



# DATA INTEGRATION IN LEARNING HEALTH CARE SYSTEMS FOR TRAUMATIC BRAIN INJURY: A WORKSHOP

Session 2: Lived Experiences

Session 3: Introduction to Learning Healthcare Systems

Session 4: Different Stakeholder Perspectives on LHS' to Address Unmet Priorities that Apply to TBI

Session 5: Illustrative Examples of LHS' in TBI

Session 6: Data Capture, Surveillance, and Supporting Long-term Care Needs

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

# NATIONAL ACADEMY OF MEDICINE THE LEARNING HEALTHCARE SYSTEM

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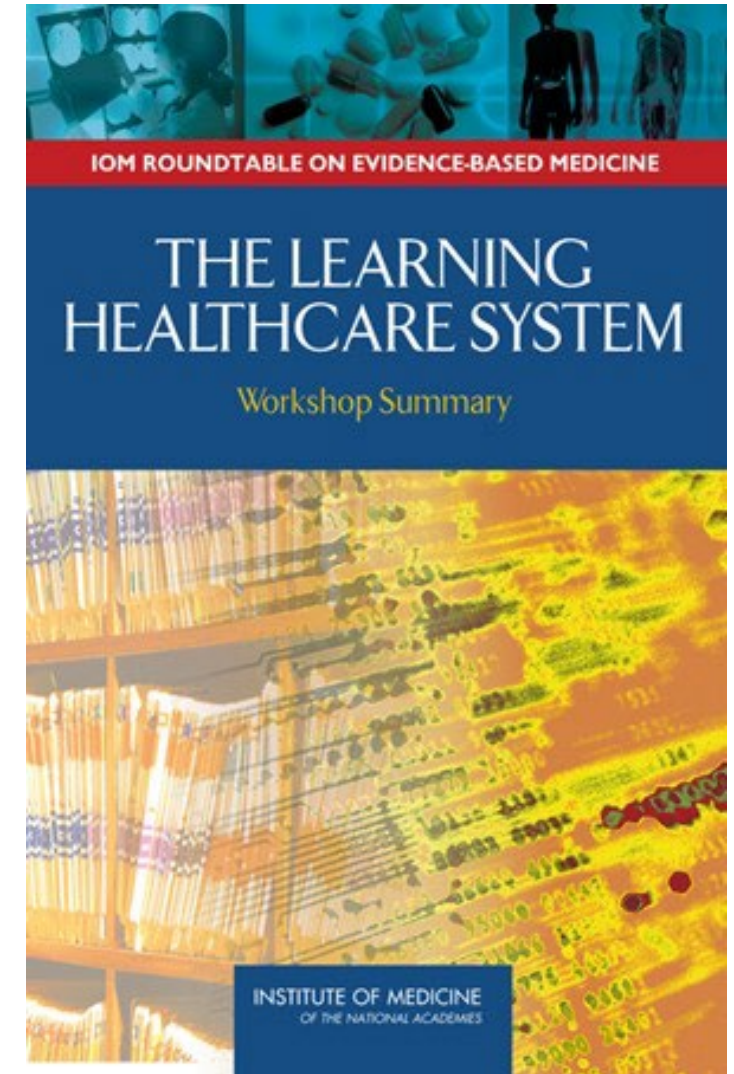
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Director, Traumatic Brain Injury Center of Excellence (TBICoE)





# INSTITUTE OF MEDICINE'S ROUNDTABLE ON EVIDENCE-BASED MEDICINE

*“Evidence-based medicine (EBM) emerged in the twentieth century as a methodology for improving care by emphasizing the integration of individual clinical expertise with the best available external evidence”*

—(Sackett et al. 1996)

- The Institute of Medicine's Roundtable on Evidence-Based Medicine convened in 2006 to help transform the way evidence on clinical effectiveness is generated and used to improve health and health care.
- Development of a Learning Healthcare System.

## Vision

Healthcare system that:

- Draws on the best evidence to provide the care most appropriate to each patient
- Emphasizes prevention and health promotion
- Delivers the most value
- Adds to learning throughout the delivery of care
- Leads to improvements in the nation's health

## Goal

By year 2020, 90% of clinical decisions will be supported by:

- Accurate clinical info
- Timely clinical info
- Up-to-date clinical info

Presents a tangible focus for progress toward our vision:

- Americans ought to expect this level of performance
- It should be feasible with existing resources and emerging tools
- Measures can be developed to track and stimulate progress

## Context

Care that is important is often not delivered. Care that is delivered is often not important.

- In part, this is because of our failure to apply the evidence we have about the medical care that is most effective (Shortfalls in provider knowledge, accountability, lack of insurance, etc.)
- Must quicken efforts to position evidence development and application as natural outgrowths of clinical care

## Approach

- The IOM Roundtable on Evidence-Based Medicine serves as a forum to facilitate the collaborative assessment and action around issues central to achieving the vision and goal stated
- Roundtable members will work with their colleagues to identify the issues not being adequately addressed, the nature of the barriers and possible solutions, and the priorities for action



# PRIORITIES

- Commitment to the right health care for each person
- Putting the best evidence into practice
- Establishing the effectiveness, efficiency, and safety of medical care delivered
- Building constant measurement into our healthcare investments
- Establishment of healthcare data as a public good
- Shared responsibility distributed equitably across stakeholders, both public and private
- Collaborative stakeholder involvement in priority setting
- Transparency in the execution of activities and reporting of results
- Subjugation of individual political or stakeholder perspectives in favor of the common good



# AIM

Roundtable is anchored in a focus on three dimensions of the challenge

- Fostering progress toward the long-term vision of a learning healthcare system, in which evidence is both applied and developed as a natural product of the care process.
- Advancing the discussion and activities necessary to meet the near-term need for expanded capacity to generate the evidence to support medical care that is maximally effective and produces the greatest value.
- Improving public understanding of the nature of evidence-based medicine, the dynamic nature of the evidence development process, and the importance of supporting progress toward medical care that reflects the best evidence.



## SUMMARY

- Increased complexity of health care requires a deepened commitment by all stakeholders to develop a healthcare system engaged in producing the kinds of evidence needed at the point of care for the treatment of individual patients.
- Simply impractical for most interventions
- A reevaluation of how health care is structured to develop and apply evidence—from health professions training, to infrastructure development, patient engagement, payments, and measurement—will be necessary to orient and direct these tools
- The nation needs a healthcare system that learns



## GOAL OF THE WORKSHOP

Discuss those issues most central to drawing research closer to clinical practice by building knowledge development and application into each stage of the healthcare delivery process, in a fashion that will not only improve today's care but improve the prospects of addressing the growing demands in the future

# THEMES

## Current Challenges

- Missed opportunities, preventable illness, and injury are too often features in health care
- Inefficiency and waste
- Deficiencies in the quantity, quality, and application of evidence
- The prevailing approach to generating clinical evidence is inadequate today and may be irrelevant tomorrow, given the pace and complexity of change
- RCT takes too much time, is too expensive, and is fraught with questions of generalizability
- The current approaches to interpreting the evidence and producing guidelines and recommendations often yield inconsistencies and confusion
- Promising developments in information technology offer prospects for improvement that will be necessary to deploy, but not sufficient to effect, the broad change needed.

## Uncertainties

- Should we continue to call the RCT the “gold standard”?
- What do we need to do to better characterize the range of alternatives to RCTs and the applications and implications for each?
- What constitutes evidence, and how does it vary by circumstance?
- How much of evidence development and evidence application will ultimately fall outside of even a fully interoperable and universally adopted electronic health record (EHR)? What are the boundaries of a technical approach to improving care?
- What is the best strategy to get to the right standards and interoperability for a clinical record system that can be a fully functioning part of evidence development and application?
- How much can some of the problems of post-marketing surveillance be obviated by the emergence of linked clinical information systems that might allow information about safety and effectiveness to emerge naturally in the course of care?

## Compelling need for change

- Adaptation to the pace of change
- Stronger synchrony of efforts
- Culture of shared responsibility
- New clinical research paradigm
- Clinical decision support systems
- Universal electronic health records
- Tools for database linkage, mining, and use
- Notion of clinical data as a public good
- Incentives aligned for practice-based evidence
- Public engagement
- Trusted scientific broker
- Leadership

# THE LEARNING HEALTH SYSTEM SERIES



VISION



THE DATA  
UTILITY



EVIDENCE



SYSTEMS  
ENGINEERING



CARE  
COMPLEXITY



EFFECTIVENESS  
RESEARCH



DIGITAL  
PLATFORM



PATIENTS &  
THE PUBLIC



COST &  
OUTCOMES



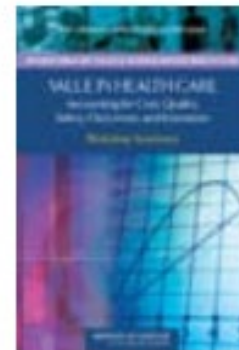
DATA QUALITY



CORE METRICS



LARGE SIMPLE  
TRIALS



VALUE



LEADERSHIP



OBSERVATIONAL  
STUDIES



RESEARCH

# THE LEARNING HEALTH SYSTEM SERIES



THE DATA  
UTILITY



DATA QUALITY



EVIDENCE



EFFECTIVENESS \*  
RESEARCH



DIGITAL  
PLATFORM



RESEARCH

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## Data Integration

# EFFECTIVENESS RESEARCH

By emphasizing effectiveness research over efficacy research.

| TABLE S-1 Characteristics of Efficacy and Effectiveness Research    |                                                                                                |
|---------------------------------------------------------------------|------------------------------------------------------------------------------------------------|
| Efficacy                                                            | Effectiveness                                                                                  |
| Clinical trials—idealized setting                                   | Clinical practice—everyday setting                                                             |
| Treatment vs. placebo                                               | Multiple treatment choices, comparisons                                                        |
| Patients with a single diagnosis                                    | Patients with multiple conditions (often excluded from efficacy trials)                        |
| Exclusions of user groups (e.g., elderly)                           | Use is generally unlimited                                                                     |
| Short-term effects measured through surrogate endpoints, biomarkers | Longer-term outcomes measured through clinical improvement, quality of life, disability, death |
| SOURCE: Clancy 2006 (July 20-21).                                   |                                                                                                |

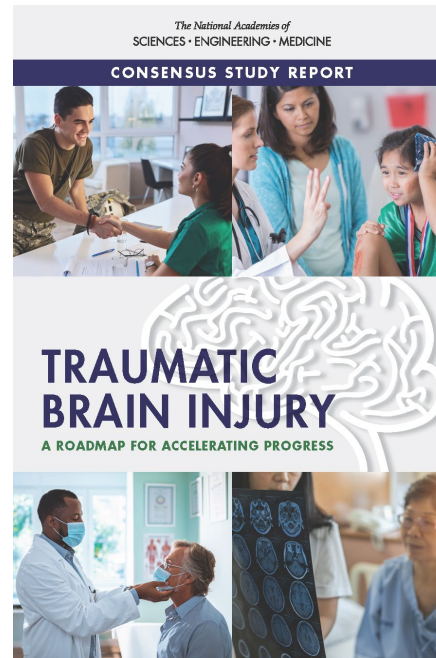


## LEARNING SYSTEMS IN PROGRESS

- Premier visions of how systems might effectively be used to realize the benefit of integrated systems of research and practice include the care philosophy and initiative at the Department of Veterans Affairs (VA)
- These examples suggest a vision for a learning healthcare system that builds upon current capacity and initiatives and identifies important elements and steps that can take progress to the next level.
- Implementing Evidence-Based Practice at the VA
  - The Department of Veterans Affairs has made important progress in implementing evidence-based practice
  - An environment that values evidence, quality, and accountability through performance measures, the leadership to create and sustain this environment, and the VA's research culture and infrastructure
  - an example demonstrating the range of possibilities in using the EHR for developing and implementing evidence at the point of care

# Traumatic Brain Injury: A Roadmap for Accelerating Progress

Committee on Accelerating Progress in Traumatic Brain Injury Research and Care



# COMMITTEE AND TASK

## TASK

Tasked to develop a report that:

- Identifies major barriers and knowledge gaps impeding progress
- Highlights opportunities for collaborative action
- Provides a roadmap to help guide the field

## HOW

Held public workshop and webinar sessions

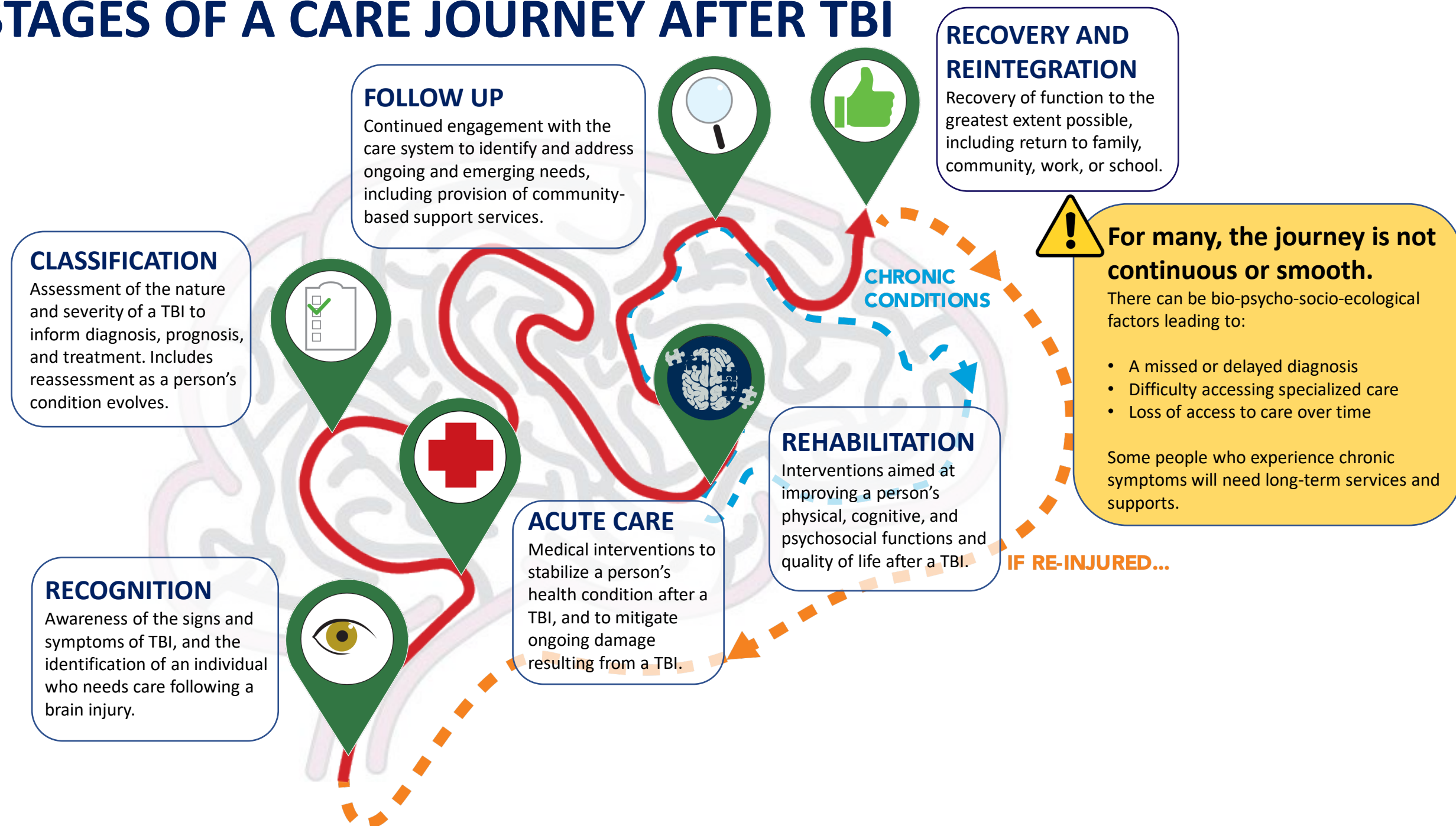
- Heard from over 50 stakeholders
- Reviewed available literature

## WHO

18 members in TBI care and research

- Emergency Medicine
- Trauma Care through rehabilitation and community reintegration
- Epidemiology
- Basic, Translational, Clinical Research
- Neuropsychology and Mental Health
- Health Care Policy

# STAGES OF A CARE JOURNEY AFTER TBI



# KEY TAKEAWAYS

TBI is not an isolated, acute event – it needs to be understood and managed as a condition influenced by biological, psychological, and socio-ecological factors and one that can have long-term effects

An updated and more precise TBI classification system is needed to guide patient care and inform research

The U.S. lacks a comprehensive framework for addressing TBI along the full continuum of care and across the many care settings people encounter

An effective TBI care system needs to anticipate, respond, and learn in a coordinated fashion

Progress has been made in TBI understanding and care, although a variety of knowledge gaps remain. But there are also many opportunities for collaborative action to advance TBI awareness, prevention, care, and research

*A learning health system is one in which science, informatics, incentives, and culture are aligned for continuous improvement, innovation, and equity—with best practices and discovery seamlessly embedded in the delivery process, individuals and families active participants in all elements, and new knowledge generated as an integral by-product of the delivery experience.*

*NAM Leadership Consortium Charter*



## ENGAGED

*Informed engagement, options, and choices for people served*



## SAFE

*Tested and updated protocols to protect from unintended harm*



## EFFECTIVE

*Evidence-based services tailored to understanding of people's goals*



## EQUITABLE

*Parity in opportunity to achieve desired health goals*



## EFFICIENT

*Optimal outcomes for accessible resources*



## ACCESSIBLE

*Effective services readily available where and when most needed*



## MEASURABLE

*Reliable assessment of consequential activities and outcomes*



## TRANSPARENT

*Clear information related to the nature, use, costs, and results of services*



## SECURE

*Validated access and use safeguards for digitally-mediated activities*



## ADAPTIVE

*Continuous learning and improvement core to organizational culture*



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## Session 7

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## Session 4

An updated and more precise TBI classification system is needed to guide patient care and inform research

## Session 5

The U.S. lacks a comprehensive framework for addressing TBI along the full continuum of care and across the many care settings people encounter

## All Sessions

An effective TBI care system needs to anticipate, respond, and learn in a coordinated fashion

## Sessions 4, 5 and 6

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