

**Data Integration in Learning Healthcare Systems for Traumatic Brain Injury: A Workshop**

12 October 2023 | National Academy of Science Building, Lecture Room

**Public Registration:** [https://events.nationalacademies.org/40992\\_10-2023\\_data-integration-in-learning-health-care-systems-for-traumatic-brain-injury-a-workshop](https://events.nationalacademies.org/40992_10-2023_data-integration-in-learning-health-care-systems-for-traumatic-brain-injury-a-workshop)

**View the Live Webcast:** [https://www.nationalacademies.org/event/40992\\_10-2023\\_data-integration-in-learning-health-care-systems-for-traumatic-brain-injury-a-workshop](https://www.nationalacademies.org/event/40992_10-2023_data-integration-in-learning-health-care-systems-for-traumatic-brain-injury-a-workshop)

**Workshop Objectives:**

Learning healthcare systems (LHSs) describe research-partnered care networks that analyze sources of patient data (e.g., electronic health records, medical billing) and use those insights to continuously improve their health services. LHSs are important contributors to progress in traumatic brain injury (TBI), where much more remains to be understood about which interventions are the most effective, and for whom. Fragmented and siloed LHS data undercuts the system's ability to learn and improve. This one-day public workshop will discuss a vision for how data integration in LHSs for TBI can accelerate research and patient care.

Invited presentations and discussions will be designed to:

- Explore the variables impacting how TBI patient data is collected, standardized, harmonized, accessed, and analyzed - and the implications for care and research in learning LHSs,
- Discuss a vision for how enhanced TBI data integration in LHSs could improve care and advance clinical and epidemiological research,
- Consider key questions and priority use cases that could be explored through integrated patient record databases and TBI registries, and
- Spotlight ongoing efforts towards building integrated research platforms and datasets for TBI.

**Workshop Planning Committee**

**Corinne Peek-Asa, PhD, MPH** - University of California, San Diego (Workshop Chair)

**David Goldstein, MS** - Department of Health and Human Services

**Odette Harris, MD, MPH** - Stanford University

**Michael Huerta, PhD** - National Library of Medicine

**Monique R. Pappadis, MEd, PhD** - University of Texas Medical Branch at Galveston

**Nsini Umoh, PhD** - National Institute of Neurological Disorders and Stroke

**Rebecca Wolfkiel, MPP** - National Association for State Head Injury Administrators

**Kristine Yaffe, MD** - University of California, San Francisco

## Session 1: Introduction to the Workshop

9:00-9:10AM (ET) **Welcome and Introductory Remarks**  
CORINNE PEEK-ASA, University of California, San Diego; *Workshop Chair; Co-chair, Forum on Traumatic Brain Injury*

## Session 2: Lived Experiences

### Session Objectives:

- Underscore the challenges that arise from fragmented and uncoordinated care, and the significance of health information exchange for improving the patient experience and supporting better outcomes.

### Discussion Questions:

- How does the fragmentation of health care records affect a patient's care, recovery, emotional well-being, and confidence in the health care system?
- How can the voice and experiences of TBI survivors be more integrated into the development of health information exchange systems?
- Based on the voices and experiences of TBI survivors, what recommendations should healthcare providers and policymakers consider to ensure that TBI patients receive cohesive and coordinated care?

9:10-9:15AM **Session Introduction**  
CORINNE PEEK-ASA, University of California, San Diego; *Workshop Chair; Co-chair, Forum on Traumatic Brain Injury*

9:15-9:35AM **The Impact of Data Fragmentation on the Experience of Seeking and Receiving Care**  
LINDSAY SIMPSON, Champion Comeback Foundation

9:35-9:45AM **Moderated Discussion/Audience Q&A**

## Session 3: Introduction to Learning Healthcare Systems

### Session Objectives:

- Provide a historical context for the conceptual origin of learning health systems.
- Articulate a definition of a learning health system: What are the essential components and functions?
- Discuss the anticipated trajectory of learning health systems over the coming years, and how they can transform the overall healthcare landscape.
- Review how the NASEM 2022 consensus report, *Traumatic Brain Injury: A Roadmap for Accelerating Progress* provides recommendations for care and research improvements involving learning health systems.

### Discussion Questions:

- How did the concept of a learning healthcare system originate; what were the primary drivers behind its inception?
- What distinguishes a learning healthcare system from a traditional healthcare system?
- How do these systems incorporate feedback loops to ensure continuous learning and adaptation?

9:45-9:50AM	<b>Session Introduction</b> ODETTE HARRIS, Stanford University
9:50-10:10AM	<b>Learning Healthcare Systems</b> J. MICHAEL MCGINNIS, National Academy of Medicine
10:10-10:30AM	<b>Moderated Discussion/Audience Q&amp;A</b>
10:30-10:50AM	<b>Break</b>

#### **Session 4: Stakeholder Perspectives on How LHSs Can Address Unmet Priorities that Apply to TBI**

##### Session Objectives:

- Articulate the priority research questions and care needs that learning healthcare systems help to address.
- Explore how different partners and stakeholders support and engage with learning healthcare systems.

##### Discussion Questions:

- How can organizations think of an LHS more strategically, and in ways which move innovation forward?
- What infrastructure is needed to make LHS solutions more accessible?
- What partnerships are needed to help learning healthcare systems implement evidence-based care delivery innovations?
- What strategies are needed to ensure that data drives policy, and that policy drives continuous improvement in care and research systems?

10:50-10:55AM	<b>Session Introduction</b> DAVID GOLDSTEIN, Department of Health and Human Services
10:55-11:30AM	<b>Perspectives Panel</b> KATHRYN DAVIDSON, Centers for Medicare and Medicaid Services EDWIN LOMOTAN, Agency for Healthcare Research and Quality LEORA HORWITZ, NYU Center for Healthcare Innovation & Delivery Science JOEL SCHOLTEN, Department of Veterans Affairs–Polytrauma System of Care
11:30-12:00PM	<b>Moderated Discussion/Audience Q&amp;A</b>
12:00-12:45PM	<b>Lunch</b>
12:45-1:00PM	<b>Halftime Touchpoint</b>

## Session 5: Illustrative Examples of LHS in TBI

### Session Objectives

- Highlight illustrative examples of how learning health systems for TBI support care delivery, improve health outcomes, and expand research opportunities.

### Discussion Questions

- In these examples, what key achievements for research and care have been observed because of the integrated linkages between care, research, and continuous learning?
- Across these examples of learning healthcare systems, what common challenges arise? What strategies are being deployed to address them?
- What are the key lessons learned?

1:00-1:05PM	<b>Session Introductions</b> NSINI UMOH, National Institute of Neurological Disorder and Stroke (NINDS)
1:05-1:55PM	<b>Exemplars of Learning Healthcare Systems in TBI</b> JENNIFER BOGNER, CARE4TBI: Comparing Treatment Approaches to Promote Inpatient Rehabilitation Effectiveness for TBI JOE GIACINO, TRACK-TBI NINDS Common Data Elements KATHARINE STOUT, Department of Defense–TBI Center of Excellence
1:55-2:40PM	<b>Moderated Discussion/Audience Q&amp;A</b>
2:40-3:00PM	<b>Break</b>

## Session 6: Data Capture, Surveillance, and Supporting Community-Based Care

### Session Objectives:

- Understand how the CDC performs data capture and surveillance to inform public health strategies and support community-based care.
- Explore how state brain health programs partner with learning healthcare systems to identify TBI survivors and create linkages to community services.
- Hear a high-level overview of the VA's approach to harnessing learning healthcare systems to enhance community care for veterans with TBI.

### Discussion Questions:

- What LHS-based programs exemplify a successful execution of data capture/surveillance leading to material improvements in how survivors are supported via community-based care?
- What are some key lessons learned?
- From the perspective of public health and community-based care, what do we need from learning healthcare systems that currently isn't in place, and why is this a priority?
- How can data insights from diverse entities like the CDC, state departments, and the VA be integrated to form a more cohesive and holistic LHS for TBI community care?

3:00-3:20PM	<b>Learning Healthcare Systems for Data Capture and Surveillance</b> KRISTINE YAFFE, University of California, San Francisco (moderator) JILL DAUGHERTY, Centers for Disease Control and Prevention (virtual)
3:20-3:40PM	<b>Learning Healthcare Systems to Support Community-Based Care</b> REBECCA WOLFKEIL, National Association of State Head Injury Administrators (moderator) CHRISTIANE MILLER, Virginia Department for Aging and Rehabilitative Services
3:40-4:00PM	<b>Learning Healthcare Systems for TBI in the Department of Veterans Affairs</b> JOEL SCHOLTEN, Department of Veterans Affairs–Polytrauma Systems of Care (moderator) STUART HOFFMAN, Department of Veterans Affairs–Office of Research & Development
4:00-4:20PM	<b>Moderated Discussion/Audience Q&amp;A</b>

#### Session 7: What's Needed from LHSs to Combat Inequitable Outcomes in TBI

##### Session Objectives:

- Examine strategies to build and enhance the capacity of community systems to respond to and manage brain injuries, especially in geographic regions or among demographic groups that are underserved.

##### Discussion Questions:

- What are the current gaps in TBI awareness and education for patients and providers?
- Why is building community capacity for TBI community care essential, and what is needed from learning healthcare systems to facilitate this?
- How might LHS-based solutions improve health outcomes for vulnerable populations of TBI-injured people – including those who are rurally-located, are survivors of intimate-partner violence, or are incarcerated?
- For vulnerable patient populations with limited access to specialized care centers, what are the greatest barriers in the way of accessing LHS-based solutions locally?

4:20-4:25PM	<b>Session Introduction</b> MONIQUE PAPPADIS, University of Texas Medical Branch at Galveston (virtual)
4:25-4:40PM	<b>Patient/Provider Education, Resource Facilitation, and Systems Capacity Building in Community for Brain Injury</b> PEGGY REISHER, Brain Injury Alliance of Nebraska
4:40-4:50PM	<b>Moderated Discussion/Audience Q&amp;A</b>
4:50-5:00PM	<b>Adjourn</b> CORINNE PEEK-ASA, University of California, San Diego; <i>Workshop Chair; Co-chair, Forum on Traumatic Brain Injury</i>
5:00PM	<b>Reception</b> (East Court, National Academy of Sciences)