



Inaugural (*virtual*) Learning Health Networks Research Conference: Accelerating Patient-Centered Outcomes Research

Thursday June 24, 2021 | 12 PM – 5:00 PM ET

Overview: The pace of clinical and health services research is too slow. Patients and clinicians have limited involvement in setting priorities and driving research agendas and findings take too long to be translated reliably into practice at a population level. Re-imagining the research infrastructure is necessary. Learning Health Networks bring patients, clinicians and researchers together to accelerate science and progress towards better health outcomes by blurring the artificial distinctions between clinical care, health system improvement and research.

The Inaugural Learning Health Network Research Conference brings these stakeholders together to share state-of-the-art research taking place in and on Learning Health Networks. The conference will include examples of innovative research underway, how this model is making clinical research more effective, impactful and efficient, as well as the science behind this new organizational form.

The Conference is intended for patients, clinicians, researchers and research sponsors interested in how to accelerate clinical and patient-centered outcomes research. It is sponsored by the James M. Anderson Center for Health Systems Excellence with funding from the Patient Centered Outcomes Research Institute and assistance from the Institute for Healthcare Improvement.

Learning Objectives

Participants will have:

1. Reviewed how an innovative Learning Health System organization, the Learning Health Network, accelerates community-driven improvement health and person-centered clinical research
2. Discussed how Learning Health Networks are advancing innovative, efficient and impactful clinical, health services and patient-centered outcomes research.
3. Identified future research needs related to optimizing and implementing networks including trustworthy data sharing, building a culture of co-production and engagement among all stakeholders, and efficient research operations.

Time (ET)	Topic & Presenter
12:00 - 12:20PM	<p>Welcome and Introduction: The journey toward a people-centered ecology of care, improvement and research <i>Michael Seid, PhD</i>, Professor of Pediatrics and Director, Pulmonary Outcomes Research, Cincinnati Children’s Hospital Medical Center <i>Kedar Mate, MD</i>, President and CEO, Institute for Healthcare Improvement</p>
12:20 – 12:50PM	<p>Patient-Powered Research: Why - When - How? <i>Harlan Krumholz, MD, SM</i>, Professor of Medicine and Director, Center for Outcomes Research and Evaluation</p>
12:50 – 1:10PM	<p>Learning Health Network Communities – Hatcheries for People Centered Research <i>Peter Margolis, MD, PhD</i>, Professor of Pediatrics and Co-Director, James M. Anderson Center for Health Systems Excellence, Cincinnati Children’s Hospital Medical Center</p>
1:10 – 1:30PM	<p>Patient-Centered Outcomes Research Institute: Priorities for Patient-Centered Research <i>Carly Parry, PhD, MSW, MA</i>, Senior Advisor, Care Coordination and Transitions Research Initiative, Patient Centered Outcomes Research Institute</p>
1:30 – 1:40PM	<p>Break</p>
<p>1:40 – 3:00PM</p> <p>1:40 – 2:20PM</p> <p>2:20 – 3: 00PM</p>	<p>Accelerating patient-centered research using Learning Health Networks: Clinical research innovations:</p> <p><u>Networking people, academia and industry: Real-world data accelerates cardiac assist device approval in children</u> <i>Angela Lorts, MD, MBA</i>, Professor of Pediatrics and Cardiology, Director Ventricular Assist Device Program, Associate Chief Quality Officer, Cincinnati Children’s Hospital Medical Center and the ACTION Network</p> <p><u>Personalized, patient-driven research: A multicenter N-of-1 trial of dietary management of Crohn’s Disease</u> <i>Lisa Opiari-Arrigan, PhD</i>, Professor of Psychiatry and Behavioral Sciences, George Washington University School of Medicine and Health Sciences; ImproveCareNow Network Investigator <i>Christopher Schmid, PhD</i>, Brown School of Public Health Professor of Biostatistics and Member of Center for Evidence Synthesis in Health and Center for Statistical Sciences.</p>
3:00 – 3:15PM	<p>Break</p>
3:15 – 4:00PM	<p>Culture as infrastructure for Learning Health Systems: Research about Learning Health Networks <i>Alexandra Vinson, PhD</i>, Assistant Professor of Learning Health Sciences, Director of Medical Education Scholars Program, University of Michigan School of Medicine. <i>Donna S. Murray, PhD, CCC-SLP</i>, Vice President of Clinical Programs and Head of the Autism Treatment Network (ATN) at Autism Speaks <i>Brandy Fureman, PhD</i>, Chief Outcomes Officer, Epilepsy Foundation; Network Coordinating Center Lead, Epilepsy Learning Health System <i>Benjamin L. Laskin, MD, MS</i>, Assistant Professor of Pediatrics, Children’s Hospital of Philadelphia; Glomerular Disease Learning Network Investigator <i>Esi Morgan, MD, MSCE</i>, Professor of Pediatrics, Division Chief, Pediatric Rheumatology, Seattle Children’s Hospital</p>
4:00 – 4:45PM	<p>Panel Discussion - Redesigning research within a Learning Health System. What have we learned? What do we need to know? <i>Pierre Barker, MD, MBChB</i>, Chief Scientific Officer, Institute for Healthcare Improvement <i>Paul Batalden, MD</i>, Professor Emeritus, Geisel School of Medicine, Dartmouth <i>Carly Parry, PhD, MSW, MA</i>, Senior Advisor, Care Coordination and Transitions Research Initiative, Patient Centered Outcomes Research Institute <i>Keith Porcaro, JD</i>, Director of the Digital Governance Design Studio at Duke Law <i>Rohit Ramaswamy, PhD, MPH</i>, Professor of Maternal and Child Health, Univ of North Carolina School of Public Health <i>Gisele Woodward</i>, Parent Co-investigator, ImproveCareNow Network</p>
4:45 – 5:00PM	<p>Closing Remarks and Adjourn <i>Michael Seid, PhD</i>, Professor of Pediatrics and Director, Pulmonary Outcomes Research, Cincinnati Children’s Hospital Medical Center</p>

Speakers

	<p>Pierre Barker, MD, MBChB Chief Scientific Officer, Institute for Healthcare Improvement</p>
	<p>Paul Batalden, MD Professor Emeritus, Geisel School of Medicine, Dartmouth</p>
	<p>Brandy Fureman, PhD Chief Outcomes Officer, Epilepsy Foundation Network Coordinating Center Lead, Epilepsy Learning Health System</p>
	<p>Harlan Krumholz, MD, SM Professor of Medicine and Director, Center for Outcomes Research and Evaluation</p>
	<p>Benjamin L. Laskin, MD, MS Assistant Professor of Pediatrics, Children's Hospital of Philadelphia Glomerular Disease Learning Network Investigator</p>



Angela Lorts, MD, MBA

Professor of Pediatrics and Cardiology, Director Ventricular Assist Device Program, Associate Chief Quality Officer, Cincinnati Children's Hospital Medical Center and the ACTION Network



Peter Margolis, MD, PhD

Professor of Pediatrics and Co-Director, James M. Anderson Center for Health Systems Excellence, Cincinnati Children's Hospital Medical Center



Kedar Mate, MD

President and CEO, Institute for Healthcare Improvement



Esi Morgan, MD, MSCE

Professor of Pediatrics, Division Chief, Pediatric Rheumatology, Seattle Children's Hospital



Donna S. Murray, PhD , CCC-SLP

Vice President of clinical programs and Head of the Autism Treatment Network (ATN) at Autism Speaks



Lisa Oipari-Arrigan, PhD

Professor of Psychiatry and Behavioral Sciences, George Washington University School of Medicine and Health Sciences
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Rohit Ramaswamy

PhD, MPH, Professor of Maternal and Child Health, Univ of North Carolina School of Public Health



Christopher Schmid, PhD

Brown School of Public Health Professor of Biostatistics and Member of Center for Evidence Synthesis in Health and Center for Statistical Sciences



Michael Seid, PhD

Professor of Pediatrics and Director, Pulmonary Outcomes Research,
Cincinnati Children's Hospital Medical Center



Alexandra Vinson, PhD

Assistant Professor of Learning Health Systems, Director of Medical
Education Scholars Program, University of Michigan School of Medicine



Gisele Woodward

Parent Co-investigator, ImproveCareNow Network