

# PEDSnet Scholars Program Description and Syllabus 2021-2022

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If you have any questions about the course including schedule, materials, learning sessions, assignments, please contact the program administrator.

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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.<sup>1,2</sup> There have been calls to create a national LHS,<sup>3</sup> to align academic medical centers around the vision of the LHS,<sup>4</sup> and to develop specialty-specific networks that promote learning across institutions.<sup>5,6</sup> 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.

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. Since 1960, rates of children living with disability increased from 2% to 8%. Current care quality and population-level outcomes for children

<sup>&</sup>lt;sup>1</sup> 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.

<sup>&</sup>lt;sup>2</sup> Berwick DM. What 'patient-centered' should mean: confessions of an extremist. Health Aff (Millwood). 2009;28(4):w555-565.

<sup>&</sup>lt;sup>3</sup> Friedman CP, Wong AK, Blumenthal D. Achieving a nationwide learning health system. Science translational medicine. 2010;2(57):57cm29.

<sup>&</sup>lt;sup>4</sup> 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.

<sup>&</sup>lt;sup>5</sup> 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.

<sup>&</sup>lt;sup>6</sup> 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.

<sup>&</sup>lt;sup>7</sup> 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.

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



remain woefully deficient by objective measures<sup>9, 10</sup> 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, <sup>19</sup> 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 childhood<sup>20</sup>: 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 expenses<sup>21</sup>; 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.<sup>22</sup>

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.

### 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 predetermined 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.

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.

<sup>&</sup>lt;sup>9</sup> 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.

<sup>&</sup>lt;sup>10</sup> 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.

<sup>11</sup> Thakrar.

<sup>12</sup> 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.

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

<sup>&</sup>lt;sup>14</sup> 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).

<sup>15</sup> Mangione-Smith

<sup>2008;299(19):2319-2321.</sup> 

 <sup>17</sup> 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.

<sup>&</sup>lt;sup>19</sup> 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.

<sup>&</sup>lt;sup>20</sup> Forrest CB, Simpson L, Clancy C. Child health services research. Challenges and opportunities. JAMA. 1997;277(22):1787-1793.

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

<sup>&</sup>lt;sup>22</sup> 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.



### **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 <u>Forrest et al. (2018)</u>. <u>Development of the Learning Health System Researcher Core Competencies</u>. <u>Health Services</u> <u>Research, 53(4), 2615- 2632</u> 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 <u>"The PCORI Methodology Standards" PCORI (Patient-Centered Outcomes Research Institute) Methodology Committee. Feb 2019</u> 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); AHRQ in person or virtual meetings as determined by AHRQ program leadership.

As a national program, interactive learning activities will primarily leverage a distance 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 three online trainings/courses that support the Engagement, QI Science, and Implementation Science, 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 on a quarterly basis.

- 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. AHRQ-PCORI leadership may also plan for program wide
    national meetings that include scholar participation (virtual or in person).

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 though 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.

Previous speakers include:

- Dr. Nancy Kass, ScD, Phoebe R. Berman Professor of Bioethics and Public Health, Johns Hopkins School of Public Health
- Dr. Lisa Simpson, MB, BCh, MPH, FAAP, President CEO Academy Health
- Dr. Peter Embi, MD, MS, President & CEO of Regenstreif
- Dr. Nilay Shah PhD, Director Division of HC Policy & Research Mayo Clinic Dr. Charles Friedman, PhD, Chair Learning Health Sciences U Michigan Dr. Flory Nkoy, MD, MS, MPH, Research Professor, Pediatrics, Adjunct Assistant Professor, Biomedical Informatics University of Utah Becky Yano, PhD, MSPH, Adjunct Professor, Health Policy & Management UCLA Fielding School of Public Health, Director, VA HSR&D Center for the Study of Healthcare Innovation, Implementation & Policy
- NIH Health Care Systems Research Collaboratory Grand Rounds- The Collaboratory aims to improve the way pragmatic clinical trials are conducted by creating a new infrastructure for collaborative research with healthcare systems. 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. https://rethinkingclinicaltrials.org/grand-rounds-hub/

### **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: <a href="https://support.zoom.us/hc/en-us/articles/201362023-System-requirements-for-Windows-macOS-and-Linux">https://support.zoom.us/hc/en-us/articles/201362023-System-requirements-for-Windows-macOS-and-Linux</a>



<b>PEDSnet Scholars I</b>	Program	Curriculum
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Objectives	Assignments/Activities and Required Readings
- 13,5001100	
Learning Session 1: January 25, 202	
Learning Session 2: February 1, 202	•
Competencies (Faculty: Christophei Children's Hospital of Philadelphia)	r Forrest, MD PhD, Professor of Pediatrics and Director of PEDSnet,
<ul> <li>Define a Learning Health         System scientifically and in         lay terms;</li> <li>Describe the system         properties that are important         to a Learning Health System;</li> <li>List and define the core         concepts of a Learning</li> </ul>	Forrest CB, Chesley FD, Tregear ML, Mistry KB. Development of the Learning Health System Researcher Core Competencies. Health Services Research. 2017;53(4):2615-2632. doi:10.1111/1475-6773.12751.  https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6051975/. Accessed October 01,2021  Friedman C, Rubin J, Brown J, et al. Toward a science of learning systems:
<ul> <li>Health System; and</li> <li>Use Snowden's Cynefin framework as a framework for examining a Learning Health System.</li> </ul>	a research agenda for the high-functioning Learning Health System. Journal of the American Medical Informatics; Association. 2014;22(1):43-50. doi:10.1136/amiajnl-2014-002977. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4433378/. Accessed Ocotber 01, 2021.
	Smith MD, Saunders, R, Stuckhardt, L. McGinnis, JM. Best Care at Lower Cost: the Path to Continuously Learning Health Care in America. 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 . Accessed October 01, 2021.
	Snowden DJ, Boone ME. A Leader's Framework for Decision Making". Harvard Business Review. 2007; 85(11): 68–76. <a href="https://hbr.org/2007/11/a-leaders-framework-for-decision-making">https://hbr.org/2007/11/a-leaders-framework-for-decision-making</a> .
Learning Session 3: February 15, 20	PEDSnet Scholar Development Plan (Faculty: Chris Forrest)
Understand the purpose and components of the PEDSnet Scholar Development plan (SDP)	Review the PEDSnet Scholars Development Plan (SDP) template. Submit a draft to program office by 2/28. Share and discuss SDP with mentorship team during first meeting and resubmit to program office after revisions.
Know how to to complete the SDP	<ul><li>Other resources</li><li>PEDSnet Scholars Development Plan (SDP) template</li></ul>
ENGAGEMENT MODULE	

### Self-guided training/learning modules

There are three modules that Scholars must complete between January and March, and provide a record of attestation by March 31, 2021. The first two are targeted at patient/parent partners in the research process. It is



### **Objectives**

### **Assignments/Activities and Required Readings**

useful to complete these to understand the types of training these individuals can receive before engaging in a research project.

- 1. **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.fyreworkstraining.com/
- 2. **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: <a href="https://www.pcori.org/engagement/research-fundamentals">https://www.pcori.org/engagement/research-fundamentals</a>
- 3. 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 Session 4: March 1, 2021 The Social Science of Learning Healthcare Systems (Faculty: Michael Seid, PhD, Cincinnati Children's Hospital Medical Center)

- Define Learning Health Networks (LHN) as communities that facilitate coproduction of health and healthcare at scale;
- Summarize key insights from social science about what makes LHNs work and a framework for understanding and improving LHNS; and
- Appreciate the importance of co-design and co-production in the design and implementation of LHNs.

- 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.
- Fjeldstad ØD, Snow CC, Miles RE, Lettl C. The architecture of collaboration. Strategic Management Journal. 2012;33(6):734-750. Doi:10.1002/smj.1968.

### Learning Session 5: March 15, 2021 Kratchman, BA, CHOP)

### Patient and Family Engagement in Research Part I (Faculty: Amy

- Describe an institution-wide response to the increased
- Assignment
- 1. View the PCORI recording Guidance for Completing PCORI's Updated Engagement Plan for New Awardees and Future Applicants.



Objectives	Assignments/Activities and Required Readings	
Objectives	Assignments/ Activities and Required Readings	
demand for family engagement in research;  • Describe processes of identifying, onboarding,	2. Review the FYREworks and PCORI Research Fundamentals trainings. Begin working on an engagement plan for your project, using the PCORI engagement template. Submit draft to program office by March 26.	
training, and mentoring Research Family Partners and researchers to establish and maintain research partnerships, and collaboratively conduct research;  Provide examples of Family Partners' varying levels of engagement in research; (PCORI Engagement Plan)  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.	Brodt A, Norton CK, Kratchman A. So much more than a "pair of brown shoes": Triumphs of patient and other stakeholder engagement in patient-centered outcomes research. Patient Experience Journal. 2015;2(1):43-49. Doi:10.35680/2372-0247.1057. https://pxjournal.org/journal/vol2/iss1/7/. Accessed October 01, 2021.  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.  Kratchman A, Barkman D, Conaboy K, de la Motte A, Biblow R, Bevans K. The Children's Hospital of Philadelphia Family Partners Program: Promoting child and family-centered care in pediatrics. Patient Experience Journal. 2015;2(1):50-60. Doi:10.35680/2372-0247.1063. https://pxjournal.org/journal/vol2/iss1/8/. Accessed October 01, 2021.  Other resources  Updated Engagement Plan Template. Patient-Centered Outcomes Research Institute. https://www.pcori.org/sites/default/files/PCORI-Updated-Engagement-Plan-Template.pdf Published October 2020. Updated April 2021. Accessed October 24, 2021.	
Learning Session 6: April 5, 2021	Patient and Family Engagement in Research Part II (Faculty: Amy	
Kratchman, CHOP)		
Discuss challenges and opportunities for engaging patients and families outlined in scholar engagement plans.	Please refer to Learning Session 5	
Learning Session 7: April 19, 2021 Complex Interventions: Pediatric KIDney Stone Care Improvement Network- Comparative Effectiveness of Pediatric Kidney Stone Surgery (Faculty: Gregory Tasian, MD, MSc, MSCE CHOP)		
<ul> <li>Identify the characteristics of complex interventions; and</li> <li>Understand the purpose and structure of process</li> </ul>	De Silva MJ, Breuer E, Lee L, et al. Theory of Change: a theory-driven approach to enhance the Medical Research Council's framework for complex interventions. <i>Trials</i> . 2014;15:267. Published 2014 Jul 5. doi:10.1186/1745-6215-15-267. <a href="https://trialsjournal.biomedcentral.com/articles/10.1186/1745-6215-15-267">https://trialsjournal.biomedcentral.com/articles/10.1186/1745-6215-15-267</a> . Accessed October 01, 2021.	



Objectives	Assignments/Activities and Required Readings
evaluations of complex interventions.	Harvey LA, Jan S. Process evaluations for large clinical trials involving complex interventions. <i>Spinal Cord</i> . 2017;55(11):963. doi:10.1038/sc.2017.107. https://www.nature.com/articles/sc2017107. Accessed October 01, 2021.  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://www.bmj.com/content/350/bmj.h1258. Accessed October 01, 2021.  Petticrew M. When are complex interventions 'complex'? When are simple interventions 'simple'?. <i>Eur J Public Health</i> . 2011;21(4):397-398. doi:10.1093/eurpub/ckr084. https://academic.oup.com/eurpub/article/21/4/397/438290. Accessed October 01, 2021.  Skeels SE, Pernigotti D, Houlihan BV, et al. SCI peer health coach influence on self-management with peers: a qualitative analysis. <i>Spinal Cord</i> . 2017;55(11):1016-1022. doi:10.1038/sc.2017.104. https://www.nature.com/articles/sc2017104 . Accessed October 01, 2021.  Tasian GE, Ellison JS; Pediatric KIDney Stone (PKIDS) Care Improvement Network. The Surgical Improvement Cycle: Improving Surgical Outcomes through Partnerships and Rigor. <i>J Urol</i> . 2021;205(6):1554-1556. doi:10.1097/JU.00000000000001626. https://pubmed.ncbi.nlm.nih.gov/33502238/ . 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. Accessed October 01, 2021.
Learning Session 9: May 17, 2021	Tips to Getting Published: An Insider's Guide to Journal Editor's is MD, MPH, Seattle Children's Hospital)  Federal Funding Opportunities for Learning Health System Science
<ul> <li>Part I (Faculty: Chris Forrest)</li> <li>Identify federal funding opportunities for LHS science and research; and</li> <li>Describe the relevance of these funding types for LHS science and research.</li> </ul>	Assignment/activity Select scholars, for your assigned federal sponsor (PCORI, NIH, AHRQ, CDC and FDA), prepare one slide providing a brief summary of the amount of research funding disbursed by the sponsor, the types of research supported, and the relevance of the sponsor/funding type to LHS science and research.



Objectives	Assignments/Activities and Required Readings
	Other resources Food and Drug Administration. Framework for FDA's Real-World Evidence Program. Published 2018. <a href="https://www.fda.gov/media/120060/download">https://www.fda.gov/media/120060/download</a> . Accessed October 01, 2021.
	PCORI Fact Sheets Better research through engagement. Available at: <a href="https://www.pcori.org/sites/default/files/PCORI-Better-Research-Through-Engagement.pdf">https://www.pcori.org/sites/default/files/PCORI-Better-Research-Through-Engagement.pdf</a> . Accessed October 01, 2021.
	PCORI's research funding. Available at: <a href="https://www.pcori.org/sites/default/files/PCORI-Research-Funding.pdf">https://www.pcori.org/sites/default/files/PCORI-Research-Funding.pdf</a> . Accessed October 01, 2021.
	Research done differently: Available at: <a href="https://www.pcori.org/sites/default/files/PCORI-Research-Funding.pdf">https://www.pcori.org/sites/default/files/PCORI-Research-Funding.pdf</a> . Accessed October 01, 2021.
Learning Session 10: June 7, 2021 II (Faculty: Chris Forrest, Children's	Federal Funding Opportunities for Learning Health System Science Part s Hospital of Philadelphia)
Please refer to Learning Session 9	Please refer to Learning Session 9
Learning Session 11: July 12, 2021 Goldmann, MD, Institute for Healtl	Building Successful Mentor Mentee Relationships (Faculty: Don h Care Improvement and BCH)
<ul> <li>Participants will understand the roles of mentor and mentee in a mentoring relationship;</li> <li>Mentors will be able to use a structured, culturally humble, approach to mentoring; and</li> <li>Mentees will understand the importance of having clear goals and using a driver diagram or similar method to visualize their development</li> </ul>	Activity Please be prepared to discuss the benefits you have experienced and received from your mentors.  Seely EW, Kram KE, Emans SJ. Developmental networks in translational science. Transl Res. 2015 Apr;165(4):531-6. doi: 10.1016/j.trsl.2014.12.002. Available at: <a href="https://www.translationalres.com/article/S1931-5244(14)00437-X/pdf">https://www.translationalres.com/article/S1931-5244(14)00437-X/pdf</a> . Accessed October 01, 2021.

Career Development forum • Working Toward Being an Independent Investigator • Advocating for Embedded Research with Leadership in Health Systems • Employment Pathways • Networking • Managing Competing Work Demands and Priorities • Employment Opportunities and LHS Career Options • Strategies and Methods for Patient-Centered Research • Scholar Presentations



### **Assignments/Activities and Required Readings**

### **IMPROVEMENT SCIENCE MODULE**

**Objectives** 

### **Self-guided learning modules**

There is one course (audit track) that Scholars must complete between August and October, and provide a record of attestation by October 31, 2021.

1. 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 codeveloper of the course. Recommended time for completion is 2-5 hours/wk over seven weeks. 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 12: August 2, 2021 Don Goldmann)

## Introduction to a personal Quality Improvement Project (Faculty:

Apply quality improvement science concepts and methods to conduct a personal quality improvement project over 10-12 weeks.

### (IHI MOOC objectives)

- Discuss why improvement science is valuable in health and healthcare:
- Explain why understanding a system is critical to improving a process;
- 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.

### **Assignment**

Please complete the charter template of the Quality Improvement Project template by July 26, and submit to the program office. The personal QIP will launch October 15 and conclude by the end of calendar year.

(IHI MOOC required reading and Improvement Guide required reading) Langley, G. J. (2009). The improvement guide: A practical approach to enhancing organizational performance 2<sup>nd</sup> edition

#### Lesson1

- Taylor, 2014.
- Langley, 2009.
  - Chapter 1, pp 15-25
  - Chapter 4, pp 75-88

### Lesson 2

- Langley, 2009.
  - Chapter 5, pp 89-108

### Lesson 3

- IHI Video What do we mean by Measurement for Judgement?
- Solberg, 1997.
- Langley, 2009. Chapter 7, pp 139-171

#### Lesson 4

- Nolan, 1997.
- Bennett, 2015.
- Langley, 2009. Chapter 6, pp 109-137

#### Lesson 5

- Goldmann, 2011.
- Langley, 2009. Chapter 8, pp 173-194



Objectives	Assignments/Activities and Required Readings		
	<ul> <li>Lesson 6</li> <li>Langley, 2009. Chapter 11, pp 237-262.</li> <li>Institute for Healthcare Improvement, 2017.</li> <li>Tomasik, 2016.</li> <li>Lesson 7</li> <li>Langley, 2009. Chapter 9, pp 195-216</li> <li>Weinberg, 2001.</li> <li>Goldmann, 2010.</li> </ul>		
Learning Session 13: September 20	2021 Engagement Plant Poor to poor discussions		
Refine project engagement plan	Activity During the learning session, meet with your assigned partners to share and discuss your respective engagement plans. During the debrief, share an innovative aspect of your partners plan, as well as an area of ongoing modification.		
	Partner's Engagement plan will be shared in advance.		
Capstone Presentations session 1, C	Capstone Presentations session 1, Cohort 1: October 7, 2021, 1:00-3:30 pm ET  Please refer to Capstone Agenda		
Learning Session 14: October 18, 2	021 QIPs: Peer to peer discussions		
Capstone Presentations session 2, C	Activity During the learning session, meet with your assigned partners to share and discuss your QIPs.  Partner's QIP charter will be shared in advance.  Cohort 1: October 21, 2021, 1:00-3:30 pm ET		
	Please refer to Capstone Agenda		
Learning Session 15: November 1, reactors: Leigh Anne Bakel and And			
	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. <a href="https://jamanetwork.com/journals/jamasurgery/fullarticle/2728194">https://jamanetwork.com/journals/jamasurgery/fullarticle/2728194</a> . Accessed October 01, 2021.  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 Implement Sci. 2018 Dec 10;13(1):148]. Implement Sci. 2018;13(1):142. Published 2018 Nov 13. doi:10.1186/s13012-018-0823-9.		



Objectives	Assignments/Activities and Required Readings	
	https://implementationscience.biomedcentral.com/track/pdf/10.1186/s13012-018-0823-9. Accessed October 01, 2021.	

### Learning Session 16: November 15, 2021 Scholar Work in Progress, Session 1

PEDSnet Scholar	Project Title	Institution
Samantha Jo Boch PhD, MS, RN	Social Justice and Equity: Bridging Data Science Approaches to Better Understand and Care for Children of Incarcerated Parents	Cincinnati Children's Hospital Medical Center
Roland Brusseau, MD	Developing A Tool for Ongoing, Real Time, Stakeholder-Specific Outcomes Analysis and Visualization	Boston Children's Hospital
Sriram Ramgopal, MD	Identifying Clinical Phenotypes of Pediatric Respiratory Disease Using Unsupervised Classification	Lurie Children's Hospital of Chicago

### Learning Session 17: December 6, 2021 Scholar Work in Progress, Session 2

PEDSnet Scholar	Project Title	Institution
Paul Enlow, PhD	Racial/Ethnic Disparities in The Use of Diabetes Technologies Among Youth with New-Onset Type 1 Diabetes	Nemours Children's Health System
Nathan Pajor, MD, MSc	Describing Ventilator Weaning in The Pediatric Long Term Mechanical Ventilator Dependent Population Using Multi-Site Data	Cincinnati Children's Hospital Medical Center
Yair Bannett, MD	Novel Quality Measures for Primary Care Management of Attention- Deficit/Hyperactivity Disorder	Seattle Children's Hospital

## Learning Session 18: December 20, 2021 Scholar Work in Progress, Session 3

PEDSnet Scholar	Project Title	Institution
Paul Enlow, PhD	Racial/Ethnic Disparities in The Use of Diabetes Technologies Among Youth with New-Onset Type 1 Diabetes	Nemours Children's Health System
Nathan Pajor, MD, MSc	Describing Ventilator Weaning in The Pediatric Long Term Mechanical Ventilator Dependent Population Using Multi-Site Data	Cincinnati Children's Hospital Medical Center



Objectives	Assignments/Activities and Required Readings	
Gina Sequeira, MD, MS	Improving Access to Gender-Affirming Care for Transgender Youth Through Telehealth	Seattle Children's Hospital

Learning Session 19:	January 10, 2021	Scholar Work in Progress, Session	3

PEDSnet Scholar	Project Title	Institution
Andrea V. Rivera- Sepulveda, MD, MSc	Development of A Clinical Scoring Tool to Predict Bronchodilator Responsiveness in Children with Bronchiolitis	Nemours Children's Health System
Michael Tchou, MD, MS	Reducing Overuse of High-Frequency, Low- Value Diagnostic Testing in Children's Hospitals	Children's Hospital Colorado

Learning Session 20: January 24, 2022 Personal Quality Improvement Project Report Out, Session 1

**Learning Session 21: February 7, 2022** Personal Quality Improvement Project Report Out, Session 2

Learning Session 22: February 14, 2022 Regulatory Considerations in Learning Health Systems Science (Faculty: Erica Sood, PhD, Nemours Children's Health)

### RESEARCH METHODS AND STUDY DESIGNS MODULE

### **Self-guided learning modules**

There are three modules of the course that Scholars must complete between February and March, and provide a record of attestation by March 31, 2022.

## Complete select modules of University of Texas EdX Course: CERTaIN: Pragmatic Clinical Trials and Healthcare Delivery Evaluations

This course discusses the key decisions a researcher needs to make when preparing for and conducting research, as well as tools for data analysis. You will learn what a pragmatic clinical trial is and how to calculate power and sample size for your study. You will also be exposed to more complex study designs sometimes used in pragmatic clinical trials, such as Bayesian and adaptive designs. Through this course, you will be able to identify and classify clinical trial designs and describe the statistical methods used to analyze pragmatic clinical trial data.

- Module 6: SMART: Adaptive Treatment Strategies
  - o Research questions which can benefit from an adaptive design
  - o Analytic methods for adaptive designs
  - o Interpreting results of adaptive designs
- Module 9: Quasi-Experiment in Health Services Research
  - Need for quasi-experiments and their limitations
  - o Difference-in-Differences (DID) estimators and models
- Module 10: Adaptive Trial Design
  - Need for quasi-experiments and their limitations
  - o Difference-in-Differences (DID) estimators and models



Objectives	Assignments/Activities and Required Readings
Course can be accessed here:	
ttps://learning.edx.org/course/	course1:MDAndersonX+CERTaIN.4x+3T2018/home
earning Session 23: March 7,	2022 Quasi-Experimental Design (Faculty: Chris Forrest, CHOP)
earning Session 24: March 2	1, 2022 Adaptive Design for Clinical Trials (Faculty: Kate Deans, MD,
AHSc, Nationwide Children's	
	Required reading for CERTaIN: Pragmatic Clinical Trials and Healthcare Delivery Evaluations, Modules 6,9,10
	Module 6
	Nahum-Shani I, Qian M, Almirall D, et al. Experimental design and primary data analysis methods for comparing adaptive interventions. Psychol Methods. 2012;17(4):457-477. doi:10.1037/a0029372. <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3825557/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3825557/</a> . Accessed Jaunuary 20, 2022. Module 9
	Bharadwaj, Prashant. 'Quasi Experimental Methods: Difference In Differences'. 2010. Presentation.
	http://cega.berkeley.edu/assets/cega_events/36/Quasi-
	Experimental Methods.pdf. Accessed January 21, 2022.
	Sommers BD, Long SK, Baicker K. Changes in mortality after Massachusetts health care reform: a quasi-experimental study. Ann Intern Med. 2014 May 6;160(9):585-93. doi: 10.7326/M13-2275. PMIE 24798521. <a href="https://pubmed.ncbi.nlm.nih.gov/24798521/">https://pubmed.ncbi.nlm.nih.gov/24798521/</a> . Accessed January 21, 2022. Module 10  Thorlund K, Haggstrom J, Park J J, Mills E J. Key design considerations for adaptive clinical trials: a primer for clinicians BMJ 2018; 360:k698 doi:10.1136/bmj.k698. <a href="https://pubmed.ncbi.nlm.nih.gov/29519932/">https://pubmed.ncbi.nlm.nih.gov/29519932/</a> . Accessed January 21, 2022.
earning Session 25: April 4, 2	022 Leadership (Faculty: Trish DeRusso, Children's Hospital of
Philadelphia) confirmed, can d	
MEASUREMENT AND OUTCO	OMES MODULE
earning Session 26: April 18, Chris Forrest, CHOP)	2022 Conceptualizing and Measuring Outcomes in Children (Faculty:
earning Session 27: May 2, 20	Patient Reported Outcomes in Children (Faculty: Carole Tucker, PT,
, ,	Medical Branch at Galveston) confirmed, can do 4/4 and 4/18 as well



Objectives Assignments/Activities and Required Readings

Learning Session 28: Quality/Safety Leader Panel Session 1

### IMPLEMENTATION SCIENCE MODULE

### **Self-guided learning modules**

There are eight modules of the course that Scholars must complete between May and June, and provide a record of attestation by Jun 30, 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
- Emerging Topics in Implementation Science

Learning Session 29: May 16, 2022	Implementation Science I (Faculty: TBD, University of Pennsylvania)
Learning Session 30: June 6, 2022	Implementation Science II (Faculty: TBD, University of Pennsylvania)
Learning Session 31: June 20, 2022 Implementation Strategies (Faculty: A dates as well	Implementation Science: Stakeholder Engagement Methods to Shape nne Kazak, Nemours Children's Health) confirmed can do two previous
Learning Session 32: week of July 11, (Faculty: Peter Margolis, MD, PhD, Ci	2022 Learning Health System Science in Learning Networks I incinnati Children's Hospital Medical Center)
Learning Session 33: July 25, 2022 Peter Margolis, Cincinnati Children's	Learning Health System Science in Learning Networks II (Faculty: Hospital Medical Center)
Learning Session 34: August 1, 2022 d Health System I (Faculty: Marc Rosen	· · · · · · · · · · · · · · · · · · ·
Learning Session 35: August 15, 2022 Health System II (Faculty: PEDSnet D	date to be confirmed The Digital Infrastructure of the Learning OCC, Children's Hospital of Philadelphia)



Objectives	Assignments/Activities and Required Readings			
Learning Session 36: week of September 5 <sup>th</sup> or 12th, 2022 Quality/Safety Leader Panel Session 2				
<b>Learning Session 37: September 19</b>	2022 Promoting Equity in Learning Health Systems Session 1			
Learning Session 38: October 3, A Learning Health System Response to COVID-19 (Faculty: Grace Lee, MD, Stanford Children's and Suchitra Rao, MBBS, MSCS, Children's Hospital Colorado)				
AHRQ K12 Annual Meeting and PC	ORI Annual Meeting October 26-28, 2022			
Learning Session 39: November 7, 2	Quality/Safety Leader Panel Session 3			
Learning Session 40: November 21,	2022 Quality/Safety Leader Panel Session 4			
<b>Learning Session 41: December 5, 2</b>	Promoting Equity in Learning Health Systems Session 2			
Learning Session 42: December 19, 2022 date to be confirmed PCORI Grantsmanship: A Rare Disease Observational Study in Pediatric Chronic Kidney Disease: PRESERVE (Faculty: Michelle Denburg, MD, MSCE, Children's Hospital of Philadelphia)				
Capstone Presentations, Cohort 2: July 2023				
Capstone Presentations, Cohort 2: July 2023				



### PEDSNET SCHOLARS PROGRAM POLICIES

*Term:* Minimum of 2-year duration; some scholars may be offered an optional 3<sup>rd</sup> 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.

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. 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. Scholars are expected to participate in the AHRQ annual meeting, if (per AHRQ) the meeting agenda incorporates scholar participation.



## 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 (<a href="https://publicaccess.nih.gov/policy.htm">https://publicaccess.nih.gov/policy.htm</a>): 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 (<a href="https://publicaccess.nih.gov/">https://publicaccess.nih.gov/</a>). A PMCID should be included as part of all eligible publication citations listed in the scholar's annual progress report.