



PEDSnet Scholars Program Syllabus 2019-2020

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PEDSnet Scholars Program Leadership

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Training Program Description

The PEDSnet Scholars program will prepare promising faculty to conduct learning health system research (LHS) that will improve both care delivery and outcomes for children. It will build upon prior efforts of a multidisciplinary faculty with decades of experience in research mentorship and the resources of nationally renowned pediatric academic medical centers that collaborate in the PEDSnet clinical research network. Scholars will use new 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 will provide the evidence base for shared clinical decisions and effective delivery system interventions that will bring us closer to the goal of improved health for individual children and populations.

The program aims are to:

1. **Community:** Create a community of junior faculty who will progress to be leaders in their institutions and the nation in Learning Health System science and research 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 master 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 research that will improve both pediatric healthcare delivery and health outcomes for children. In so doing, they will provide the knowledge and know-how for shared clinical decisions and effective population-based interventions that bring us closer to the goal of improved health for individual children and populations.

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 researchers 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 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 pre-determined given the nascent and developing nature of the field. LHS scientists may seek independent investigator

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.

status, or may focus on advancing outcomes of the health system through the use improvement and research tools in clinical operations. An LHS scientist could also pursue a mix of funded research and clinical operations. 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.

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. Research proposal (required as part of the scholar application);
2. Research project;
3. Monthly learning sessions; featuring core content delivered by program faculty and guest presenters;
4. Monthly work in progress sessions; featuring articles for discussion and scholar research presentations;
5. Self-guided, multimedia learning modules;
6. Mentoring, including the assignment of PEDSnet Scholars mentor; and
7. In-person workshops, rotating at PEDSnet institutions (2 per year).

As a national program, interactive learning activities will primarily leverage a video/web conferencing platform.

Description of components

1. *Research 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, and analysis plans, and a brief section on the significance and innovation of the proposed work. The purpose of the proposal is not to lock the Scholar into the project, but rather to assess the promise of each applicant in research, 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 research 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 report as a deliverable.
2. *Monthly learning sessions*
 - Learning sessions of 1.5 hour in duration will be held monthly. The learning session is led by a faculty member and will cover curriculum content addressing AHRQ LHS competencies and PCORI methodologies standards. Learning sessions may include required readings and homework assignments to be completed in advance.
3. *Monthly work in progress sessions (WIP)*
 - Work in progress sessions of 1 hour in duration will be held monthly. WIPs are an opportunity for additional scholar engagement, featuring a faculty led discussion of timely or classic journal articles, and also giving scholars a platform to present progress on their projects.
4. *Self-guided, multimedia learning modules*
 - The Scholars program will leverage existing multimedia resources to supplement curriculum on topics such as patient-centered care, improvement, safety, leadership and implementation science. In this cycle, scholars will complete the HarvardX/ Institute Healthcare Institute (IHI) Massive Online Open Course (MOOC) *Practical Improvement Science in Health Care: A Roadmap for Getting Results*, as part of the improvement science learning material. This is a 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.
5. *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. Upon entry into the program, one of the program co-directors are assigned as the scholar's PEDSnet mentor, and will meet on a quarterly basis. As part of the curriculum, scholars will also complete an exercise on *Mapping Your Developmental Network*, based on the work of Kram and others that began in helping individuals with careers in business.²³

²³ Kram KE, Higgins MC. A new approach to mentoring. *The Wall Street Journal* 2008.

6. *In-person workshops, rotating at PEDSnet institutions (2 per year)*

- Two in-person meetings 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 the same room. In addition, these workshops will build the professional peer relationships among junior faculty that we have found critical to the development of a successful research career. Day 1 will focus on select topic areas and day 2 will highlight the learning health system environment of the host institution. The agenda will delve into how the health system is structured and led, its strategic priorities, the approach to improving quality and safety, how research is integrated into clinical operations, the informatics strategy, and patient/family-centered care programs. 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. Guest speakers for 2020-21 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
- *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 will be multi-faceted and include feedback assessments for didactic as well as mentoring activities. Completion of assessments is required by scholars, and will include:

- Learning Health System competency pre/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 GoToMeeting as the main platform for instruction and discussion. GoToMeeting has the following technical requirements:

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| <p>Operating system</p> | <p>Windows 7 - Windows 10 Mac OS X 10.9 (Mavericks) - macOS Catalina (10.15) Linux/Ubuntu (Web App only) Google Chrome OS (Web App only) iOS 11 - iOS 12 Android OS 5 (Lollipop) - Android 9 (Pie) Windows Phone 8, Windows 8RT or later</p> |
| <p>Web browser (Applies to Web App only)</p> | <p>Google Chrome v57 or later Microsoft Edge v77 or later</p> |
| <p>Internet connection</p> | <p>Computer: 1 Mbps or better (broadband recommended) (see How much bandwidth is used during a session?) Mobile device & Chromebook: 3G or better (WiFi recommended for VoIP audio)</p> |
| <p>Software</p> | <p>GoToMeeting desktop app (JavaScript enabled) GoToMeeting Web App and screensharing extension GoToMeeting app from the Apple Store, Google Play Store, or Windows Store</p> |

PEDSnet Scholars Program Curriculum

| Objectives | Readings | Assignments/Activities |
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| Learning Session 1: July 17, 2019 Introductions and Program Launch | | |
| Learning Session 2: August 19, 2019 Introduction to Learning Health Systems (Faculty: Chris Forrest, Children's Hospital of Philadelphia) | | |
| <ul style="list-style-type: none"> Define a Learning Health System scientifically and in lay terms; Describe the system properties that are important to a Learning Health System; and List and define the core concepts of a Learning Health System. | <p>Required Forrest C, Chesley F Jr, Tregear M and Mistry K. Development of the Learning Health System Researcher Core Competencies. Health Serv Res. 2018 Aug;53(4):2615-2632. doi:10.1111/1475-6773.12751.</p> <p>Smith M, Saunders R, Stuckhardt L, McGinnis JM, Editors; Committee on the Learning Health Care System in America; Institute of Medicine. Best Care at Lower Cost: The Path to Continuously Learning Health Care in America. Institute of Medicine 2013. Washington, DC: The National Academies Press. doi:10.17226/13444. Available at: https://www.nap.edu/catalog/13444/best-care-at-lower-cost-the-path-to-continuously-learning</p> <p>Recommended Greene SM, Reid RJ, Larson EB. Implementing the learning health system: from concept to action. Ann Intern Med. 2012 Aug 7;157(3):207-10. doi:10.7326/0003-4819-157-3-201208070-00012.</p> | <ol style="list-style-type: none"> Briefly describe what a Learning Health System is in 3-5 bullets, with no more than a few sentences of accompanying text for each bullet Please be prepared to present/critique each AHRQ LHS Competencies assigned to you. Each scholar has been assigned 3 competencies. (attachment) |
| Learning Session 3: September 16, 2019 Building Successful Mentor-Mentee Relationships Part 1 (Faculty: Don Goldmann) | | |
| <ul style="list-style-type: none"> Participants will understand the roles of mentor and mentee in a mentoring relationship; Mentors will be able to use a structured, culturally humble, approach to mentoring; and | <p>Required 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: https://www.translationalres.com/article/S1931-5244(14)00437-X/pdf</p> | <ol style="list-style-type: none"> Please complete the Network Mapping exercise. © S. Jean Emans, MD; Maxine Milstein, MBA; Ellen W. Seely, MD; and Audrey Haas, MBA; 2015. This Developmental Network Exercise was adapted, with permission, from the work of Kathy Kram, PhD, (Boston University School of Management) by S. Jean Emans, MD and Maxine Milstein, MBA |

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| <ul style="list-style-type: none"> • Mentees will understand the importance of having clear goals and using a driver diagram or similar method to visualize their development needs. | <p>Recommended UW Institute for Clinical and Translational Research- Mentor-Mentee Resources. Available at: https://ictr.wisc.edu/mentoring/</p> <p>Mentorship, Sponsorship, and Networks: The Power and Value of Professional Connections. A Curated Research Report, Prepared by Center for Women and Business at Bentley University. Available at: https://www.bentley.edu/centers/center-for-women-and-business/mentorship-sponsorship-research-report-request#DownloadReport</p> | <p>(Boston Children’s Hospital) and Ellen W. Seely, MD and Audrey Haas, MBA (Brigham & Women’s Hospital).</p> |
| <p>Learning Session 4: October 21, 2019 Building Successful Mentor-Mentee Relationships Part 2 and Improvement Science Building Blocks (Faculty: Don Goldmann)</p> | | |
| <ul style="list-style-type: none"> • Understand and apply the 4 pillars of so-called “profound knowledge,” which are simply the basic attributes of improvement science; • Understand the similarities, and synergies differences between improvement science and implementation science; and • Understand why improvement science mirrors the experimental method of other sciences and the importance of theory, prediction, and specifying the causal pathway between changes and predicted outcomes. | <p>Required Taylor MJ, et al. Systematic review of the application of the plan-do-study-act method to improve quality in healthcare. <i>BMJ Qual Saf</i> 2014 Apr;23(4):290-298. doi: 10.1136/bmjqs-2013-001862. Epub 2013 Sep 11. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3963536/pdf/bmjqs-2013-001862.pdf.</p> <p>Recommended Langley GJ, Moen RD, Nolan KM, Nolan TW, Norman CL, Provost LP. <i>The improvement guide: A practical approach to enhancing organizational performance</i> (2nd edition). San Francisco, CA, Jossey-Bass. 2009</p> | <p>Please complete the MOOC over the next two months.</p> <p>The Institute Healthcare Institute (IHI) and HarvardX. Practical Improvement Science in Health Care: A Roadmap for Getting Results, A Free Massive Online Open Course.</p> |

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| <p>Learning Session 5: November 18, 2019 Connecting Improvement Science and Research (Faculty: Peter Margolis, Cincinnati Children’s Hospital Medical Center (CCHMC))</p> | |
| <ul style="list-style-type: none"> • Define the stages of development for studies of complex interventions; • Apply an improvement framework to design of an improvement initiative; and • Discuss how an improvement framework applies to your own project. | <p>Required</p> <p>Campbell M, Fitzpatrick R, Haines A, et al. Framework for design and evaluation of complex interventions to improve health. <i>BMJ</i>. 2000;321(7262):694–696. doi:10.1136/bmj.321.7262.694. Available at: https://www.bmj.com/content/bmj/321/7262/694.full.pdf</p> <p>Moen R. <i>A Guide to Idealized Design</i>. Cambridge, Massachusetts: Institute for Healthcare Improvement; 2002. Available at: http://www.ihl.org/resources/Pages/Publications/AGuidetoIdealizedDesign.aspx</p> <p>Recommended</p> <p>Campbell NC, Murray E, Darbyshire J, et al. Designing and evaluating complex interventions to improve health care. <i>BMJ</i>. 2007;334(7591):455–459. doi:10.1136/bmj.39108.379965.B. Available at: https://www.bmj.com/content/bmj/334/7591/455.full.pdf</p> <p>Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. <i>BMJ</i>. 2008 Sep 29;337:a1655. doi: 10.1136/bmj.a1655. Available here: https://www.bmj.com/content/bmj/337/bmj.a1655.full.pdf</p> |
| <p>Learning Session 6: December 16, 2019 Responsible Conduct of QI and QI Research (Faculty: Jon Finkelstein, Boston Children's Hospital)</p> | |
| <ul style="list-style-type: none"> • Describe two or more ways in which typical QI projects differ from human subjects research; • Assess whether your own project should require IRB review from an ethical perspective, and whether | <p>Required</p> <p>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. Available here: http://www.healthsciences.uci.edu/nursing/docs/research-resources/IRB/May%20June%202017%20IRB%20Ethics%20and%2</p> |

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| <p>it does require IRB review in your own institution; and</p> <ul style="list-style-type: none"> In two minutes or less, make a logical argument for why local IRBs should create an alternate and simplified pathway for review and approval of QI projects. | <p>0Human%20Resesarch%20-%20New%20Common%20Rule%20and%20QI%20an....pdf</p> <p>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</p> | |
| <p>Work in Progress (WIP) 1: December 18, 2019 12 pm ET. (Faculty: Chris Forrest, CHOP; Featured scholars: Stephanie Bourque and Erica Sood; Article reactors: Suchitra Rao)</p> | | |
| <p>NA</p> | <p>Featured article Horwitz L, Kuznetsova M, Jones S. Creating a Learning Health System through Rapid-Cycle, Randomized Testing. <i>The New England journal of medicine</i>. 2019. 381:1175-1179. Available here: https://www.nejm.org/doi/full/10.1056/NEJMs1900856</p> | <p>NA</p> |
| <p>Work in Progress (WIP) 2: January 6, 2020 (Faculty: Chris Forrest, CHOP; Featured scholars: Corinna Schultz and Melissa Smith-Parrish; Article reactors: Aimee Hildenbrand and Thida Ong)</p> | | |
| <p>NA</p> | <p>Featured article 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. Available here: https://onlinelibrary.wiley.com/doi/full/10.1002/lrh2.10206</p> | <p>NA</p> |
| <p>Learning Session 7: January 27, 2020 The Digital Infrastructure of the Learning Health System; Introduction of Scholar Team Projects (Faculty: Chris Forrest)</p> | | |
| <ul style="list-style-type: none"> Identify key elements of a high-functioning digital architecture for a Learning Health System; Identify the key dimensions | <p>Required Gliklich RE, Leavy MB, Dreyer NA, editors. <i>Tools and Technologies for Registry Interoperability, Registries for Evaluating Patient Outcomes: A User’s Guide, 3rd Edition, Addendum 2</i> [Internet]. Rockville (MD): Agency for Healthcare Research and Quality (US);</p> | <p>If the CDC asked you to generate population level incidence and prevalence rates, what denominator would you use? Let’s say that they want rates of psoriasis. How would you estimate the numerator?</p> |

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| <p>and processes of data science; and</p> <ul style="list-style-type: none"> Describe how electronic health record data can be used for research and registries. | <p>2019 Oct. Available here: https://www.ncbi.nlm.nih.gov/books/NBK551879/pdf/Bookshelf_NBK551879.pdf</p> | <p>Team Project:</p> <ol style="list-style-type: none"> 1. Define a research question: novel and feasible to complete within 4 weeks, concluding at the in-person meeting; 2. Create the scientific specifications; 3. Develop the code-sets; 4. Implement the specifications; 5. Review results; and 6. Report results at in-person meeting. |
| <p>Work in Progress (WIP) 3: February 3, 2020 (Faculty: Don Goldmann, IHI; Featured scholar: Katie Chiotos; Article reactors: Corinna Schultz and Erica Sood)</p> | | |
| <p>NA</p> | <p>Featured articles</p> <p>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. <i>JAMA Surg.</i> 2019 May 1;154(5):e190145. doi: 10.1001/jamasurg.2019.0145. Epub 2019 May 15. Available here: https://jamanetwork.com/journals/jamasurgery/fullarticle/2728194</p> <p>Peden CJ, Stephens T, Martin G, Kahan BC, Thomson A, Rivett K, Wells D, Richardson G, Kerry S, Bion J, Pearse RM; Enhanced Peri-Operative Care for High-risk patients (EPOCH) trial group. 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 Jun 1;393(10187):2213-2221. doi: 10.1016/S0140-6736(18)32521-2. Available here: https://spiral.imperial.ac.uk/bitstream/10044/1/71383/2/documentJuly19.pdf</p> <p>Recommended</p> <p>Navathe AS, Lee VS, Liao JM. How to Overcome Clinicians' Resistance to Nudges. <i>Harvard Business Review.</i> 2019. Available here:</p> | <p>NA</p> |

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| | <p>https://hbr.org/2019/05/how-to-overcome-clinicians-resistance-to-nudges</p> <p>Stephens, T.J., Peden, C.J., Pearse, R.M. et al. Improving care at scale: process evaluation of a multi-component quality improvement intervention to reduce mortality after emergency abdominal surgery (EPOCH trial). Implementation Sci 13, 142 (2018). doi:10.1186/s13012-018-0823-9. Available here: https://implementationscience.biomedcentral.com/track/pdf/10.1186/s13012-018-0823-9</p> | |
| Learning Session 8: February 17, 2020 Applied Informatics and Data Networks (Faculty: Charlie Bailey) | | |
| | Please refer to reading from Learning Session 7 | Learning session 1/27 assignment |
| March 2, 2020 Applied Informatics Team Project meetings | | |
| <p>1.5 day In- Person Meeting March 9-10, 2020 Nemours/Alfred I. duPont Hospital for Children Wilmington, Delaware (Faculty: Anne Kazak, Tim Bunnell, Charlie Bailey, Chris Forrest, Don Goldmann, Hanieh Razzaghi, Levon Utidjian, and Nemours leadership) Day 1: Applied Informatics workshop Day 2: Nemours Learning Health System</p> | | |
| Work in Progress (WIP) 4: April 6, 2020 (Faculty: Mandy Dempsey, Children's Hospital Colorado; Featured scholar: Chuck Varnell; Article reactors: Katie Chiotos and Melissa Smith-Parrish) | | |
| NA | <p>Featured article Elizabeth L. Ciemins, Michelle Jerry, Jill Powelson, Erin Leaver-Schmidt, Vaishali Joshi, Danielle Casanova, John W. Kennedy, and Jerry Penso. Population Health Management. Feb 2020.29- 37. http://doi.org/10.1089/pop.2019.0019</p> | NA |
| Learning Session 9: April 20 | Evaluating interventions: randomized clinical trials (Faculty: Kate Deans, Nationwide Children's Hospital) | |
| <ul style="list-style-type: none"> Understand the definition of a <u>clinical trial</u> according to the NIH, and the implications of standardization. (https://gra | <p>Required Marquis-Gravel G, Roe MT, Robertson HR, Harrington RA, Pencina MJ, Berdan LG, Hammill BG, Faulkner M, Muñoz D, Fonarow GC, Nallamothu BK, Fintel DJ, Ford DE, Zhou L, Daugherty SE, Nauman E, Kraschnewski J, Ahmad FS, Benziger CP, Haynes K, Merritt JG,</p> | |

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| <p>https://www.nih.gov/policy/clinical-trials/definition.htm)</p> <ul style="list-style-type: none"> • Define and discuss pragmatic clinical trials and their particular relevance to LHS research. • Define and discuss the strengths and limitations of adaptive trial designs and their suitability to LHS research. | <p>Metkus T, Kripalani S, Gupta K, Shah RC, McClay JC, Re RN, Geary C, Lampert BC, Bradley SM, Jain SK, Seifein H, Whittle J, Roger VL, Effron MB, Alvarado G, Goldberg YH, VanWormer JL, Girotra S, Farrehi P, McTigue KM, Rothman R, Hernandez AF, Jones WS. Rationale and Design of the Aspirin Dosing-A Patient-Centric Trial Assessing Benefits and Long-term Effectiveness (ADAPTABLE) Trial. <i>JAMA Cardiol.</i> 2020 Mar 18. doi: 10.1001/jamacardio.2020.0116.</p> <p>Pallmann, P., Bedding, A.W., Choodari-Oskooei, B. et al. Adaptive designs in clinical trials: why use them, and how to run and report them. <i>BMC Med</i> 16, 29 (2018). https://doi.org/10.1186/s12916-018-1017-7. Available here: https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-018-1017-7.</p> <p>Marsolo, Keith & Brown, Jeffrey & Hernandez, Adrian & Hammill, Bradley & Raman, Sudha & Syat, Beth & Platt, Richard & Curtis, Lesley. (2020). Considerations for Using Distributed Research Networks to Conduct Aspects of Randomized Trials. <i>Contemporary Clinical Trials communications.</i> doi: 10.1016/j.conctc.2019.100515. Available here: https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-018-1017-7</p> | |
| <p>Work in Progress (WIP) 5: May 4, 2020 (Faculty: Don Goldmann, IHI ; Featured scholar: Suchitra Rao; Article reactors: Anita Shah and Chuck Varnell)</p> | | |
| <p>NA</p> | <p>Featured article Finkelstein A, Zhou A, Taubman S, Doyle J. Health care hotspotting—a randomized, controlled trial. <i>N Engl J Med.</i> 2020;382(2):152-162. Available here: https://www.nejm.org/doi/full/10.1056/NEJMsa1906848?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%20pubmed</p> | <p>NA</p> |
| <p>Learning Session 10: May 18 Implementation Science Models, Framework, and Methods (Faculty: Rinad Beidas, University of Pennsylvania)</p> | | |

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| <ul style="list-style-type: none"> • The participants will be able to describe the foundations of implementation science. • The participants will be able to explain the application of implementation science principles to the transportation of evidence-based practices for firearm safety promotion in pediatric primary care. • The participants will be able to apply principles of implementation science to their own work and to link concepts to learning health systems. | <p>Required</p> <p>Curran GM, Bauer M, Mittman B, Pyne JM, Stetler C. Effectiveness-implementation hybrid designs: combining elements of clinical effectiveness and implementation research to enhance public health impact. <i>Med Care</i>. 2012 Mar;50(3):217-26. doi: 10.1097/MLR.0b013e3182408812. Available here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3731143/pdf/nihms480660.pdf</p> <p>Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. <i>Implement Sci</i>. 2009 Aug 7;4:50. doi: 10.1186/1748-5908-4-50. Available here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2736161/pdf/1748-5908-4-50.pdf.</p> <p>Lane-Fall MB, Curran GM, Beidas RS. Scoping implementation science for the beginner: locating yourself on the "subway line" of translational research. <i>BMC Med Res Methodol</i>. 2019 Jun 28;19(1):133. doi: 10.1186/s12874-019-0783-z. Available here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6599376/pdf/12874_2019_Article_783.pdf</p> <p>Powell BJ, Waltz TJ, Chinman MJ, Damschroder LJ, Smith JL, Matthieu MM, Proctor EK, Kirchner JE. A refined compilation of implementation strategies: results from the Expert Recommendations for Implementing Change (ERIC) project. <i>Implement Sci</i>. 2015 Feb 12;10:21. doi: 10.1186/s13012-015-0209-1. Available here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4328074/pdf/13012_2015_Article_209.pdf</p> <p>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. <i>Adm Policy Ment Health</i>. 2011 Mar;38(2):65-76. doi:</p> | <p>NA</p> |
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| | <p>10.1007/s10488-010-0319-7. Available here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3068522/pdf/10488_2010_Article_319.pdf</p> | |
| <p>Work in Progress (WIP) 6: June 1, 2020 Implementation of family psychosocial risk screening with the Psychosocial Assessment Tool (PAT) (Faculty: Anne Kazak, Nemours Children's Health System; Featured scholar: Anita Shah)</p> | | |
| <ul style="list-style-type: none"> • Highlight the importance of systematic family psychosocial risk screening to enhance clinical care. • Introduce the Psychosocial Assessment Tool (PAT). • Outline background and plans for implementation of the PAT across 18 pediatric cancer programs around the United States. | <p>Required Kazak AE, Hwang WT, Chen FF, Askins MA, Carlson O, Argueta-Ortiz F, Barakat LP. Screening for Family Psychosocial Risk in Pediatric Cancer: Validation of the Psychosocial Assessment Tool (PAT) Version 3. J Pediatr Psychol. 2018 Aug 1;43(7):737-748. doi: 10.1093/jpepsy/jsy012.</p> <p>Price J, Beidas RS, Wolk CB, Genuario K, Kazak AE. Implementation Science in Pediatric Psychology: The Example of Type 1 Diabetes. J Pediatr Psychol. 2019 Oct 1;44(9):1068-1073. doi: 10.1093/jpepsy/jsz030.</p> <p>Scialla MA, Canter KS, Chen FF, Kolb EA, Sandler E, Wiener L, Kazak AE. Delivery of care consistent with the psychosocial standards in pediatric cancer: Current practices in the United States. Pediatr Blood Cancer. 2018 Mar;65(3). doi: 10.1002/pbc.26869. Epub 2017 Oct 28. Available here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5766412/pdf/nihms913585.pdf</p> | <p>NA</p> |
| <p>Learning Session 11: June 15, 2020 Observational Studies' Role in Learning Health Systems (Faculty: Mandy Dempsey, CHC; Featured scholar: Aimee Hildenbrand)</p> | | |

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| <ul style="list-style-type: none"> • Understand key differences between OS and the “gold standard” of RCTs. • Understand when observational studies may provide valuable input to LHS in place or, or in addition to, RCT data. • Become familiar with some analytic methods pertinent to observational studies. | <p>Required A Learning Health System Activity; Roundtable on Value and Science-Driven Health Care; Institute of Medicine. Observational Studies in a Learning Health System: Workshop Summary. Washington (DC): National Academies Press (US); 2013 Dec 2. 1, Introduction. Available here: https://www.ncbi.nlm.nih.gov/books/NBK201320/</p> <p>Stoto M, Oakes M, Stuart E, Savitz L, Priest EL, Zurovac J. Analytical Methods for a Learning Health System: 1. Framing the Research Question. eGEMs (Generating Evidence & Methods to improve patient outcomes). 2017;5(1):28. DOI: http://doi.org/10.5334/egems.250. Available here: https://egems.academyhealth.org/article/10.5334/egems.250/</p> | NA |
| <p>Work in Progress (WIP) 7: July 6, 2020 The state of telehealth/medicine at PEDSnet institutions: Scholar report outs (Faculty: Don Goldmann, IHI; Jon Finkelstein, BCH)</p> | | |
| <p>Learning Session 12: July 20, 2020 Patient and Family Engagement in Research Part I (Faculty: Amy Kratchman, CHOP; Featured Scholar: Thida Ong)</p> | | |
| <ul style="list-style-type: none"> • 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 <u>and</u> researchers to: <ul style="list-style-type: none"> • establish and maintain research partnerships, and • collaboratively conduct research. | <p>Required Kratchman, BA, Amy; Barkman, MA, Darlene; Conaboy, BA, Kathy; de la Mo e, MSed, Anna; Biblow, MSW, Rachel; and Bevans, PhD, Katherine (2015) " e Children’s Hospital of Philadelphia Family Partners Program: Promoting child and family-centered care in pediatrics," Patient Experience Journal: Vol. 2 : Iss. 1 , Article 8. Available at: https://pxjournal.org/journal/vol2/iss1/8</p> <p>Brodt, M.P.P., Amanda; Norton, M.A., Christine K.; and Kratchman, Amy (2015) "So much more than a “pair of brown shoes”: Triumphs of patient and other stakeholder engagement in patient-centered outcomes research," Patient Experience Journal: Vol. 2 : Iss. 1 , Article 7. Available at:https://pxjournal.org/journal/vol2/iss1/7</p> <p>Forsythe LP, Carman KL, Szydlowski V, et al. Patient Engagement In Research: Early Findings From The Patient-Centered Outcomes</p> | NA |

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| <ul style="list-style-type: none"> Provide examples of Family Partners' varying levels of engagement in research. | <p>Research Institute. <i>Health Aff (Millwood)</i>. 2019;38(3):359-367. doi:10.1377/hlthaff.2018.05067. Available at:https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2018.05067</p> | |
| <p>Learning Session 13: August 3, 2020 12:00- 1:00 pm ET Patient and Family Engagement in Research Part II (Faculty: Amy Kratchman, CHOP)</p> | | |
| <p>Please refer to reading from Learning Session 12</p> | <p>NA</p> | <ol style="list-style-type: none"> 1. Please complete Unit 1 of the FYREworks training. You will need to create an account. www.fyreworkstraining.com 2. Please be prepared to share your patient/parent engagement plan and consider the following questions. Amy will share her thoughts and reactions to your plan. <ul style="list-style-type: none"> • What have you done so far? • What can you do to expand engagement? • Have you experienced barriers? • Do you feel you have meaningful engagement from patient and family stakeholders? |
| <p>Learning Session 14: September 21, 2020 Promoting Equity in Community-Based Learning Health Systems (Faculty: Robert Kahn, CCHMC)</p> | | |
| <p>Work in Progress (WIP) 8: September 28th, 2020 TBD</p> | | |
| <p>Learning Session 15 October 19, 2020 Leadership in Learning Health Systems (Faculty: Patricia DeRusso (CHOP), Sesh Cole (St. Louis Children's Hospital (SLCH), Jon Finkelstein (BCH))</p> | | |
| <p>Work in Progress (WIP) 9: November 2, 2020 Scholar presentations (Faculty: Sesh Cole, SLCH)</p> | | |
| <p>Nov 2020 TBD 1 Day Virtual Meeting Cincinnati Children's Hospital Medical Center Cincinnati, Ohio (Faculty: Chris Forrest, Peter Margolis, Michael Seid, and CCHMC leadership) CCHMC Learning Health System</p> | | |

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| November 16, 2020 <i>[date to be confirmed]</i> Evaluating complex interventions in randomized and observational clinical trials; Case Study Presentation: Comparative Effectiveness of Pediatric Kidney Stone Surgery (Faculty: Chris Forrest and Greg Tasian, CHOP) |
| Work in Progress (WIP) 10: December 12, 2020 Scholar presentations |
| Learning Session 16: December 21, 2020 Scholar presentations |