How to solve a problem like disconnected and incomplete healthcare data: Neurotrauma Care Pathways in action

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Background

Evaluating the current quality of care for traumatic brain and spinal cord injuries (TBI & tSCI) remains challenging due to inconsistent data collection, heavily siloed information, and a lack of common quality indicators for these complex chronic conditions.

Poor data integration between public and third-party healthcare systems in Ontario has created challenges in understanding and evaluating care quality and equity across the province for people living with TBI & tSCI.

Purpose

To collaborate with a diverse group of stakeholders from across Ontario to develop a comprehensive set of quality indicators for TBI and tSCI that map onto the evidence-based Neurotrauma Care Pathways. These indicators will provide data that can evaluate key components at each stage of care, identify quality improvement opportunities, and address gaps in service across the care continuum.
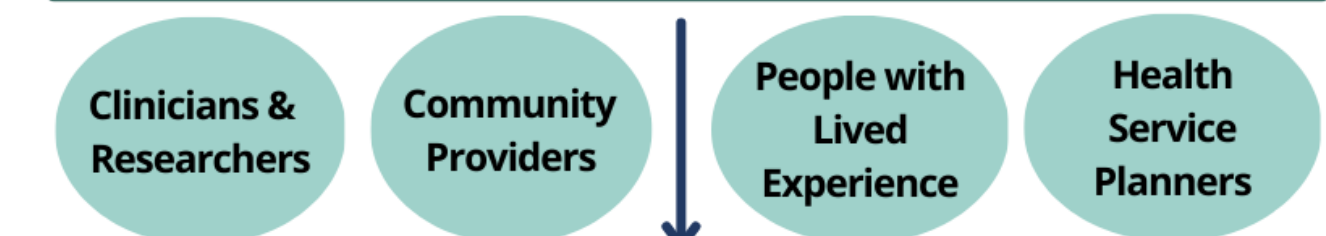
The goal of this initiative is to enhance overall care quality for TBI and tSCI by addressing the gaps in quality evaluation through data-focused strategies.
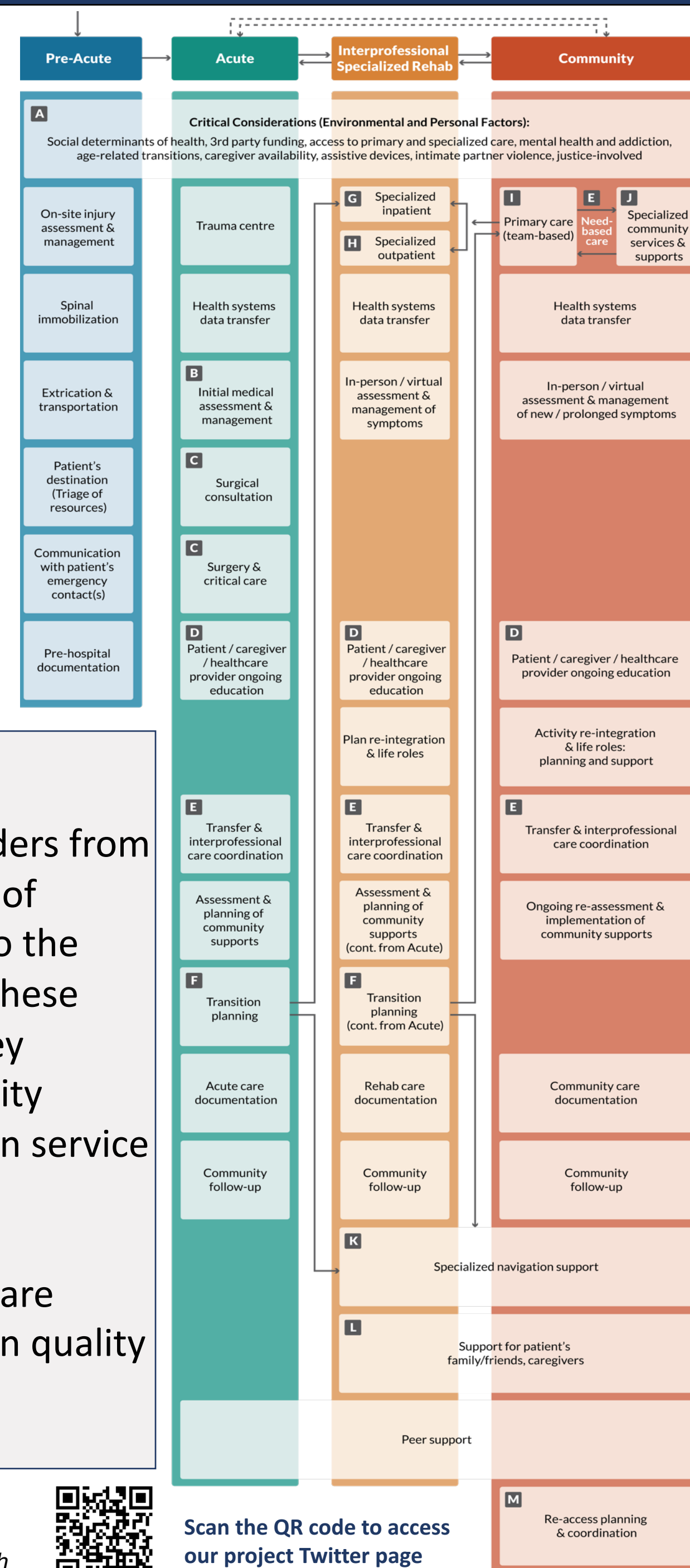
Methodology and Process

### 1. Indicator Development & Prioritization

90+ diverse partners were recruited to develop quality data indicators that evaluate TBI & tSCI care standards

- Clinicians & Researchers
- Community Providers
- People with Lived Experience
- Health Service Planners

3 Stage of Care Working Groups were formed to create & prioritize sector-specific indicators, with an additional group focused on health equity considerations
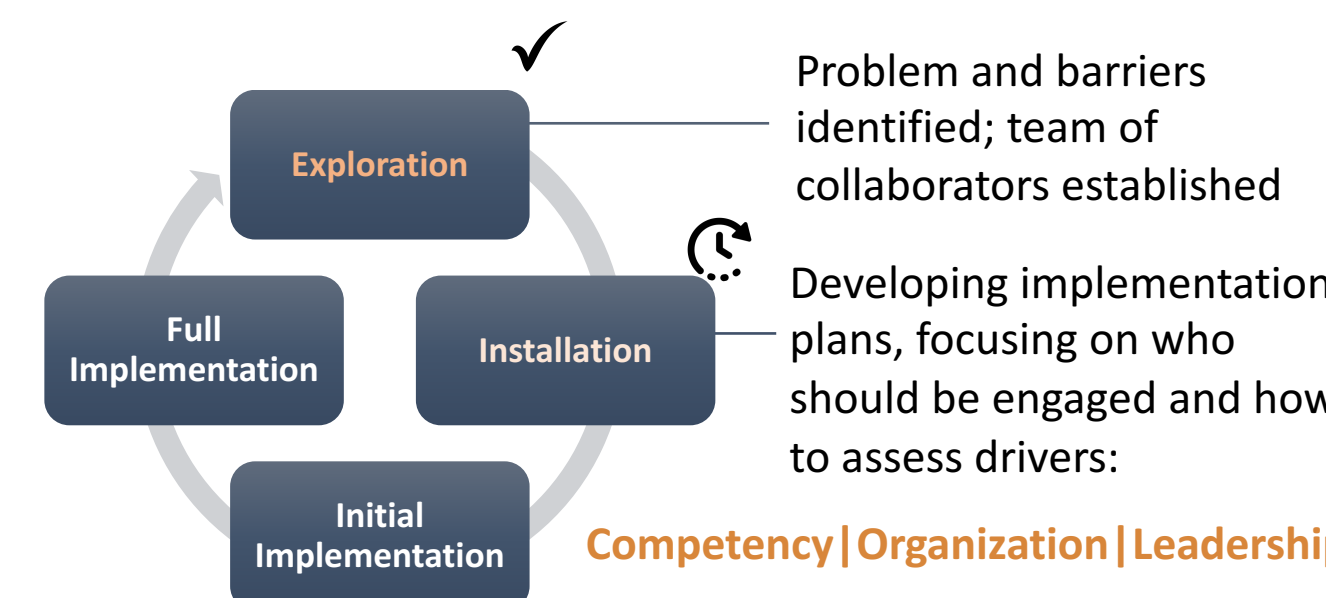
4 Working Groups   20 meetings

67 Quality Indicators were developed; 22 were prioritized as essential to implement ("Core")

Pre-Acute	Acute	Rehab	Community
1	7	4	7
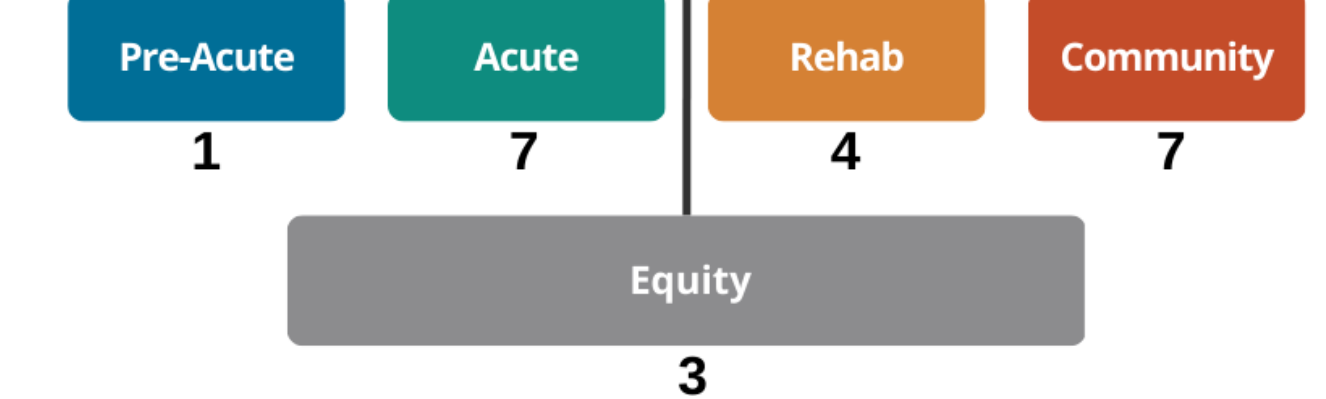
Equity
3

Indicator Type	Equity	Pre-Acute	Acute	Rehab	Community	Total
Core set	3	1	7	4	7	22
Must-have	2	0	3	4	8	17
Should-have	3	0	12	3	2	20
Nice-to-have	3	1	2	1	1	8
Total	11	2	24	12	18	67

An Implementation Science Approach

- Exploration — Problem and barriers identified; team of collaborators established
- Developing implementation plans, focusing on who should be engaged and how to assess drivers:
- Full Implementation
- Installation
- Initial Implementation

Competency | Organization | Leadership

2. Definitions & Implementation

Goals of Data Working Groups
(Acute, Rehab, Community, Equity)

- Operationally define high-priority indicators
- Develop data collection mechanisms
- Identify implementation resources and engage collaborators

Key Partner Focus Groups: Data Consultations

- People with Lived Experience
- Third-party providers
- Community TBI Navigation Specialists

Focus Groups ensured that implementation plans and definitions for quality indicators were comprehensive, feasible, and addressed system gaps

The following questions were addressed for each indicator:

- What are the data sources?
- Does it measure a key structure, process, or outcome?
- Who is collecting the data?
- What are the implementation challenges?
- How is the data to be collected? (i.e.,mechanism)
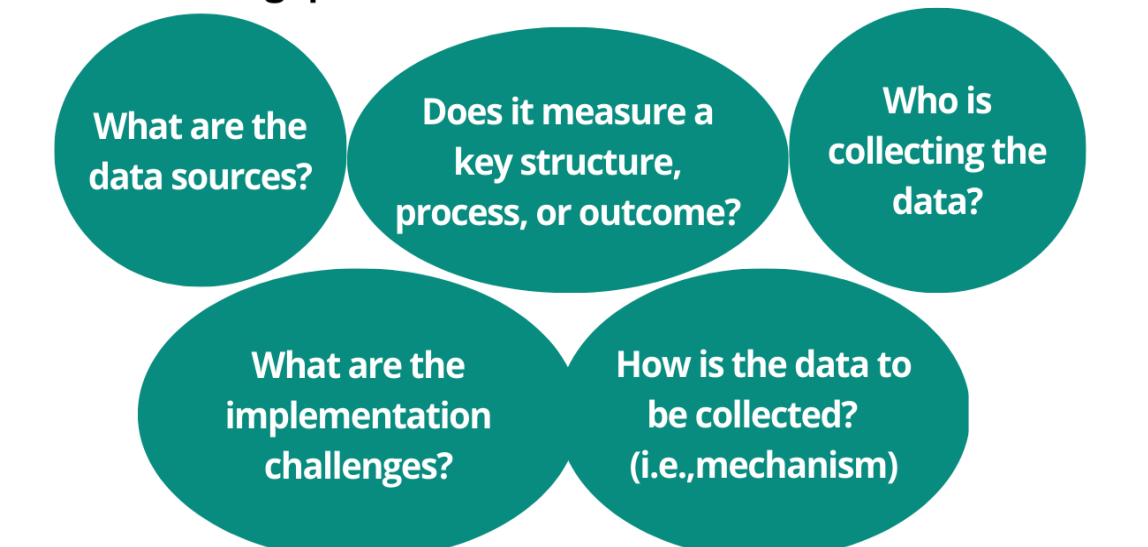
Key Challenge

Evaluating services for TBI & tSCI outside of public funding is challenging due to the variety of third-party funding sources that hold their own siloed data. Third party funding sources can include: Health Claims for Auto Insurance (HCAI), Workplace Safety Insurance Board (WSIB), Extended Health Benefits, long-term disability benefits, self-pay etc.

Key Outcomes

67 Quality Indicators were developed in collaboration with key stakeholders from across the care continuum to evaluate Ideal Care Pathway adherence and quantify any care gaps through structure, process, and outcome indicators

Future Directions:

- Outline technical specifications and context-specific details for all high priority indicators ('Core' & 'Must')
- Identify resources to support indicator implementation, including other pilot projects across Ontario
- Cultivate public and 3rd party data partnerships to standardize data collection and sharing mechanisms (WSIB, Home and Community Care, Ontario Rehab Alliance)

Impact

This project represents a significant practical step towards implementing a provincial data strategy that maps onto the Ideal Neurotrauma Care Pathways, to ensure consistency and equity in care quality across Ontario.

Neurotrauma Care Pathways

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