and techniques to conduct a small test of change for a personal quality improvement project.
5. *Scholar Career development plan*
 - The Scholar Development Plan (SDP) is a planning document for identifying the scholar's career objectives, professional development needs, and academic progress, specifically in relation to the PEDSnet Scholars Learning Health System (LHS) Scientist Training program.

This SDP will serve as a communication tool for the scholar, their mentors and the leadership team to outline the scholar's training needs and to identify strategies for overcoming obstacles and maximizing opportunities.

6. *Mentoring, including assignment of PEDSnet Scholars mentor*

- Required as part of the application, scholars construct a local mentor team that will minimally include a research scientist and a health systems leader. The scientific mentor will supervise the proposed career development and research experience. The purpose of the health system mentor is to assist the development of the Scholar's knowledge base regarding how their health system operates, its strategy, its governance, and current learning activities that are designed to promote patient, clinician, and health system outcomes. Activities are likely to include periodic meetings with the mentor, connecting with other health system leaders to better understand their role in the organization, participation in health system committee meetings, such as quality, safety, strategic, and patient experience governance meetings and Board meetings, and review of institutional financial, strategic, and operational reports and documents. Upon entry into the program, a PEDSnet Executive Committee Members is assigned as the scholar's PEDSnet mentor and will meet as agreed upon, 3-4 times annually.

7. *In-person workshops, rotating at PEDSnet institutions (annually, or as permitted given the current institutional travel policies)*

- One in-person meeting will be held per year, with rotating PEDSnet institutions serving as a host. Two-day workshops will be designed for deeper dives into essential material, but also to stimulate the sharing of perspectives that occurs best with individuals in person. Attendance is mandatory.

Lastly, the PEDSnet scholars will leverage other existing resources such as:

- *Learning Health System (LHS) Leaders Series* (<https://nwlhs.org/lhs-series>) — The LHS Leaders Series was launched through the AHRQ LHS program network and is led by the Northwest Center of Excellence LHS Sciences Program. It features leaders across the LHS space, aims to provide a platform for scholars to hear stories and advice from LHS leaders, as well as directly engage them.
- *NIH Health Care Systems Research Collaboratory*- The Collaboratory aims to improve the way pragmatic clinical trials are conducted by creating a new infrastructure for collaborative research with healthcare systems.
<https://rethinkingclinicaltrials.org/grand-rounds-hub/>
 - The Grand Rounds webinar series, held monthly for one hour, is one of the many dissemination platforms of the Collaboratory. Scholars will be encouraged to participate in sessions of high relevance to LHS.

Program Evaluation

The evaluation of the program is multi-faceted and includes feedback assessments for didactic as well as mentoring activities. Completion of assessments is required by scholars and includes:

- Learning Health System competency pre/interim/post self-assessment;
- Learning session evaluations;
- Workshop evaluations;
- Mentoring assessments;
- Research project milestone tracking; and
- Scholar career development tracking (during and after program).

Technical Requirements

The program primarily utilizes a video/web conferencing called ZOOM as the main platform for instruction and discussion. Please review the technical requirements here:

<https://support.zoom.us/hc/en-us/articles/201362023-System-requirements-for-Windows-macOS-and-Linux>

PEDSnet Scholars Program Curriculum

Objectives	Assignments/Activities and Required Readings
DATA SCIENCE MODULE Self-guided learning modules There are seven modules of the course that Scholars must complete between July and August 2022. Complete the <i>PEDSnet Scholars Program Data Science Curriculum</i> The goals of the PEDSnet Scholars Data Science module are to: • Provide a vision for informatics in a high functioning LHS; • Define and discuss essential applied informatics concepts; • Describe the Digital architecture for research networks (e.g., PEDSnet); • Review how the EHR can be used for research and registries; and • Describe approaches and challenges to computable phenotyping and population denominators. 2022 PEDSnet Scholars Program Data Science Recordings can be accessed at: https://pedsnet.org/data/data-science-training/ Atlas Tutorial videos can be accessed at: https://www.youtube.com/playlist?list=PLpzbqK7kvfeUXjgnpNMFOff3PDOwv61IZ Reference The Book of OHDSI (Observational Health Data Sciences and Informatics) 2021-01-11, can be accessed at: https://ohdsi.github.io/TheBookOfOhdsi/	
July self-study PEDSnet Database and Data Privacy (Faculty: Charles Bailey, MD PhD, CHOP) and Common data models (CDM) (Faculty: Hanieh Razzaghi, MPH, CHOP)	
<i>Data Analyst Training Module 3</i> • Describe the terms and conditions for data sharing in PEDSnet • Know how to access PEDSnet servers and databases: structure, content, and permissions • Know how to protect against data breaches • Understand PEDSnet's standard techniques for reducing privacy risk <i>Data Analyst Training Module 4</i> • Widely adopted CDMs—OMOP, PCORnet/Sentinel	Please view the 2022 PEDSnet faculty recordings (https://pedsnet.org/data/data-science-training/) and complete the readings for assigned modules <i>Data Analyst Training Module 3</i> PEDSnet Database and Data Privacy (Bailey) PEDSnet Participation and Data Use Agreement. https://pedsnet.org/resources/governance/ . Culnane, C.; Rubinstein, B.I.P; Teague, V (2017). Health Data in an Open World. https://www.researchgate.net/publication/321873477_Health_Data_in_an_Open_World . Accessed June 1, 2022. <i>Data Analyst Training Module 4</i> Common data models (Razzaghi)

Objectives	Assignments/Activities and Required Readings
- Types of data structures and representation - Differences in PEDSnet and OMOP data models (extensions, additions) - ETL workflow in PEDSnet - Translations and interoperability between data models - Process for data model changes in PEDSnet	The Book of OHDSI, Ch. 4 https://ohdsi.github.io/TheBookOfOhdsi/
Learning Session 1: July 18, 2022 Program Introduction for Cohort 3 and The Digital Infrastructure of the Learning Health System I (Faculty: Marc Rosenman, MD, Lurie Children's Hospital)	
- Understand the infrastructure and uses of a research data network <i>Data Analyst Training Module 1</i> - PEDSnet as a national pediatric clinical research infrastructure - Types of research that PEDSnet can do - Types of research that PEDSnet does not do - Strategies that PEDSnet uses to improve patients' health and well-being <i>Data Analyst Training Module 2</i> - Be able to define an electronic health record system; what it comprises and what is not included - Describe and explain the limitations associated with secondary analysis of EHR data - Understand the types of data that EHRs can be linked to	Please view the 2022 PEDSnet faculty recordings (https://pedsnet.org/data/data-science-training/) and complete the readings for assigned modules <i>Data Analyst Training Module 1</i> PEDSnet Clinical Research Network (Forrest) Forrest CB, Margolis P, Seid M, Colletti RB. PEDSnet: how a prototype pediatric learning health system is being expanded into a national network. <i>Health Aff (Millwood)</i>. 2014 Jul;33(7):1171-7. <i>Data Analyst Training Module 2</i> Electronic health records (Bailey) Martin-Sanchez, F. J., V. Aguiar-Pulido, G. H. Lopez-Campos, N. Peek and L. Sacchi (2017). "Secondary Use and Analysis of Big Data Collected for Patient Care." <i>Yearb Med Inform</i> 26(1): 28-37. Methodology Committee of the Patient-Centered Outcomes Research Institute (PCORI). The PCORI Methodology Standards. https://www.pcori.org/sites/default/files/PCORI-Methodology-Standards.pdf Published 2019. Updated February 2019. <i>Standards:</i> - Standards for Data Integrity and Rigorous Analyses - Standards for Preventing and Handling Missing Data - Standards for Data Registries - Standards for Data Networks as Research-Facilitating Structures
Learning Session 2: August 1, 2022 Standardized Vocabularies and Atlas Part I (Faculty: Levon Utidjian, MD, MBI, CHOP)	

Objectives	Assignments/Activities and Required Readings
<i>Data Analyst Training Module 5</i> • How to use Atlas • Vocabularies used in PEDSnet CDM • Key differences between ICD and SNOMED • Strategies for codeset development	Please view the 2022 PEDSnet faculty recordings (https://pedsnet.org/data/data-science-training/) and complete the readings for assigned module <i>Data Analyst Training Module 5</i> Standardized Vocabularies and Atlas The Book of OHDSI, Ch. 5 https://ohdsi.github.io/TheBookOfOhdsi/StandardizedVocabularies.html The Book of OHDSI, Section 8.3 https://ohdsi.github.io/TheBookOfOhdsi/OhdsiAnalyticsTools.html#atlas Atlas Tutorial Videos: (1-8, 11-14, others as desired) https://www.youtube.com/playlist?list=PLpzbqK7kvfeUXjgnpNMfFoff3PDOwv61lZ
Learning Session 3: August 15, 2022 Standardized Vocabularies and Atlas Part II and Computable phenotypes (Faculty: Levon Utidjian, MD MBI CHOP) To be completed as self-study between August 15 and September 30. Data Analyst Training Module 7 Study-specific Data Quality (Faculty: Hanieh Razzaghi, PhD MPH CHOP)	
<i>Data Analyst Training Module 6</i> • Describe what a computable phenotype is and alternative approaches for developing them • Explain how to evaluate a computable phenotype • Understand the advantages and disadvantages of rule-based vs machine learning phenotypes <i>Data Analyst Training Module 7</i> • Types of data quality problems in EHR data and reasons they exist • Approaches to study-specific data quality assessment • Describe differences between data quality and data cleaning • Statistical approaches for handling missing data	Please view the 2022 PEDSnet faculty recordings (https://pedsnet.org/data/data-science-training/) and complete the readings for assigned modules Assignment • Develop a code set for asthma using diagnosis codes, download the codes, and use the codeset to determine the number of individuals in the PEDSnet database with 1+ asthma diagnosis codes. • Develop a codeset for angiotensin-converting enzyme (ACE) inhibitors, download the codes, and use the codeset to determine the number of individuals in the course PEDSnet database with 1+ exposures to ACE inhibitors. • Find all the mappings from the ICD10 code M08.80 to SNOMED and identify potential issues while mapping. • Complete the codeset lists, summary of the counts, and a summary of the ICD10 conversion to pedsnet@chop.edu before the next class, in order to ask questions/troubleshoot during 8/15 session. <i>Data Analyst Training Module 6</i> Computable phenotypes (Utidjian) Richesson RL, et al. Electronic health records-based phenotyping. <i>In</i> NIH Collaboratory Living Textbook of Pragmatic Clinical Trials.

Objectives	Assignments/Activities and Required Readings
	https://rethinkingclinicaltrials.org/chapters/conduct/electronic-health-records-based-phenotyping/electronic-health-records-based-phenotyping-introduction/ Denburg MR, Razzaghi H, Bailey LC, et al. Using Electronic Health Record Data to Rapidly Identify Children with Glomerular Disease for Clinical Research. <i>J Am Soc Nephrol</i>. 2019;30(12):2427-2435. doi:10.1681/ASN.2019040365. https://pubmed.ncbi.nlm.nih.gov/31732612/. Accessed June 1, 2022. Data Analyst Training Module 7 Study-specific Data Quality (Razzaghi) The Book of OHDSI, Ch. 15 https://ohdsi.github.io/TheBookOfOhdsi/DataQuality.html Razzaghi H, Greenberg J, Bailey LC. Developing a systematic approach to assessing data quality in secondary use of clinical data based on intended use. <i>Learn Health Syst</i>. 2021;6(1):e10264. Published 2021 May 3. doi:10.1002/lrh2.10264. https://pubmed.ncbi.nlm.nih.gov/35036548/. Accessed June 1, 2022.
Learning Session 4: September 12, 2022 Introduction to Learning Health Systems (Faculty: Don Goldmann, MD Boston Children's Hospital)	
- Describe the system properties that are important to a Learning Health System - List and define the core concepts of a Learning Health System	Forrest CB, Chesley FD, Tregear ML, Mistry KB. Development of the Learning Health System Researcher Core Competencies. <i>Health Services Research</i>. 2017;53(4):2615-2632. doi:10.1111/1475-6773.12751. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6051975/ Required video recording https://www.youtube.com/watch?v=dkas3l4YCWo Reference book Smith MD, Saunders, R, Stuckhardt, L. McGinnis, JM. <i>Best Care at Lower Cost: the Path to Continuously Learning Health Care in America</i>. Washington, D.C.: National Academies Press; 2013. doi:10.17226/13444. https://www.nap.edu/catalog/13444/best-care-at-lower-cost-the-path-to-continuously-learning. Supplementary reading Friedman C, Rubin J, Brown J, et al. Toward a science of learning systems: a research agenda for the high-functioning Learning Health System. <i>Journal of the American Medical Informatics Association</i>. 2014;22(1):43-50. doi:10.1136/amiajnl-2014-002977.

Objectives	Assignments/Activities and Required Readings
	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4433378/ . Accessed October 01, 2021.
ENGAGEMENT Self-guided training/learning modules There are three modules that Scholars must be complete between September and October 2022. The first two are targeted at patient/parent partners in the research process. It is useful to complete these to understand the types of training these individuals can receive before engaging in a research project. FYREworks. Family, Youth and Researcher Education. FYREworks is a set of interactive, web-based trainings and toolkits that will help youth and researchers create research partnerships and do Patient Centered Outcomes Research together. It is designed to help researchers, teens, and families work together to answer questions about children's health. The course, developed with support from PCORI, can be accessed here: https://www.fyeworkstraining.com/ Research Fundamentals: Preparing You to Successfully Contribute to Research. Research Fundamentals is a free online training for those who are new to health research and want to learn more about the research process. Developed by the Patient-Centered Outcomes Research Institute Research, this is a self-paced, on-demand training that uses plain language to describe patient-centered outcomes research and can help everyone, regardless of experience, engage and contribute with confidence. The course can be accessed here: https://www.pcori.org/engagement/research-fundamentals Guidance for Completing PCORI's Updated Engagement Plan for New Awardees and Future Applicants Webinar Recording. When study teams are awarded PCORI funding, they are now asked to submit updated information about their engagement plans shortly after the project period begins. In this webinar, PCORI offers guidance on elements to consider when planning and implementing engagement activities and suggestions for developing a structured approach for integrating the perspective of partners throughout the conduct of the study. This webinar was recommended for recent awardees, future applicants and study teams planning engaged research. Available at: https://www.pcori.org/video/guidance-completing-pcoris-updated-engagement-plan-new-awardees-and-future-applicants-webinar	
Learning Sessions 5: September 19, 2022	
Patient and Family Engagement in Research (Faculty: Amy Kratchman, CHOP)	
Learning Points: - Describe an institution-wide response to the increased demand for family engagement in research; - Describe processes of identifying, onboarding, training, and mentoring Research Family Partners and researchers to establish and maintain research partnerships, and collaboratively conduct research; and	Please complete the self-guided learning modules Scholars will submit engagement plans for feedback to Amy Kratchman in January 2023 Browne T, Swoboda A, Ephraim PL, et al. Engaging patients and family members to design and implement patient-centered kidney disease research. <i>Res Involv Engagem.</i> 2020;6(1):66. Published 2020 Nov 1. doi:10.1186/s40900-020-00237-y. https://pubmed.ncbi.nlm.nih.gov/33292683/. Accessed September 13, 2022. Carman KL, Workman TA. Engaging patients and consumers in research evidence: Applying the conceptual model of patient and family engagement. <i>Patient Educ Couns.</i> 2017;100(1):25-29.

Objectives	Assignments/Activities and Required Readings
- Provide examples of Family Partners' varying levels of engagement in research. (<i>PCORI Engagement Plan</i>) - Learn more about the updated PCORI Engagement Plan and its purpose; - Leverage the PCORI updated Engagement Plan template as a tool for conceptualizing and planning patient and stakeholder engagement in a research project; and - Learn how other researchers have utilized the updated engagement plan template to guide their overall engagement strategy.	doi:10.1016/j.pec.2016.07.009. https://pubmed.ncbi.nlm.nih.gov/27473639/ . Accessed September 13, 2022. Forsythe LP, Carman KL, Szydlowski V, et al. Patient Engagement In Research: Early Findings From The Patient-Centered Outcomes Research Institute. Health Aff (Millwood). 2019 Mar;38(3):359-367. Doi:10.1377/hlthaff.2018.05067. https://pubmed.ncbi.nlm.nih.gov/30830822/. Accessed October 01, 2021. Methodology Committee of the Patient-Centered Outcomes Research Institute (PCORI). The PCORI Methodology Standards. https://www.pcori.org/sites/default/files/PCORI-Methodology-Standards.pdf Published 2019. Updated February 2019. Standard 2 Patient Centeredness

IMPLEMENTATION SCIENCE MODULE

Self-guided learning modules

There are seven modules of the course that Scholars must complete between August and October 2022.

NIH course, Training Institute for Dissemination and Implementation Research in Cancer (TIDIRC).

Dissemination and implementation (D&I) research seeks to address this gap by understanding how to deliver evidence-based strategies to improve health and prevent disease in clinical and public health practice. D&I research draws from a variety of behavioral and social science disciplines and employs approaches and methods that balances rigor with relevance, and employs study designs and methods appropriate for the complex processes involved in D&I. Eight modules include videos, readings, and self-reflection questions make up the TIDIRC open access course. The course can be accessed here:

<https://cancercontrol.cancer.gov/is/training-education/training-in-cancer/TIDIRC-open-access>

- Introduction to Dissemination & Implementation
- Theories, Models, and Frameworks
- Implementation Science Measures
- Dissemination & Implementation Research Designs
- Qualitative and Mixed Methods in Dissemination & Implementation Research
- Implementation Strategies
- Adaptation and Fidelity of Interventions in Implementation Research
- Optional: Emerging Topics in Implementation Science

Learning Session 6: October 3, 2022 Harnessing implementation science to transform health and healthcare (Faculty: Rinad Beidas, PhD Northwestern University)

Please complete modules 1-5 before session

Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC.

Objectives	Assignments/Activities and Required Readings
	Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci. 2009 Aug 7;4:50. doi: 10.1186/1748-5908-4-50. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2736161/pdf/1748-5908-4-50.pdf. Accessed September 20, 2022. Lane-Fall MB, Curran GM, Beidas RS. Scoping implementation science for the beginner: locating yourself on the "subway line" of translational research. BMC Med Res Methodol. 2019 Jun 28;19(1):133. doi: 10.1186/s12874-019-0783-z. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6599376/pdf/12874_2019_Article_783.pdf. Accessed September 20, 2022. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, Griffey R, Hensley M. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. Adm Policy Ment Health. 2011 Mar;38(2):65-76. doi: 10.1007/s10488-010-0319-7. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3068522/pdf/10488_2010_Article_319.pdf. Accessed September 20, 2022.
Learning Session 7: October 26-27, 2022 PCORI 2022 Annual Meeting: Pathways to Health Equity, Please register at https://www.pcorievents.org/event/4ee5e655-7152-46c0-9b13-44956f258a8c/summary?RefId=9.22%20HE%20Email, and plan to attend sessions that are of greatest interest to you and your work.	
Learning Session 8: November 7, 2022 Health System Leader Panel featuring Daniel Hyman, MD, MMM Chief Safety and Quality Officer at the Children's Hospital of Philadelphia (CHOP) and Stephen Muething, MD, Chief Quality Officer and the Co-Director of the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center	
Learning Session 9: December 5, 2022 Implementation Science (Faculty: Shannon Wiltsey Stirman, PhD, Stanford University)	
To understand the differences and the relationship between adaptation and fidelity.	Please complete Modules 6-7 before session https://cancercontrol.cancer.gov/is/training-education/training-in-cancer/TIDIRC-open-access Kirk MA, Moore JE, Wiltsey Stirman S, Birken SA. Towards a comprehensive model for understanding adaptations' impact: the model for adaptation design and impact (MADI). Implement Sci. 2020;15(1):56. Published 2020 Jul 20. doi:10.1186/s13012-020-01021-y. https://pubmed.ncbi.nlm.nih.gov/32690104/ . Accessed October 20, 2022. Miller CJ, Wiltsey Stirman S, Baumann AA. Iterative Decision-making for Evaluation of Adaptations (IDEA): A decision tree for balancing adaptation, fidelity, and intervention impact. J Community Psychol. 2020;48(4):1163-1177. doi:10.1002/jcop.22279.

Objectives	Assignments/Activities and Required Readings
	https://pubmed.ncbi.nlm.nih.gov/31970812/. Accessed October 20, 2022. Perez Jolles M, Lengnick-Hall R, Mittman BS. Core Functions and Forms of Complex Health Interventions: a Patient-Centered Medical Home Illustration [published correction appears in J Gen Intern Med. 2019 Apr 1;:]. J Gen Intern Med. 2019;34(6):1032-1038. doi:10.1007/s11606-018-4818-7. https://pubmed.ncbi.nlm.nih.gov/30623387/. Accessed October 20, 2022. Wiltsey-Stirman S, Baumann AA, Miller CJ. The FRAME: an expanded framework for reporting adaptations and modifications to evidence-based interventions. Implement Sci. 2019;14(1):58. Published 2019 Jun 6. doi:10.1186/s13012-019-0898. https://pubmed.ncbi.nlm.nih.gov/31171014/. Accessed October 20, 2022.
IMPROVEMENT SCIENCE MODULE Self-guided learning module There is one course (audit track) that Scholars must complete between December and January. Institute for Healthcare Improvement (IHI) and HarvardX course Practical Improvement Science in Health Care: A Roadmap for Getting Results, A Free Massive Online Open Course. This is an introductory, 7-part, on-line, self-directed learning series that explores a scientific approach to improvement - a practical, rigorous methodology that includes a theory of change, measurable aims, and iterative, incremental small tests of change to determine if improvement concepts can be implemented effectively in practice. PEDSnet Scholars Program Co-Director, Don Goldmann is a co-developer of the course. Recommended time for completion is 2-5 hours/week over seven weeks. <i>Please note that access to courses expire at a specified period after you register.</i> The course (audit option is available for no charge) can be accessed here: https://www.edx.org/course/practical-improvement-science-in-health-care-a-roa	
Learning Session 10: January 9, 2023 Introduction to a personal Quality Improvement Project and Building Blocks of Improvement Science (Faculty: Don Goldmann)	
- Apply quality improvement science concepts and methods to conduct a personal quality improvement project over 10-12 weeks. <i>(IHI MOOC objectives)</i> - Discuss why improvement science is valuable in health and healthcare; - Explain why understanding a system is critical to improving a process;	Please complete the charter template of the Quality Improvement Project template by the end of January and submit for comments. The personal QIP will launch late January and conclude by March. Final reports are due in advance of report presentations in May/June.

Objectives	Assignments/Activities and Required Readings
- Discuss the value of conducting iterative tests of change; - Explain how an improvement project becomes reliable, standard work; and - Design and execute a personal improvement project, including an aim, measures, and tests of change.	
Learning Session 11: January 23, 2023 Engagement Plan WIP Breakout Session (Faculty: Amy Kratchman) Small Groups 1. Abbas Zaidi, Amanda O'Halloran, Megan Waldrop 2. Shireen Hayatghaibi, Nicole Kahn, Lucy Kohn 3. Jordee Wells, Becky Scobell, Jessica Bloom	
Learning Session 12: February 13, 2023 Improvement Science Part II (Faculty: Don Goldmann)	
Learning Session 13: March 6, 2023 Learning Health System Science Funding Opportunities (Faculty: Chris Forrest)	
- Identify federal funding opportunities for LHS science and research; and - Describe the relevance of these funding types for LHS science and research.	Supplementary readings: Food and Drug Administration. Framework for FDA's Real-World Evidence Program. Published 2018. https://www.fda.gov/media/120060/download . Accessed October 01, 2021. PCORI Applicant Resources. https://www.pcori.org/funding-opportunities/applicant-and-awardee-resources/applicant-resources .
Learning Session 14: April 2023 Personal Quality Improvement Project Report Out, Session 1 (Jessica Bloom, Becky Scobell, Nicole Kahn)	
May 30, 2023 Cohort 2 Capstone Presentations Session 1: Spring 2023	
12:10 – 12:35 pm	Michael Tchou, MD, MSc, Children's Hospital Colorado <i>Reducing overuse of high-frequency, low-value diagnostic testing in children's hospitals</i>
12:35 – 1:00 pm	Andrea Rivera-Sepulveda, MD MSc, Nemours Children's Health <i>Development of a clinical scoring tool to predict bronchodilator responsiveness in children with bronchiolitis</i>
1:00 – 1:25 pm	Paul Enlow, PhD, Nemours Children's Health <i>Promoting Equity in the Use of Diabetes Technologies Among Youth with New-Onset Type 1 Diabetes</i>
1:25 – 1:50 pm	LeighAnne Bakel, MD, MSc, Children's Hospital Colorado

Objectives	Assignments/Activities and Required Readings
	<i>A Learning Health Systems Approach to Clinical Pathway Optimization through Provider Adherence, Patient Outcomes, and Patient/Family Experience</i> Research mentors: Suchitra Rao, MD, Children's Hospital Colorado
June 2, 2023 Cohort 2 Capstone Presentations Session 2: Spring 2023 12:10- 12:35 pm 12:35 – 1:00 pm 1:00 – 1:25 pm 1:25 – 1:50 pm	Nathan Pajor, MD, MS, Cincinnati Children's Hospital Medical Center <i>Describing ventilator weaning in the pediatric long-term mechanical ventilator dependent population using multi-site data</i> Samantha Jo Boch, PhD, MS, RN, Cincinnati Children's Hospital Medical Center <i>Social Justice and Equity: Bridging Data Sciences Approach to Improve the Care of Children of Incarcerated Parents</i> Gina Sequeira, MD, MS, Seattle Children's Hospital <i>Improving Access to Gender-Affirming Care for Transgender Youth through Telehealth</i> Yair Bennett, MD, Stanford Children's Health <i>Novel Quality Measures for Primary Care Management of Attention-Deficit/Hyperactivity Disorder</i>
Learning Session 15: June 6, 2023	Building Learning Health System Research Networks (Faculty: Michelle Denburg, MD, MSCE, and Greg Tasian, MD, MSc, MSCE Children's Hospital of Philadelphia)
Learn approaches to building and growing LHS specialty networks	Ellison JS, Lorenzo M, Beck H, Beck R, Chu DI, Forrest C, Huang J, Kratchman A, Kurth A, Kurth L, Kurtz M, Lendvay T, Sturm R, Tasian G; Pediatric KIDney Stone Care Improvement Network. Comparative effectiveness of paediatric kidney stone surgery (the PKIDS trial): study protocol for a patient-centred pragmatic clinical trial. <i>BMJ Open</i>. 2022 Apr 5;12(4):e056789. doi: 10.1136/bmjopen-2021-056789. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8983998/ Accessed July 01, 2023. Gluck CA, Forrest CB, Davies AG, Maltenfort M, McDonald JR, Mitsnefes M, Dharnidharka VR, Dixon BP, Flynn JT, Somers MJ, Smoyer WE, Neu A, Hovinga CA, Skversky AL, Eissing T, Kaiser A, Breitenstein S, Furth SL, Denburg MR. Evaluating Kidney Function Decline in Children with Chronic Kidney Disease Using a Multi-Institutional Electronic Health Record Database. <i>Clin J Am Soc Nephrol</i>. 2023 Feb 1;18(2):173-182. doi: 10.2215/CJN.0000000000000051. https://pubmed.ncbi.nlm.nih.gov/36754006/ Lannon C, Schuler CL, Seid M, Provost LP, Fuller S, Purcell D, Forrest CB, Margolis PA. A maturity grid assessment tool for learning networks. <i>Learn Health Syst</i>. 2020 Jun 26;5(2):e10232. doi: 10.1002/lrh2.10232. PMID: 33889737; PMCID: PMC8051339. https://pubmed.ncbi.nlm.nih.gov/33889737/ Accessed June 5, 2023. Methodology Committee of the Patient-Centered Outcomes Research Institute (PCORI). The PCORI Methodology Standards. https://www.pcori.org/sites/default/files/PCORI-Methodology-Standards.pdf Published 2019. Updated February 2019. Standard 13 Complex Interventions

Objectives	Assignments/Activities and Required Readings
	Moore GF, Audrey S, Barker M, et al. Process evaluation of complex interventions: Medical Research Council guidance. BMJ. 2015;350:h1258. Published 2015 Mar 19. doi:10.1136/bmj.h1258. https://pubmed.ncbi.nlm.nih.gov/25791983/ <i>Supplementary readings</i> Batalden M, Batalden P, Margolis P, et al. Coproduction of healthcare service. BMJ Quality & Safety. 2016;25(7):509-517. Doi:10.1136/bmjqs-2015-004315. https://qualitysafety.bmj.com/content/25/7/509 Accessed October 01, 2021. Britto MT, Fuller SC, Kaplan HC, et al. Using a network organizational architecture to support the development of Learning Healthcare Systems. BMJ Quality & Safety. 2018;27(11):937-946. Doi:10.1136/bmjqs-2017-007219. https://qualitysafety.bmj.com/content/27/11/937.info Accessed October 01, 2021.
Learning Session 16: June 26, 2023 Personal Quality Improvement Project Report Out, Session 2 (Abbas Zaidi, Lucy Kohn, Megan Waldrop, Shireen Hayatghaibi, Jorjee Wells, Amanda O'Halloran)	
Research Methods and Study Designs Self-guided learning modules Scholars must complete the following between June and August. • NIH Health Care Systems Research Collaboratory- The Collaboratory aims to improve the way pragmatic clinical trials are conducted by creating a new infrastructure for collaborative research with healthcare systems. The Collaboratory has organized resources around four primary modules: ▪ Design; ▪ Data, Tools and Conduct; ▪ Dissemination; and ▪ Ethics and Regulatory. The site can be accessed here: https://rethinkingclinicaltrials.org/grand-rounds-hub/. Scholars should review topics for all four modules. Scholars have discretion as to the effort they should devote to specific chapters (readings and papers) based on their existing knowledge and skills, and desire to expand competency level.	
Learning Session 17: July 10, 2023 Biologic Abatement and Capturing Kids' Outcomes and Flare Frequency in Juvenile Spondyloarthritis (BACK-OFF JSa): A Randomized Pragmatic Trial (Faculty: Pamela Weiss, MD MSCE, Children's Hospital of Philadelphia)	
• Learn key components to	
Learning Session 18: July 17, 2023 Unequal Treatment, 20 Years Later (Faculty: Deena Chisolm, PhD, Nationwide Children's Hospital)	

Objectives	Assignments/Activities and Required Readings
Apply an equity lens to learning health system science in order to improve outcomes in children	Institute of Medicine (US) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care; Smedley BD, Stith AY, Nelson AR, editors. Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Washington (DC): National Academies Press (US); 2003. EXECUTIVE SUMMARY. Available from: https://www.ncbi.nlm.nih.gov/books/NBK220355/
Learning Session 19: July 31, 2023 PEDSnet Real World Data Simulation- Trial Emulations and Beyond (Faculty: Yong Chen, PhD, University of Pennsylvania)	
Understanding the value of target trial emulation methods with real world data	Hernán MA, Wang W, Leaf DE. Target Trial Emulation: A Framework for Causal Inference From Observational Data. <i>JAMA</i>. 2022;328(24):2446-2447. doi:10.1001/jama.2022.21383 Hernán MA, Robins JM. Using Big Data to Emulate a Target Trial When a Randomized Trial Is Not Available. <i>Am J Epidemiol</i>. 2016;183(8):758-764. doi:10.1093/aje/kwv254 Suchard MA, Schuemie MJ, Krumholz HM, et al. Comprehensive comparative effectiveness and safety of first-line antihypertensive drug classes: a systematic, multinational, large-scale analysis. <i>Lancet</i>. 2019;394(10211):1816-1826. doi:10.1016/S0140-6736(19)32317-7 <i>Preprint (please do not distribute):</i> Real-world Effectiveness of BNT162b2 in Children and Adolescents Qiong Wu, Jiayi Tong, Bingyu Zhang, Dazheng Zhang, Jie Xu, Yishan Shen, Lu Li, L. Charles Bailey, Jiang Bian, Dimitri A. Christakis, Megan L. Fitzgerald, Kathryn Hirabayashi, Ravi Jhaveri, Alka Khaitan, Tianchen Lyu, Suchitra Rao, Hanieh Razzaghi, Hayden T. Schwenk, Fei Wang, Margot I. Witvliet, Eric J. Tchetgen Tchetgen, Jeffrey S. Morris, Christopher B. Forrest, Yong Chen medRxiv 2023.06.16.23291515; doi: https://doi.org/10.1101/2023.06.16.23291515
Learning Session 20: September 18, 2023 Review of Scholars Meeting Agenda and QIP Presentation	
Measurement and Pediatric Patient Reported Outcomes HealthMeasures.net consists of PROMIS, Neuro-QoL, ASCQ-Me, and NIH Toolbox. These four precise, flexible, and comprehensive measurement systems assess physical, mental, and social health, symptoms, well-being and life satisfaction; along with sensory, motor, and cognitive function. The site includes information on the measurement systems, measures, and measurement science. - The site can be accessed here: https://www.healthmeasures.net/ - Introductory presentations to the four measurement systems. https://www.healthmeasures.net/index.php?option=com_content&view=category&layout=blog&id=159&Itemid=1075 - Computer adaptive tests and demonstrations: https://www.healthmeasures.net/resource-center/measurement-science/computer-adaptive-tests-cats	

Objectives	Assignments/Activities and Required Readings
PRO Planning Toolkit- Summarizes the empirical knowledge and guidance about PRO implementation in routine clinical care. 1. The document entitled PRO Planning Toolkit Overview explains the toolkit more fully and provides a full list of authors and acknowledgements. This document also provides brief instructions for using these planning tools. http://doi.org/10.18131/g3-ejp7-cb85 2. The PRO Planning Guide includes structured lists of specific questions that should be answered to implement PROs as well as resources to aid in decision making. http://doi.org/10.18131/g3-0shy-pn30 3. The Decision Log based on the PRO Planning Guide was created to serve as a record of planning decisions. http://doi.org/10.18131/g3-vy44-c949 4. The Implementation Plan Template functions as a model for a clinic implementation plan. https://doi.org/10.18131/g3-fev6-hc15	
Learning Session 21: October 2, 2023 Conceptualizing and Measuring Outcomes in Children (Faculty: Adam Carle, PhD MA Cincinnati Children's Hospital Medical Center)	
	Weinfurt KP. Constructing arguments for the interpretation and use of patient-reported outcome measures in research: an application of modern validity theory. Qual Life Res. 2021;30(6):1715-1722. doi:10.1007/s11136-021-02776-7 https://link.springer.com/article/10.1007/s11136-021-02776-7 Chang CH, Reeve BB. Item response theory and its applications to patient-reported outcomes measurement. Eval Health Prof. 2005;28(3):264-282. doi:10.1177/0163278705278275 https://journals.sagepub.com/doi/10.1177/0163278705278275
Learning Session 22: October 17, 2023 Small group meetings	
Learning Session 23: October 25 PEDSnet Scholars Annual Meeting, Philadelphia PA Meeting Goals: 1. To strengthen PEDSnet Scholar cohort relationships; and 2. To gain competency in how to use PEDSnet and PCORnet for research.	
Learning Session 24: November 6, 2023 Small group Presentations	
Learning Session 25: November 20, 2023 Featured article discussion (Faculty: Don Goldmann, Scholar reactors: TBD)	
	Aggarwal G, Peden CJ, Mohammed MA3, Pullyblank A, Williams B, Stephens T, Kellett S, Kirkby-Bott J, Quiney N; Emergency Laparotomy Collaborative. Evaluation of the Collaborative Use of an Evidence-Based Care Bundle in Emergency Laparotomy. JAMA Surg. 2019 May 1;154(5):e190145. doi: 10.1001/jamasurg.2019.0145. Epub 2019 May 15. https://jamanetwork.com/journals/jamasurgery/fullarticle/2728194 . Accessed October 01, 2021.

Objectives	Assignments/Activities and Required Readings
	Stephens TJ, Peden CJ, Pearse RM, et al. Improving care at scale: process evaluation of a multi-component quality improvement intervention to reduce mortality after emergency abdominal surgery (EPOCH trial) [published correction appears in <i>Implement Sci.</i> 2018 Dec 10;13(1):148]. <i>Implement Sci.</i> 2018;13(1):142. Published 2018 Nov 13. doi:10.1186/s13012-018-0823-9. https://implementationscience.biomedcentral.com/track/pdf/10.1186/s13012-018-0823-9. Accessed October 01, 2021. Peden CJ, Stephens T, Martin G, et al. Effectiveness of a national quality improvement programme to improve survival after emergency abdominal surgery (EPOCH): a stepped-wedge cluster-randomised trial. <i>Lancet.</i> 2019;393(10187):2213-2221. doi:10.1016/S0140-6736(18)32521-2
Learning Session 26: December 18, 2023 Tips to Getting Published: An Insider's Guide to Journal Editor's Thinking (Faculty: Dimitri Christakis MD, MPH, JAMA Pediatrics Editor in Chief, Seattle Children's Hospital)	
Learning Session 27: January 8, 2024 Process Evaluation (Faculty: Don Goldmann)	
	Methodology Committee of the Patient-Centered Outcomes Research Institute (PCORI). The PCORI Methodology Standards. https://www.pcori.org/sites/default/files/PCORI-Methodology-Standards.pdf Published 2019. Updated February 2019. 13 Standards for Complex Interventions (page 13) Moore GF, Audrey S, Barker M, et al. Process evaluation of complex interventions: Medical Research Council guidance. <i>BMJ.</i> 2015;350:h1258. Published 2015 Mar 19. doi:10.1136/bmj.h1258. https://pubmed.ncbi.nlm.nih.gov/25791983/ OPTIONAL: Semrau KEA, Herlihy J, Grogan C, Musokotwane K, Yeboah-Antwi K, Mbewe R, Banda B, Mpamba C, Hamomba F, Pilingana P, Zulu A, Chanda-Kapata P, Biemba G, Thea DM, MacLeod WB, Simon JL, Hamer DH. Effectiveness of 4% chlorhexidine umbilical cord care on neonatal mortality in Southern Province, Zambia (ZamCAT): a cluster-randomised controlled trial. <i>Lancet Glob Health.</i> 2016 Nov;4(11):e827-e836. doi: 10.1016/S2214-109X(16)30215-7. Epub 2016 Sep 29. PMID: 27693439.
Learning Session 28: January 22, 2024 Regulatory Considerations in Learning Health Systems Science (Faculty: Chris Forrest)	
	Faden RR, Kass NE, Goodman SN, Pronovost P, Tunis S, Beauchamp TL. An ethics framework for a learning health care system: a departure from traditional research ethics and clinical ethics. <i>Hastings Cent Rep.</i> 2013 Jan-Feb;Spec No:S16-27. doi: 10.1002/hast.134. PMID: 23315888. Kass NE, Faden RR. Ethics and Learning Health Care: The Essential roles of engagement, transparency, and accountability. <i>Learn Health Syst.</i> 2018 Sep 18;2(4):e10066. doi: 10.1002/lrh2.10066. PMID: 31245590; PMCID: PMC6508806.
Learning Session 29: February 5, 2024 Paper Discussion (Faculty: Don Goldmann)	

Objectives	Assignments/Activities and Required Readings
	Semrau KEA, Herlihy J, Grogan C, Musokotwane K, Yeboah-Antwi K, Mbewe R, Banda B, Mpamba C, Hamomba F, Pilingana P, Zulu A, Chanda-Kapata P, Biemba G, Thea DM, MacLeod WB, Simon JL, Hamer DH. Effectiveness of 4% chlorhexidine umbilical cord care on neonatal mortality in Southern Province, Zambia (ZamCAT): a cluster-randomised controlled trial. <i>Lancet Glob Health</i> . 2016 Nov;4(11):e827-e836. doi: 10.1016/S2214-109X(16)30215-7. Epub 2016 Sep 29. PMID: 27693439
Learning Session 30: April 1, 2024	WIP presentations
Learning Session 31: April 15, 2024	WIP presentations
Learning Session 32: May 6, 2024	WIP presentations
Learning Session 33: May 20, 2024	WIP presentations, Program Debrief
Learning Session 34: June 3, 2024 (Faculty: Suchitra Rao, MD, Children's Hospital of Colorado)	Leveraging PEDSnet to Study Short and Long term COVID-19
Learning Session 34: June 17, 2024	Health Systems Leader Panel (Faculty: James Chamberlain, MD, Children's National Hospital, and Grace Lee, MD, Stanford Children's)
Additional topics	
Regulatory Considerations in Learning Health Systems Science	
Baily MA, Bottrell M, Lynn J, Jennings B, Hastings Center. The ethics of using QI methods to improve health care quality and safety. <i>Hastings Cent Rep</i>. 2006;36(4):S1-S40. doi:10.1353/hcr.2006.0054. https://pubmed.ncbi.nlm.nih.gov/30830822/. Accessed October 01, 2021. Cumyn, A, Barton, A, Dault, R, Cloutier, A-M, Jalbert, R, Ethier, J-F. Informed consent within a learning health system: A scoping review. <i>Learn Health Sys</i>. 2019; e10206. https://doi.org/10.1002/lrh2.10206. https://onlinelibrary.wiley.com/doi/10.1002/lrh2.10206. Accessed October 01, 2021. Faden RR, Kass NE, Goodman SN, Pronovost P, Tunis S, Beauchamp TL. An ethics framework for a learning health care system: a departure from traditional research ethics and clinical ethics. <i>Hastings Cent Rep</i>. 2013 Jan-Feb;Spec No:S16-27. doi: 10.1002/hast.134. https://pubmed.ncbi.nlm.nih.gov/23315888/. Accessed October 01, 2021. Joshua R, Downing NL, Shieh L, Heidenreich P, and Cho MK. "Ethical Oversight of Quality Improvement and the Research- QI Boundary: A New Common Rule Changes Little," <i>Hasting Center Report</i> 39 (2017): 2-10. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4574354/. Accessed October 01, 2021. Lynn J, Baily MA, Bottrell M, et al. The ethics of using quality improvement methods in health care. <i>Ann Intern Med</i>. 2007;146(9):666-673. doi:10.7326/0003-4819-146-9-200705010-00155. https://pubmed.ncbi.nlm.nih.gov/17438310/. Accessed October 01, 2021. Office for Human Research Protections (OHRP) Website. Quality Improvement Activities FAQs. Available here: https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/quality-improvement-activities/index.html	

PEDSNET SCHOLARS PROGRAM POLICIES

Term: Minimum of 2-year duration; some scholars may be offered an optional 3rd year. Scholars must obtain commitment from their institutions for 75% protected time for the duration of the program. For institutional/other funded applicants only, up to 25% of that effort may include operations, QI, informatics, or other administrative responsibilities related to LHS activities.

Salary Support: (1) AHRQ sponsored scholars: up to \$90,000 direct costs annually, per scholar, plus associated fringe benefits. The K12 requires the appointed scholar to devote a minimum of 75 percent of annual full-time effort to the grant (i.e. at least 30 hours per week). Each scholar must be appointed for a minimum of two and a maximum of three years. Scholars are not allowed to reduce their level of effort below 75% over the course of the award. (2) Institutional or other extramural sponsored scholars: commitment from institution/organization to cover required salary effort and research expenses.

Research Development Costs (AHRQ budgets): up to \$15,000 for costs such as: travel to scientific meetings; consultant costs; research supplies; reimbursement of patient participation costs; equipment, tuition, fees, and books related to didactic courses or career development; health insurance (self-only or family); and statistical services including personnel and computer time. These expenses need to be specifically identified in the budget justification and must be allowable, reasonable, allocable, and necessary. Research mentors should be offered a \$5,000 stipend. Annual budgets must be prepared and submitted to the program office. For institutional/other funded applicants, appropriate research development costs should be accounted for in the overall program budget.

Appointment Process: xTrain is an eRA Commons module that allows program directors/principal investigators, university administrators, and trainees electronically prepare and submit PHS 2271 Statement of Appointment Forms and PHS 416-7 Termination Notices associated with institutional research training grants, institutional career development awards, individual fellowships, and research education awards. AHRQ appointed scholars must provide the required information to the PEDSnet Scholars program office to comply with the administrative policies and processes for scholar appointment and termination.

Meeting Attendance: PEDSnet Scholar learning sessions are mandatory. Scholar attendance is recorded and should not fall below 80% participation. PEDSnet Scholar in person meetings (annual) are mandatory and may rotate among PEDSnet institutions. Travel expenses should be accounted for in the overall program budget.

PEDSNET SCHOLARS RESEARCH POLICIES AND REQUIREMENTS

Responsible Conduct of Research: PEDSnet Scholars are expected to fulfill all educational requirements of Responsible Conduct of Research for their home institution. This includes but is not limited to Humans Subject Research requirements. Scholars will provide the program office with documentation of project IRB approvals or waivers.

Program Acknowledgement: Suggested verbiage for publication acknowledgment, where applicable. AHRQ- PCORI funded scholars should include the contents within brackets.
"This publication was supported in part by the [AHRQ-PCORI funded] PEDSnet Scholars Training Program [(5K12HS026393-03)], which is a national faculty development program that trains individuals in the competencies of learning health systems science.

NIH Public Access Policy (<https://publicaccess.nih.gov/policy.htm>): PEDSnet Scholars are expected to comply with NIH Public Access Policies, per AHRQ requirements. For all applicable publications, please follow instructions to be in compliance (<https://publicaccess.nih.gov/>). A PMCID should be included as part of all eligible publication citations listed in the scholar's annual progress report.

PEDSnet Scholars Program Data Science Curriculum *(adapted from the PEDSnet Data Analyst Training Curriculum Winter/Spring 2022)*

Background

PEDSnet (pedsnet.org) is a multi-institutional clinical research network that standardizes EHR and other types of clinical data from several of the nation's largest children's healthcare organizations to enable observational research, population health surveillance, and pragmatic clinical trials. Participating institutions currently include: Children's Hospital of Philadelphia; Cincinnati Children's Hospital Medical Center; Children's Hospital of Colorado; Lurie Children's Hospital; Nationwide Children's Hospital; Children's National Medical Center; Nemours Children's Health System (a Delaware and Florida health system); Seattle Children's Hospital; and, Stanford Children's Health.

PEDSnet standardizes EHR data across institutional data marts to the PEDSnet common data model (CDM), which is based on the Observational Medical Outcomes Partnership (OMOP) common data model. PEDSnet has accrued data for millions of children seen since 2009 from all inpatient and outpatient clinical settings. Although patients in the PEDSnet database reside in all 50 states, the following states have the highest numbers: California; Colorado; Delaware; Florida; Illinois; Indiana; Kentucky; Maryland; New Jersey; Ohio; Pennsylvania; Washington; and, Washington DC.

The PEDSnet Data and Statistical Coordinating Center (DSCC) is based at the Children's Hospital of Philadelphia (CHOP). The network, however, has endorsed the concept of a Coordinating Center without Walls, which will enable any PEDSnet institution to serve as the DSCC for a given study. Institutions that serve in the DSCC capacity are required to adhere to the standards, process, and protocols that the CHOP DSCC maintains.

To serve as a DSCC, an institution has two options: data analysis only OR data science and data analytics. In the former, the CHOP DSCC will develop an analysis dataset for institutional analysts. In the latter scenario, the institution will develop their own analysis files, conduct necessary data quality assessments, and execute the analyses specified in the data analysis plan.

Purpose of Curriculum

The goals of the PEDSnet Scholars Data Science curriculum are to:

- Provide a vision for informatics in a high functioning LHS;
- Define and discuss essential applied informatics concepts;
- Describe the Digital architecture for research networks (e.g. PEDSnet, CAPriCORN);
- Review how the EHR can be used for research and registries;
- Describe approaches and challenges to computable phenotyping and population denominators.

Course Faculty

- L Charles Bailey, MD, PhD
- Christopher B. Forrest, MD, PhD
- Hanieh Razzaghi, MPH

- Marc Rosenman, MD
- Levon Utidjian, MD

Recordings

PEDSnet Data Science videos can be accessed at: <https://pedsnet.org/data/data-science-training/>

Atlas Tutorial videos can be accessed at:

<https://www.youtube.com/playlist?list=PLpzbqK7kvfeUXjgnpNMFOff3PDOwv61lZ>

Reference

The Book of OHDSI (Observational Health Data Sciences and Informatics) 2021-01-11, can be accessed at: <https://ohdsi.github.io/TheBookOfOhdsi/>

Sessions

Research Network

1. PEDSnet Clinical Research Network (Forrest)

Readings:

(1) Forrest CB, Margolis P, Seid M, Colletti RB. PEDSnet: how a prototype pediatric learning health system is being expanded into a national network. *Health Aff (Millwood)*. 2014 Jul;33(7):1171-7.

Learning Points:

- PEDSnet as a national pediatric clinical research infrastructure
- Types of research that PEDSnet can do
- Types of research that PEDSnet does not do
- Strategies that PEDSnet uses to improve patients' health and well-being

2. Electronic health records (Bailey)

Readings:

(1) Martin-Sanchez, F. J., V. Aguiar-Pulido, G. H. Lopez-Campos, N. Peek and L. Sacchi (2017). "Secondary Use and Analysis of Big Data Collected for Patient Care." *Yearb Med Inform* 26(1): 28-37.

Learning Points:

- Be able to define an electronic health record system; what it comprises and what is not included
- Describe and explain the limitations associated with secondary analysis of EHR data
- Understand the types of data that EHRs can be linked to

3. PEDSnet Database and Data Privacy (Bailey)

Readings:

(1) PEDSnet Participation and Data Use Agreement

(2) Culnane, C.; Rubinstein, B.I.P; Teague, V (2017). "Health Data in an Open World."

<https://arxiv.org/ftp/arxiv/papers/1712/1712.05627.pdf>

Learning Points:

- Describe the terms and conditions for data sharing in PEDSnet
- Know how to access PEDSnet servers and databases: structure, content, and permissions
- Know how to protect against data breaches

- Understand PEDSnet's standard techniques for reducing privacy risk

4. Common data models (CDM) (Razzaghi)

Reading:

(1) The Book of OHDSI, Ch. 4

Learning Points:

- Widely adopted CDMs--OMOP, PCORnet/Sentinel
- Types of data structures and representation
- Differences in PEDSnet and OMOP data models (extensions, additions)
- ETL workflow in PEDSnet
- Translations and interoperability between data models
- Process for data model changes in PEDSnet

5. Standardized Vocabularies and Atlas (Utidiyan)

Readings:

(1) The Book of OHDSI, Ch. 5

(2) The Book of OHDSI, Section 8.3

(3) Atlas Tutorial Videos --

<https://www.youtube.com/playlist?list=PLpzbqK7kvfeUXjgnpNMFoff3PDOWv61lZ>

You may focus on videos: 1-8, 11-14, and view others as needed.

Learning Points:

- How to use Atlas
- Vocabularies used in PEDSnet CDM
- Key differences between ICD and SNOMED
- Strategies for codeset development

Exercise:

- Develop a codeset for asthma using diagnosis codes, download the codes, and use the codeset to determine the number of individuals in the PEDSnet database with 1+ asthma diagnosis codes.
- Develop a codeset for angiotensin-converting enzyme (ACE) inhibitors, download the codes, and use the codeset to determine the number of individuals in the course PEDSnet database with 1+ exposures to ACE inhibitors.

Option for scholars with data science specialization (requires additional access)

Exercise:

- Find all the mappings from the ICD10 code M08.80 to SNOMED and identify potential issues while mapping.

6. Computable phenotypes (Utidiyan)

Readings:

(1) Richesson RL, et al. Electronic health records-based phenotyping. *In* NIH Collaboratory Living Textbook of Pragmatic Clinical Trials.

<https://rethinkingclinicaltrials.org/chapters/conduct/electronic-health-records-based-phenotyping/electronic-health-records-based-phenotyping-introduction/>

(2) Denburg MR, Razzaghi H, Bailey LC, Soranno DE, Pollack AH, Dharnidharka VR, Mitsnefes MM, Smoyer WE, Somers MJG, Zaritsky JJ, Flynn JT, Claes DJ, Dixon BP, Benton M, Mariani LH,

Last Updated 2024 05 16

Forrest CB, Furth SL. Using Electronic Health Record Data to Rapidly Identify Children with Glomerular Disease for Clinical Research. J Am Soc Nephrol. 2019 Dec;30(12):2427-2435.

Learning Points:

- Describe what a computable phenotype is and alternative approaches for developing them
- Explain how to evaluate a computable phenotype
- Understand the advantages and disadvantages of rule-based vs machine learning phenotypes

Option for scholars with data science specialization (requires additional access)

Exercise:

- Review R code used to execute a computable phenotype for T2DM and describe the scientific specifications of the phenotype.

7. Study-specific Data Quality (Razzaghi)

Readings:

(1) The Book of OHDSI, Ch. 15

(2) Razzaghi, H., J. Greenberg and L. C. Bailey (2021). "Developing a Systematic Approach to Assessing Data Quality in Secondary Use of Clinical Data Based on Intended Use." Learning Health Systems(e10264): 1-10.

Learning Points

- Types of data quality problems in EHR data and reasons they exist
- Approaches to study-specific data quality assessment
- Describe differences between data quality and data cleaning
- Statistical approaches for handling missing data