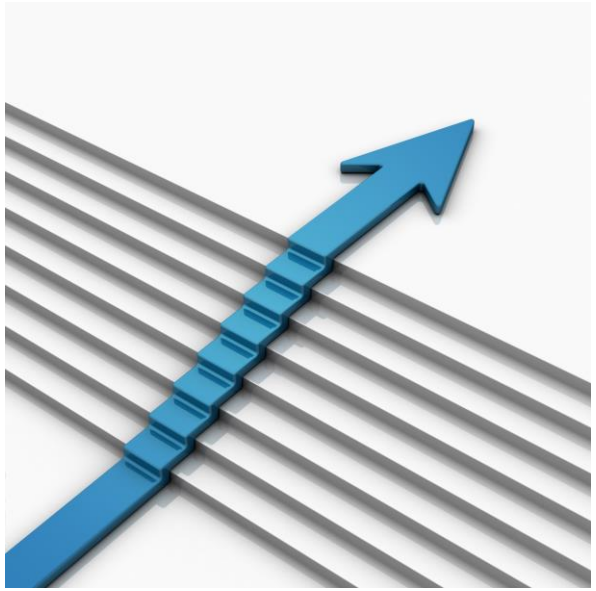
Neurotrauma Care Pathways

Can we get there from here? Developing and Implementing an Ideal Neurotrauma Care Pathway



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Objectives

1. Understand the process for the development of Ideal Neurotrauma Care Pathways in Ontario
2. List the key elements of care during different stages of care provision across the lifespan, from acute to community care
3. Identify mitigation strategies to address barriers to equitable care (e.g., social determinants of health, access to third party funding, access to primary care)
4. Understand the implementation process for the Ideal Care Pathways
5. Learn the perspectives of stakeholder representatives regarding the strengths and challenges of the Ideal Neurotrauma Care Pathways

Quality of care for persons after Neurotrauma (TBI and tSCI) varies

- Initial medical assessment and care
- Access to specialized rehab
- Connection to appropriate community supports
- Integration of individualized comprehensive care that considers: comorbidities, social determinants of health and access to primary care

Implement evidence-based standard yet adaptable Ideal Neurotrauma Care Pathways

Methods

Stakeholders (N=125)

- People with lived experience, clinicians, researchers, funders, health system planners, policymakers and community service providers from different sectors
- Across the province (rural to urban)

Working Groups (N=4)

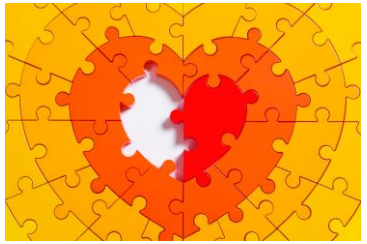
- Acute, Rehabilitation, Community, and Critical Considerations Working Groups
- Developed the building blocks for the Ideal Neurotrauma Care Pathways.

Stakeholder checking

- Focus groups and interviews:
  - people with lived experience, lawyers, Insurance Bureau of Canada (IBC) and Workplace Safety and Insurance Bureau (WSIB).

System Evaluation

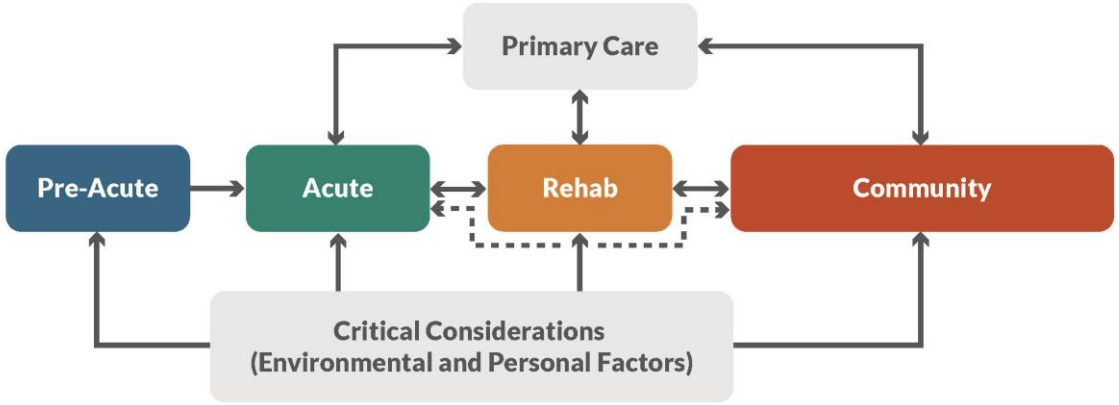
- A core set of indicators was developed as a companion to the Ideal Care Pathways



Current Gaps in Neurotrauma Care

Neurotrauma Care Pathways

1. Lack of **access** to specialized clinicians
2. No agreed upon **standards** of care by publicly funded organizations, 3rd party/insurance and public service providers, resulting in inconsistent and at times inappropriate care.
3. Lack of **awareness** of neurotrauma; need for cross-training and collaboration
4. No strategy to optimally utilize the limited **specialist resources** to serve all Ontarians
5. Lack of consistent **long-term anticipatory follow-up**.
6. Poor **integration of care** from pre-acute (at site of injury) to returning to the community This lack of integration exists at both the service and data collection/sharing levels.
7. **Peer support and ongoing education** not built into care at every stage.



3 related but separated Pathways :

- Concussion
- Moderate to severe TBI
- tSCI

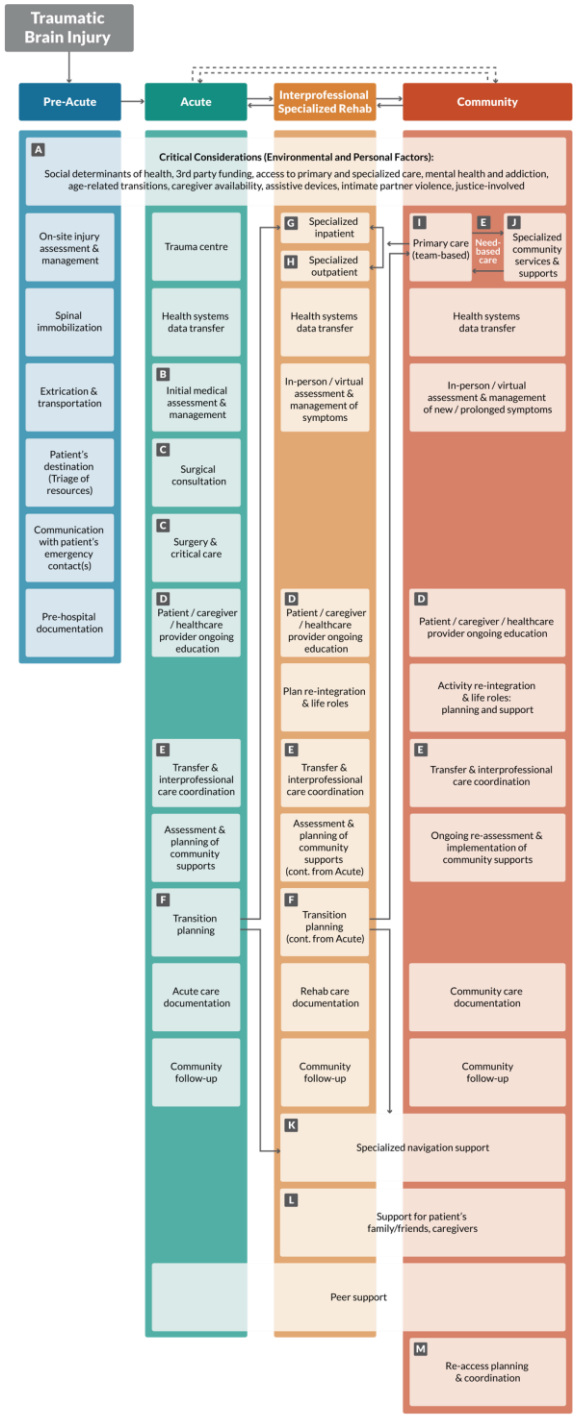


- **address** the identified **gaps** in the current system of care
- provide a **framework** to develop strategies to assess the quality and equity of care across the healthcare system and lifespan
- identify the types of care using **building blocks** derived from clinical practice guidelines and consensus

- allow for **personalization** based on geography and equity considerations of complexities and individual circumstances
- Identify **ongoing needs** for re-access specialized care and evolution of supports and housing to address issues related to ageing

The Pathways: Key aspects

- **Critical Considerations (Equity)**:
  - Social determinants of health, marginalized populations, mental health issues
- **Across all care stages:**
  - Effective specialized navigation
  - Ongoing education and supports
- **Pre-Acute/Acute**:
  - Timely comprehensive and appropriate assessment and diagnosis
- **Rehab**:
  - Access to specialized rehab when needed
  - Ongoing follow-up by Primary Care
- **Community**:
  - Navigation into community supports
  - Follow-up and comprehensive support for patients and caregivers/families over the lifespan (e.g., aging, comorbidities)



Mitigation strategies

- Engage in group efforts to promote policy change
  - Access to specialized care
  - Funding for publicly-funded rehab
- Increase public awareness of neurotrauma, focusing on Intimate Partner Violence, undiagnosed injuries after falls in the elderly
- Improve access to standardized assessment, tools and resources
- Mandate screening for common comorbidities
- Increase equitable access to technology and information

Mitigation strategies - 2

- Increase cross sector education and capacity building
- Formalize collaboration and communication practices
- Increase awareness of ALL the community resources that are available and relevant to the PERSON with the injury
- Mandate cultural sensitivity created by cultural groups
- Mandate ANTI-racist/homophobia training and examination of both covert and overt sources of bias

Data Collection

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- It is **not possible to fully characterize care** that is received over the lifespan and even when data are collected, they are not integrated, federated and readily available. This can cause issues of data integrity and duplication.

- The data collection system has **insufficient data that addresses health equity** issues by characterizing the care of persons from traditionally marginalized, racialized and vulnerable communities with multiple comorbidities.

- The type and amount of data collected across each sector of care should be expanded, with particular attention to the community sector and integration of administrative datasets with other data holdings to create a set of **common data elements**.

Data Indicators

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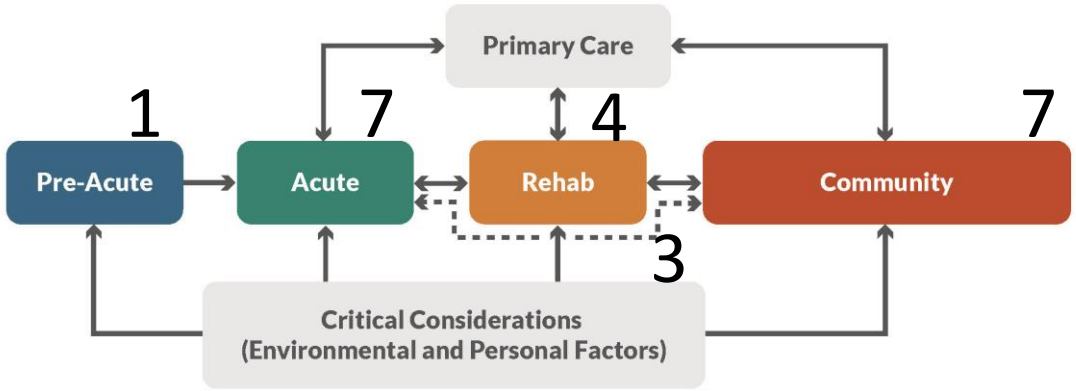
67 Indicators

- Across all stages of care in the Ideal Care Pathway

22 Core Set

- Prioritized as essential to implement

12 are ‘new’



- 10 indicators are already being collected
- 3 indicators need better collection
- 9 indicators need to be developed

Next Steps – Pathways of care

Neurotrauma Care Pathways

- ✓Tailor the Ideal Pathways to specific disadvantaged/marginalized groups

- ✓Provide OHTs/regions with specific guidance to tailor to regional realities

- ✓Continue to engage 3rd party funders, lawyers and government to develop effective mechanisms for integration of care across the different funding mechanisms

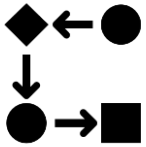
- ✓Create implementation tools for health care providers, patients and family/caregivers, funders and lawyers

- ✓Plan for a larger-scale implementation phase in order to influence practice

Next Steps (data)

In order to effectively evaluate the quality of care provided to persons after neurotrauma, the proposed set of Data Indicators should be refined and implemented in Phase 2 with a focus on:

1. Creating operational definitions that can be applied and supported across funding mechanisms



2. Implementing data sharing platforms to reduce duplication and increase the amount of information that is available to all healthcare providers

3. Enacting policy support and directions for data collection across the continuum of care, particularly in the community

4. Collecting data to understand health equity and variations in care across the whole population

5. Developing training materials to support the implementation of core set of indicators

Implementation

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Pre-Exploration: Phase 1

Exploration

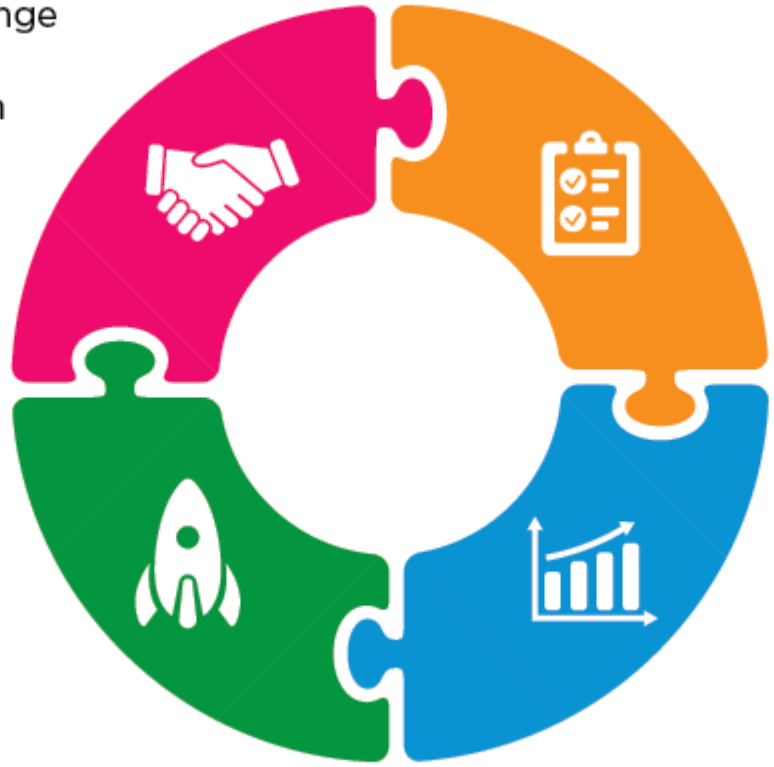
Stage 1: Engage and explore

- Define what needs to change and for whom
- Select and adopt program or practice
- Set up an implementation team
- Assess readiness; consider barriers and enablers

Installation

Stage 2: Plan and prepare

- Choose implementation strategies
- Develop an implementation plan
- Decide how to monitor implementation quality
- Build readiness to use program or practice



Stage 4: Sustain and scale

- Sustain the program or practice, embedding as 'business as usual'
- Scale-up the program or practice

Stage 3: Initiate and refine

- Start using the program or practice
- Continuously monitor and improve

Full Implementation

Initial Implementation

https://aifs.gov.au/cfca/publications/guidelines/implementation-action

Who is needed?

- We have already been ‘Engaging’ and ‘Exploring’ but there is more needed before we can proceed to Stage 2

- We need to actively integrate local, regional and provincial perspectives into the work

- We need to make sure we understand all the drivers – financial, clinical, structural, organizational, personal….

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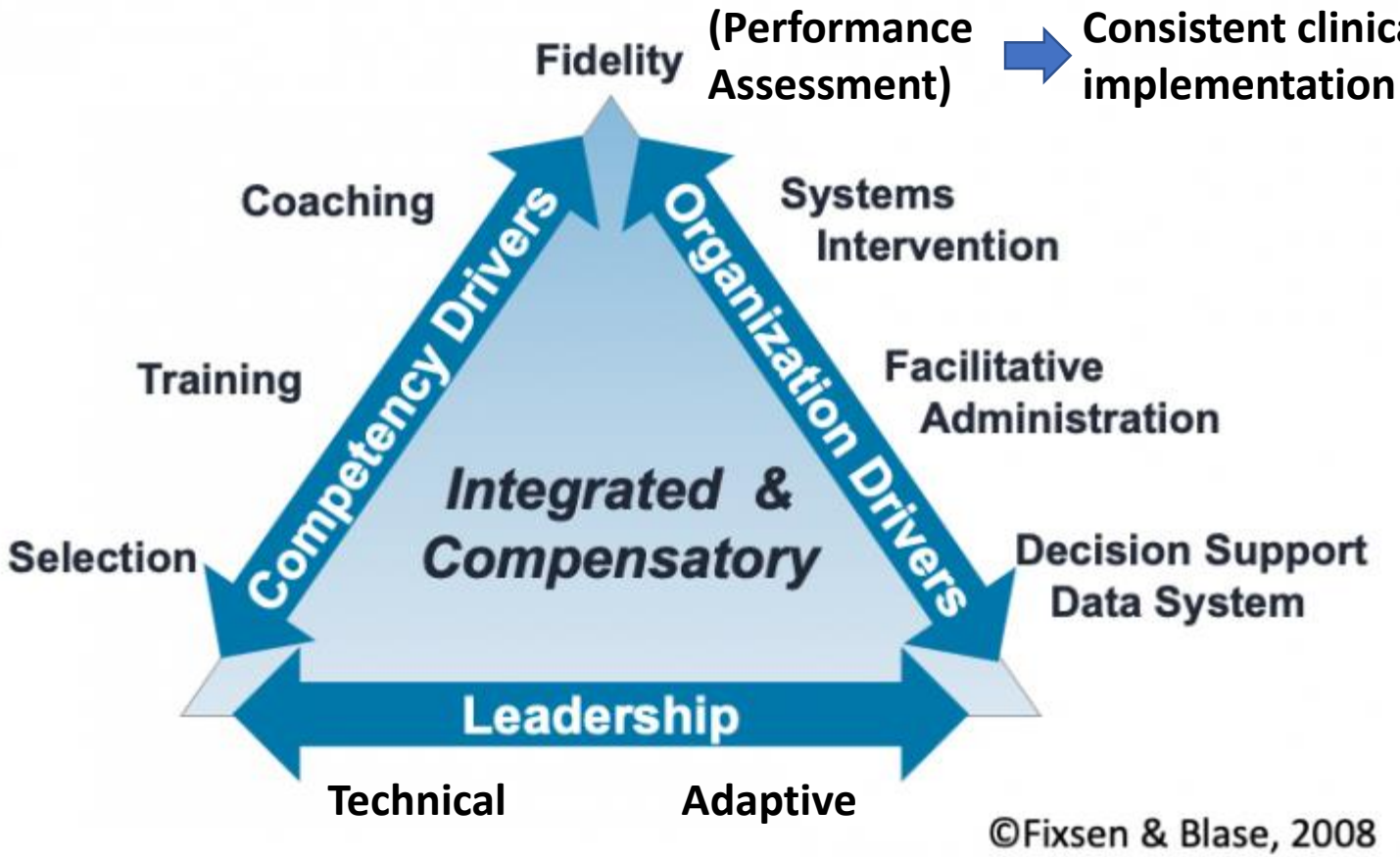
Implementation Drivers



(Performance Assessment) → Consistent clinical implementation → Improved Outcomes

Without developing a plan encompassing all these drivers in the both *internal* and *external* environments there will be

NO SUSTAINABLE CHANGE

Some contradictions

- People think being fast is easy and efficient; people are in a rush to change, and planning feels too bureaucratic

- The ON Ministry of Health wants substantive progress by March 31, 2023; Implementation Science research says it will take 2-4 years

- It will be hard because if it was easy, it would have been done already; there are lots of competing interests

Panel discussion

Anita Kaiser,
Person with lived experience of SCI

Cathy Halovanic,
ABI Navigator

Viivi Riis,
Insurance Bureau of Canada

Judy Gargaro,
Manager Pathways Project

Mark Bayley,
Program Medical Director,
UHN-Toronto Rehab Institute

Audience Participation

- You can ask questions and provide answers by using Slido

- We will integrate as much of your comments into the live discussion as we can, but we will have a record of your comments if we are not able to address them in the session

https://app.sli.do/event/bg38FbQHmEFz9wZWTTJb3t

Event code: 2582749

Questions

- What are the opportunities to capitalize on for implementation?
- What are the challenges we face in implementation?
- What we can we accomplish in 1 year (the low hanging fruit)?
- Who are the key partners to engage in implementation?

Policy Recommendations

Neurotrauma Care Pathways

- ✓Policy support and directives for **appropriate screening and referral** using standardized and documented tools
- ✓Policy support and directives for **follow-up in the community** by primary care in collaboration with specialized rehabilitation professionals to minimize secondary complications and unplanned and inadequate use of the healthcare system
- ✓Mechanisms for linking and coordination at each stage of care, ensuring that there **are clear hand-offs and communication (written, verbal and online) about needed next steps**
- ✓**'Right-sized' community-supports to account for greater demand for service than turnover allows; in particular, residential and supported independent living capacity should be increased to reduce pressure on long-term care and Alternate Level of Care**

Next Steps

Neurotrauma Care Pathways

- Develop regional adaptations to facilitate implementation
- Make adaptations to ensure traditionally marginalized groups are properly included in the pathways
- Ensure that the need and timing for cross-sector partnership are clearly identified in the Pathways
- Collaborate with all funders to develop systemic implementation and policy support and directives
- Collect and present data for a core set of quality indicators to evaluate system performance

Longer term plan…..

- Show the ON Ministry of Health that there:
  - are possibilities within the existing system to standardize
  - is support for the Ideal Pathway
  - is willingness to collaborate across the continuum of care and sectors
  - is broad engagement in implementation planning and activities
  - is willingness to collect and share meaningful data across funders/sectors
- **Neurotrauma is a chronic condition that needs to be treated like other chronic conditions**

- needs a provincial strategy that encompasses navigation and access to specialized clinical services/community supports
  - needs fair billing codes
  - needs meaningful integrated data collection

Contact Information

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