UHN Toronto Rehabilitation Institute
The KITE Research Institute

Neurotrauma Care Pathways

How Far Are We From Achieving A+ Care? Evaluating Care After TBI Through the Provincial Report Card

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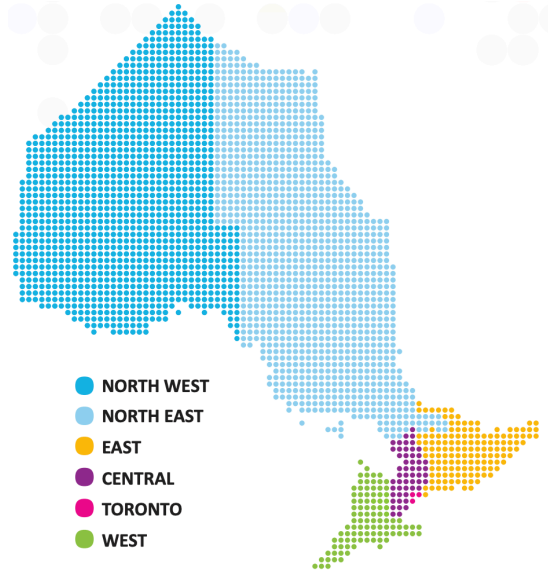

Vista Centre Brain Injury Awareness Day
June 14, 2023

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Land Acknowledgement

We acknowledge the sacred land on which the University Health Network operates. For thousands of years, it has been the traditional territory of the Huron-Wendat, the Haudenosaunee, and most recently, the Mississaugas of the Credit River.

This territory was the subject of the Dish With One Spoon Wampum Belt Covenant, an agreement between the Haudenosaunee Confederacy and the Confederacy of the Ojibwe and allied nations to peaceably share and care for the resources around the Great Lakes.

Today, the meeting place of Toronto is still the home to many Indigenous people from across Turtle Island and we are grateful to have the opportunity to work and learn on this territory.

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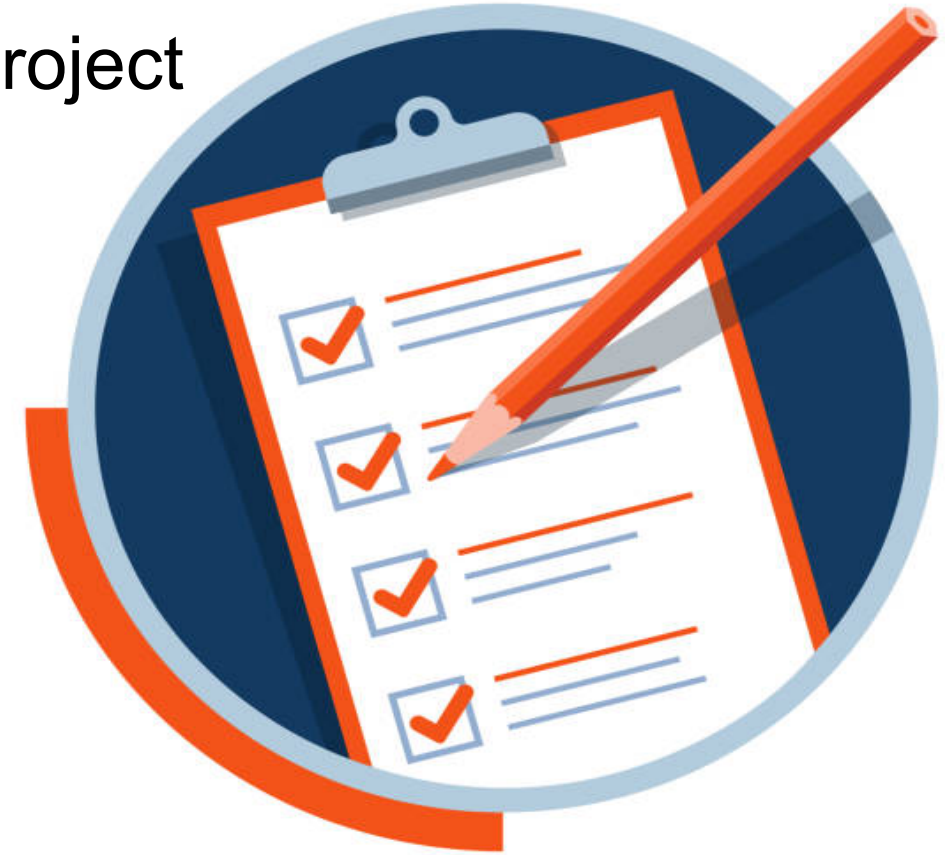
Objectives

- Understand the rationale and process behind the TBI Report Card
- Highlight key findings from the administrative healthcare data (provincial and Champlain) and supplementary surveys
- Discuss the significance of the data, current data gaps, and the future of the report card

Agenda

1. The Neurotrauma Care Pathways Project
2. Why TBI Report Cards?
3. TBI Report Card Process
4. Provincial and Regional-level Data
5. Provincial Survey Data
6. Conclusions



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The Larger Context of this Work

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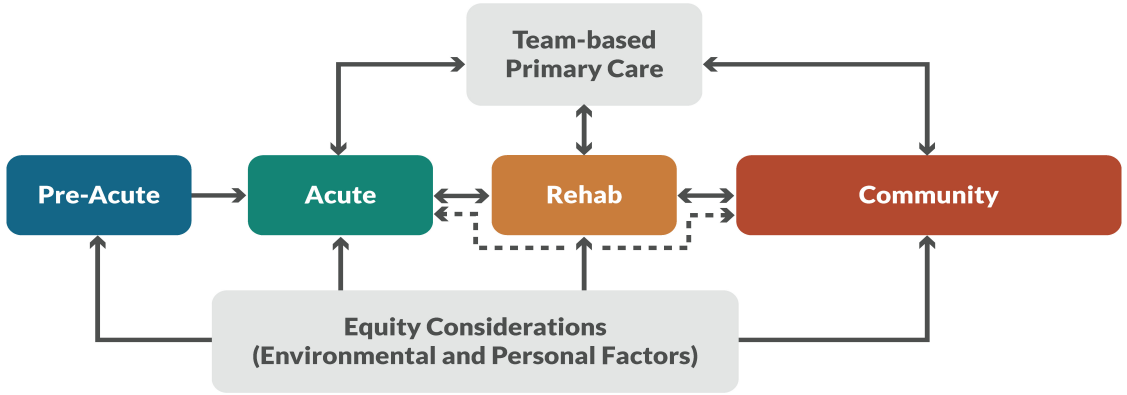
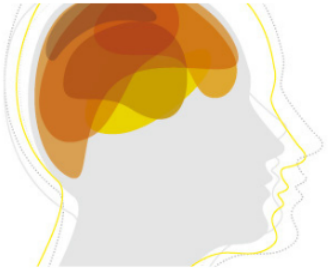
What we have done to date:

- Funded by the Ministry of Health, the Neurotrauma Care Pathways Project is a novel system-level initiative to develop injury-specific chronic care models for neurotrauma
- Over 100 diverse partners were engaged across the province to inform the development of a TBI Care Pathway, identify current gaps along the continuum of care, and develop novel quality indicators to evaluate pathway adherence
- Additional Focus Groups were held for people with lived experience to share their insights and concerns, which were made a priority to incorporate into the models



TBI Living Guidelines



CANADIAN
CLINICAL PRACTICE GUIDELINE
FOR THE REHABILITATION OF ADULTS
WITH MODERATE TO SEVERE TBI

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- The Canadian TBI Guideline was designed to provide evidence-based recommendations for the rehabilitation of adults having sustained a moderate to severe TBI

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Background: Traumatic Brain Injury (TBI)

- Traumatic Brain Injury (TBI) is a **chronic** disease condition that continues to evolve years after initial injury
- TBI can cause complex cognitive, behavioural, and physical changes with various long-term negative impacts
- However, we know very little about the current landscape of care and how to improve it
- **How can we evaluate the system and identify key gaps to drive improvements across the care continuum?**

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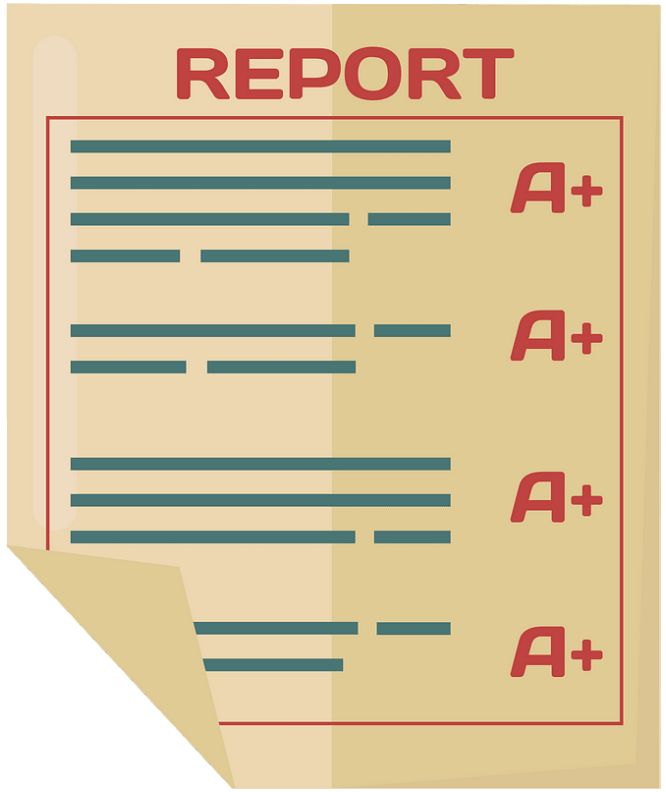
Why Report Cards?

- A trip down memory lane…



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TBI Report Cards Allow Us To:

- **Evaluate** the current state of TBI care by measuring care quality and equity at provincial and regional levels
- **Identify** opportunities for system improvement through quality indicators that call attention to challenges and gaps across the care continuum
- **Highlight** inequities in care related to the social determinants of health, such as income, marginalization, rurality etc.
- **Provide** data to facilitate sharing of successes and learnings to inform services across Ontario

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The Power of Data

Without data there appears to be no need for change

No Data ≠ No Problem!

The Power of Data: A Poll (1)

Question: What percentage of people with mod-severe TBI in Ontario get access to specialized rehab?

a) >50%

b) 20-50%

c) <10%

Answer: Only 9.37% of people with mod-severe TBI were admitted to specialized rehab within 1 year of their injury (2016-2022 data) This percentage is even lower for older adults (65+)

The Power of Data: A Poll (2)

Question: What percentage of people with TBI are **not** followed up by a physician (GP or specialist) within 1-month of discharge from hospital?

a) >50%

b) 20-50%

c) <10%

Answer: 54.8% of people with TBI were not followed up by a GP or specialist within 30 days of hospital discharge (2016-2022 data)
This percentage is even higher for those living in rural areas

The Power of Data: A Poll (3)

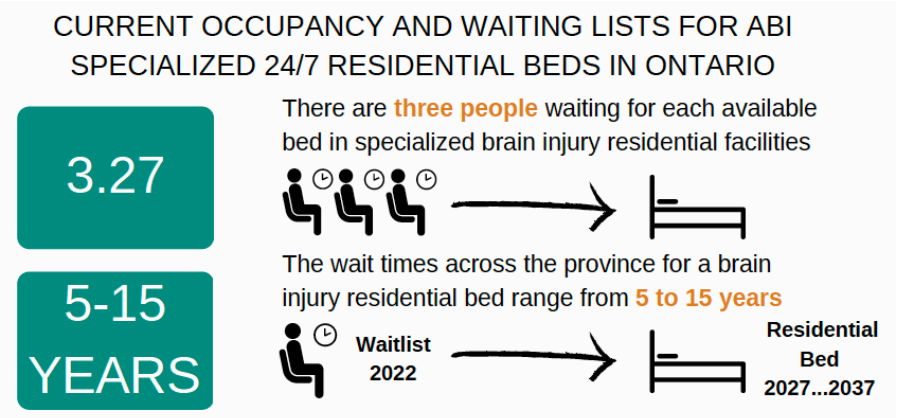
Question: What is the average time on a waitlist for TBI residential services (i.e., supportive housing)?

a) <6 months

b) 6 months to 2 years

c) 2-5 years

d) >5 years



Answer: Survey data from 8 programs across the province indicate that the average time spent on waiting list for TBI residential services is 7.4 years, with wait times as long as 15+ years

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What Does The Data Tell Us?

Improvement is needed across the care continuum!

The first step in improving care quality, equity, and access is identifying where the gaps are…

Without data there appears to be no need for change

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TBI Report Card: Data Collection and Reporting

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Data Sources

1. Majority of data from the report card comes from administrative databases (data reported to the government using OHIP numbers)
2. Rehab Supplemental Surveys
   a) General
   b) Specialized
   c) Neuro
3. Community Service Providers Supplemental surveys
   a) Publicly funded
   b) Third-party (Ontario Rehab Alliance)
4. Ontario Brain Injury Association (OBIA) impact survey

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Cohort Creation

mTBI/Concussion

No days in hospital

Complex-mild TBI

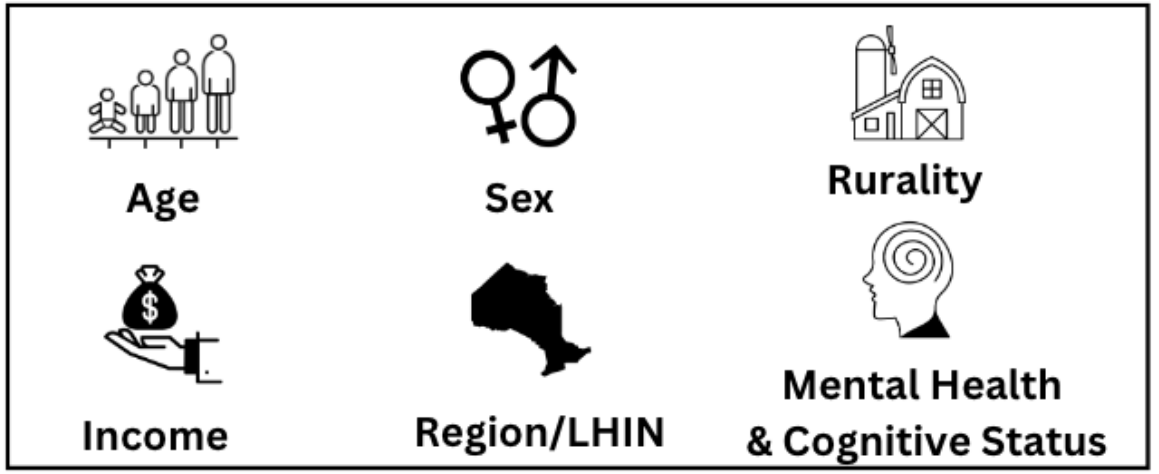
1-3 days in hospital

Mod-severe TBI

3+ days in hospital

Report Card Indicators

Stratifiers (How data is broken down)



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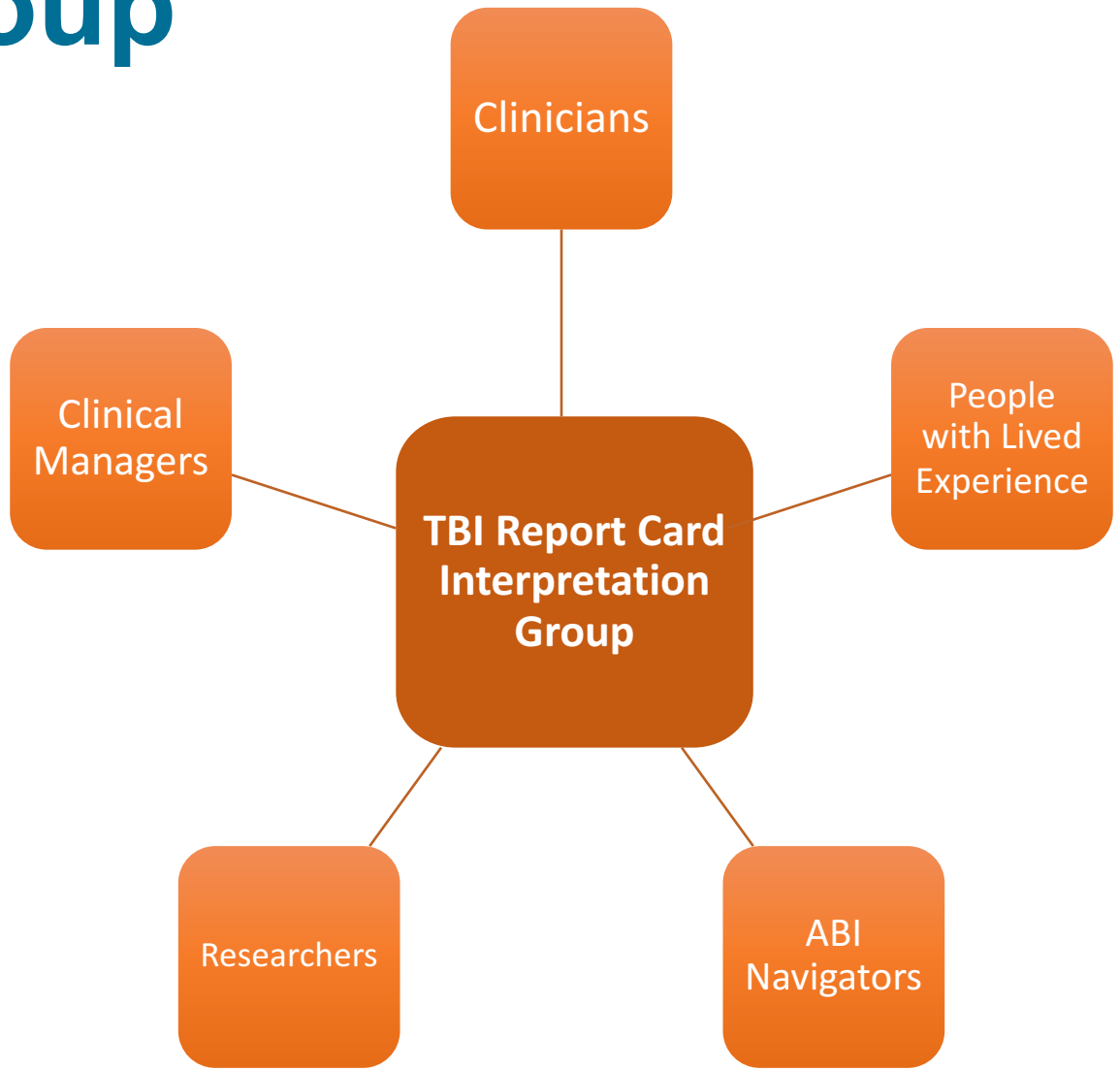
Indicator Summary Table

Indicator No.	Care Continuum Category	Quality Domain[1]	Definition
1	Prevention	Surveillance	Annual age- and sex-adjusted incidence rate per 1,000 population for a) moderate to severe TBI and b) concussion/mild TBI
2	Prevention	Surveillance	Risk-adjusted TBI mortality rate within 30 days of admission to hospital for TBI per 100 patients[2]
3	Acute management	Efficiency	Proportion of alternate level of care (ALC) days to total length of stay (LOS) in acute care
4	Acute management	Integration	Proportion of acute patients with TBI discharged from acute care and admitted to: a) specialized ABI inpatient rehabilitation and b) general inpatient rehabilitation
5	Rehabilitation	Efficiency	Median number of days from TBI onset and admission to inpatient TBI rehabilitation
6	Rehabilitation	Effectiveness	Median FIM change of: a) specialized ABI inpatient rehabilitation b) general inpatient rehabilitation Median FIM efficiency of: a) specialized ABI inpatient rehabilitation b) general inpatient rehabilitation
7	Rehabilitation	Access	Median time from discharge from acute care or inpatient rehabilitation to first Home and Community Care (HCC) visit for a) physiotherapy b) occupational therapy c) speech language pathology d) social work
8	Rehabilitation	Access	Median number of HCC visits within 60 days of discharge from acute care or inpatient rehabilitation for a) physiotherapy b) occupational therapy c) speech language pathology d) social work
9	Reintegration	Access	Proportion of patients with TBI discharged from inpatient rehabilitation with a follow-up assessment within 30, 180 and 365 days by a a) general practitioner/family practitioner (any reasons) b) general practitioner/family practitioner (mental health reason) c) specialist (physical medicine, neurosurgeon, neurology) d) specialist (psychiatry) e) no general practitioner/family practitioner or specialist follow-up assessment
10	Reintegration	Access	Proportion of patients with TBI discharged from acute care to a) complex continuing care (CCC) b) long term care (LTC) (excluding patients originating from LTC/CCC)
11	Reintegration	Integration	Age- and sex-adjusted all-cause readmission rate at 30 days for patients with TBI per 100 patients
12	Reintegration	Integration	Total number of patients with TBI discharged from in patient rehabilitation to a) complex continuing care (CCC) b) long term care (LTC) (excluding patients originating from LTC/CCC)

Surveillance: 2
Efficiency: 2
Integration: 4
Effectiveness: 1
Access: 4

Interpretation Group

- **Once the data is received, a diverse group of key partners come together for analysis and interpretation**



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Provincial Indicator Data

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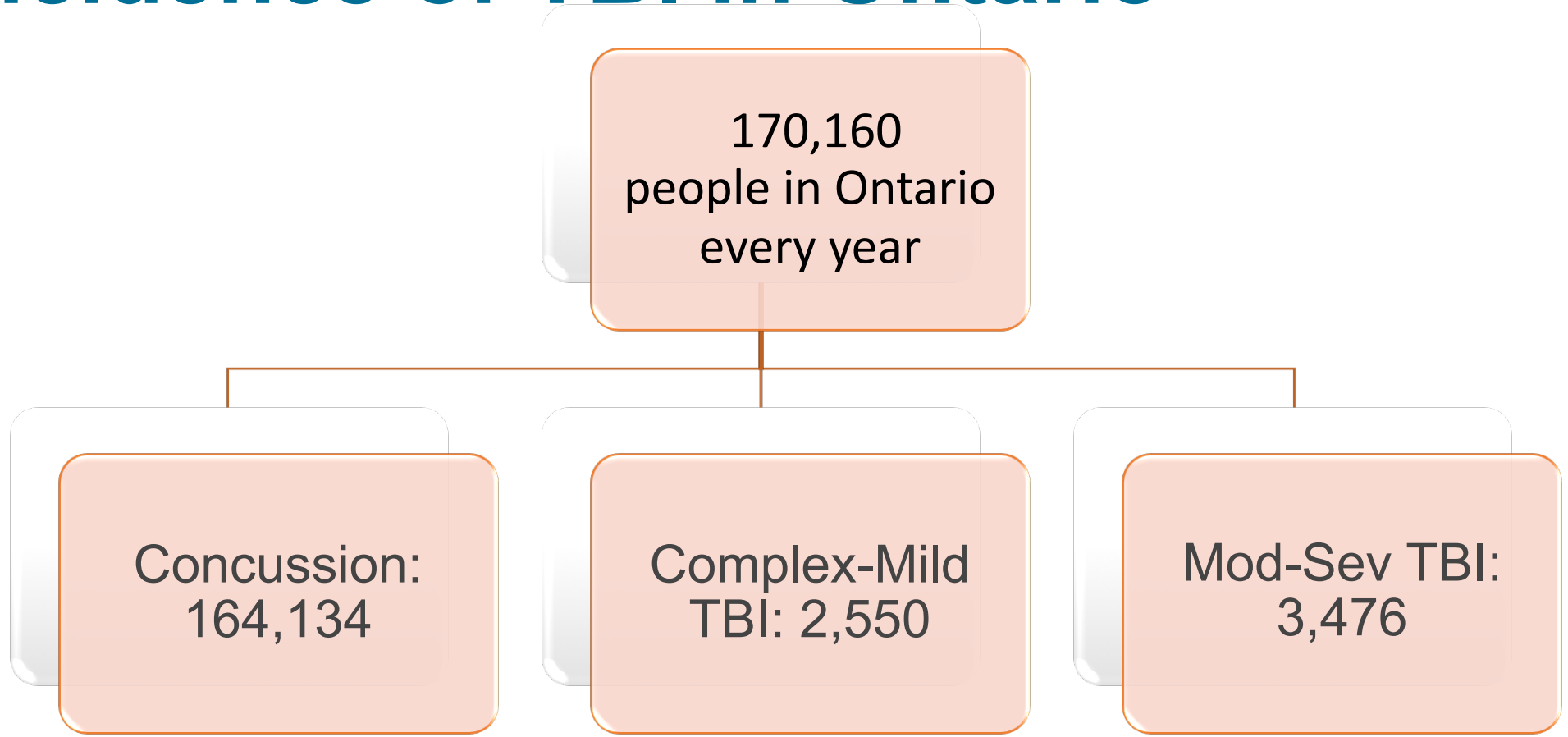
Incidence of TBI in Ontario



TBI Incidence Rate: Age

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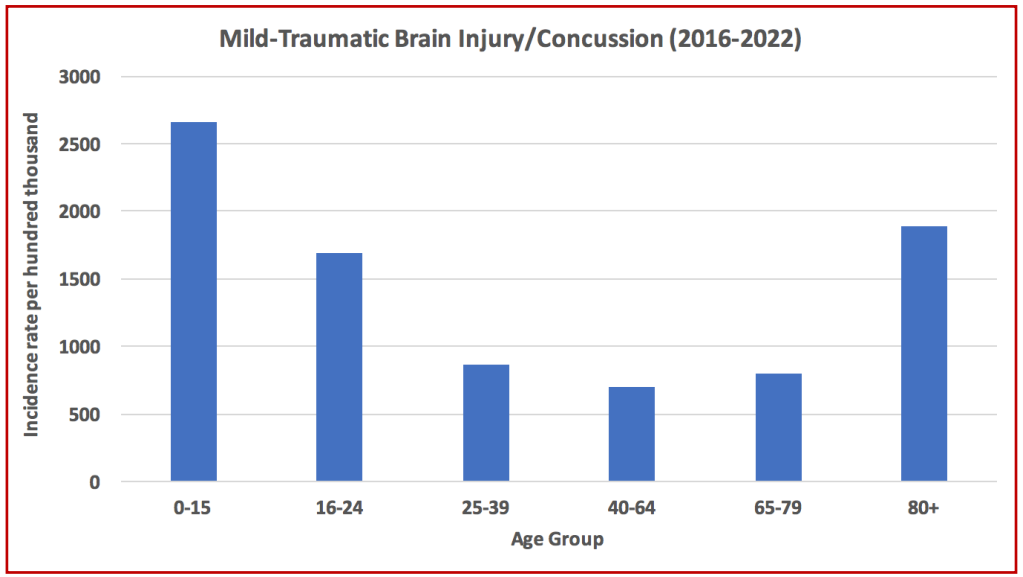

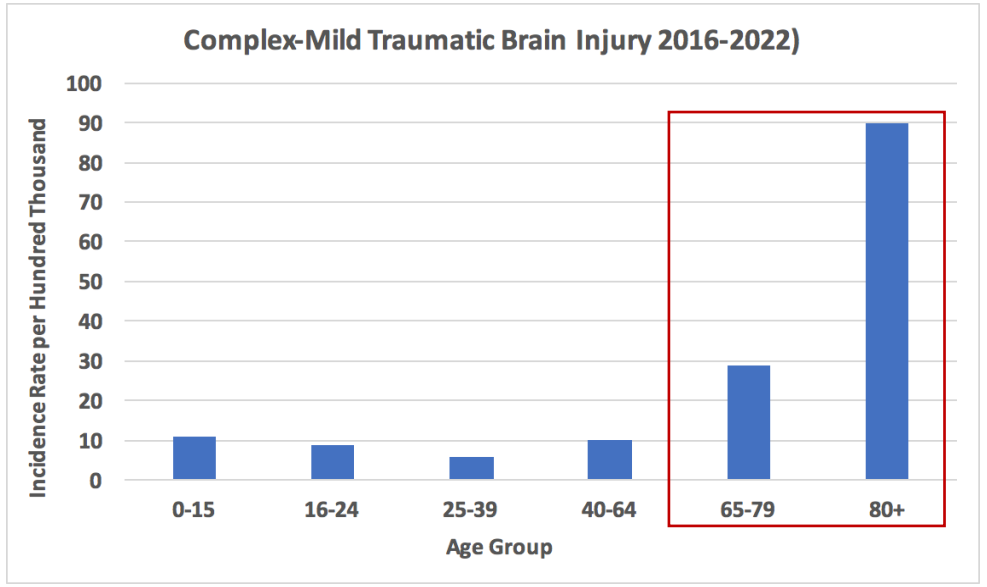

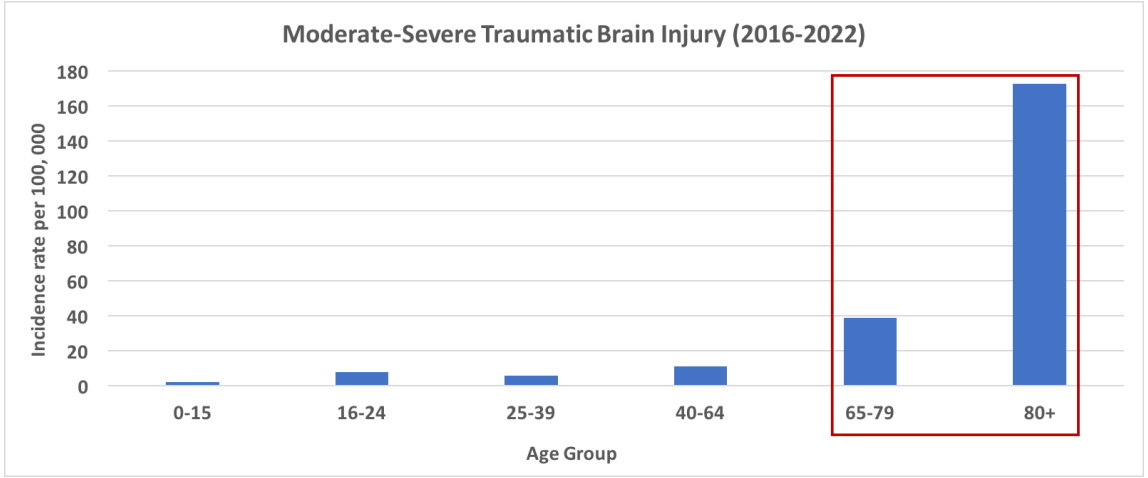

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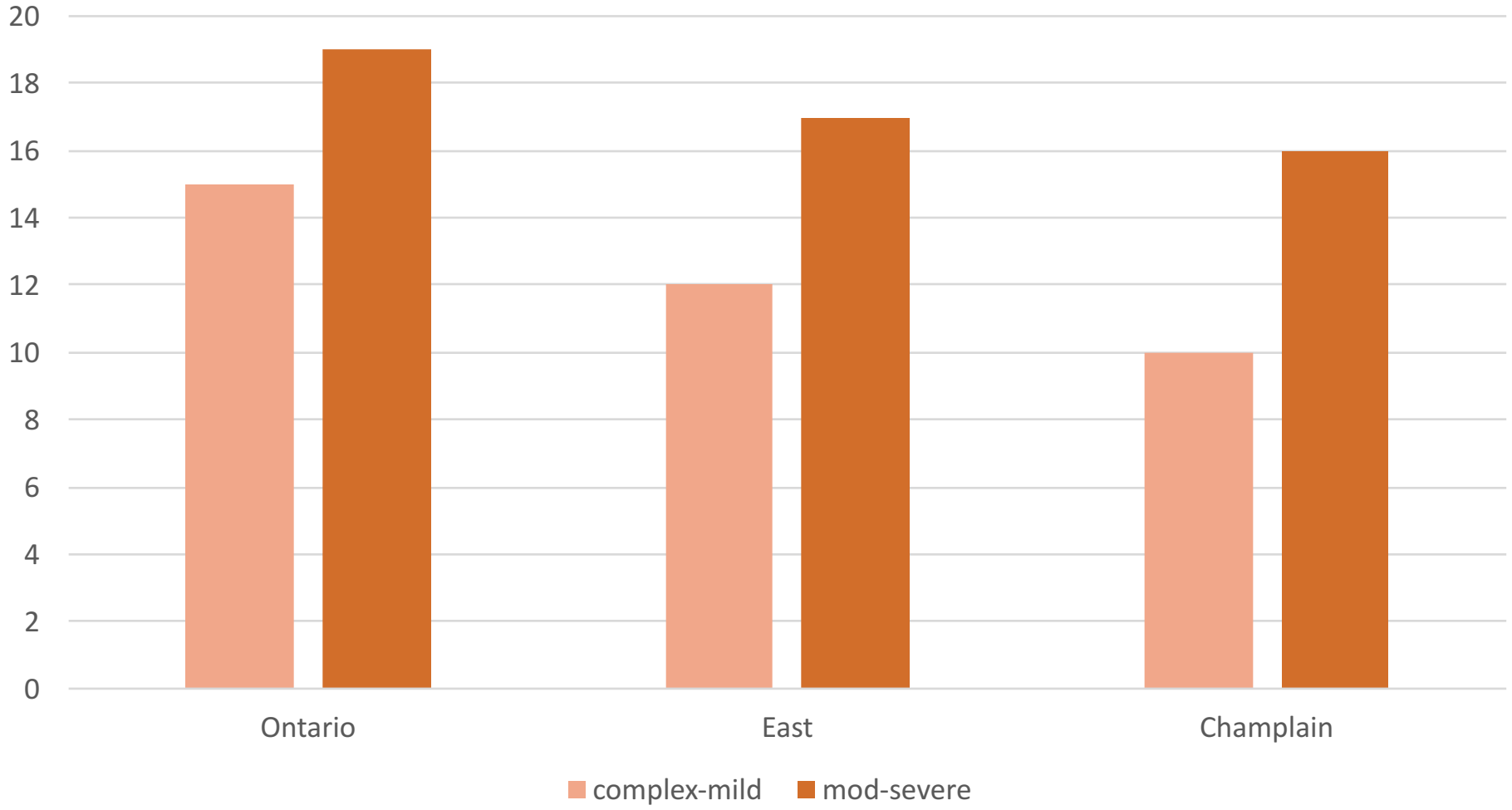
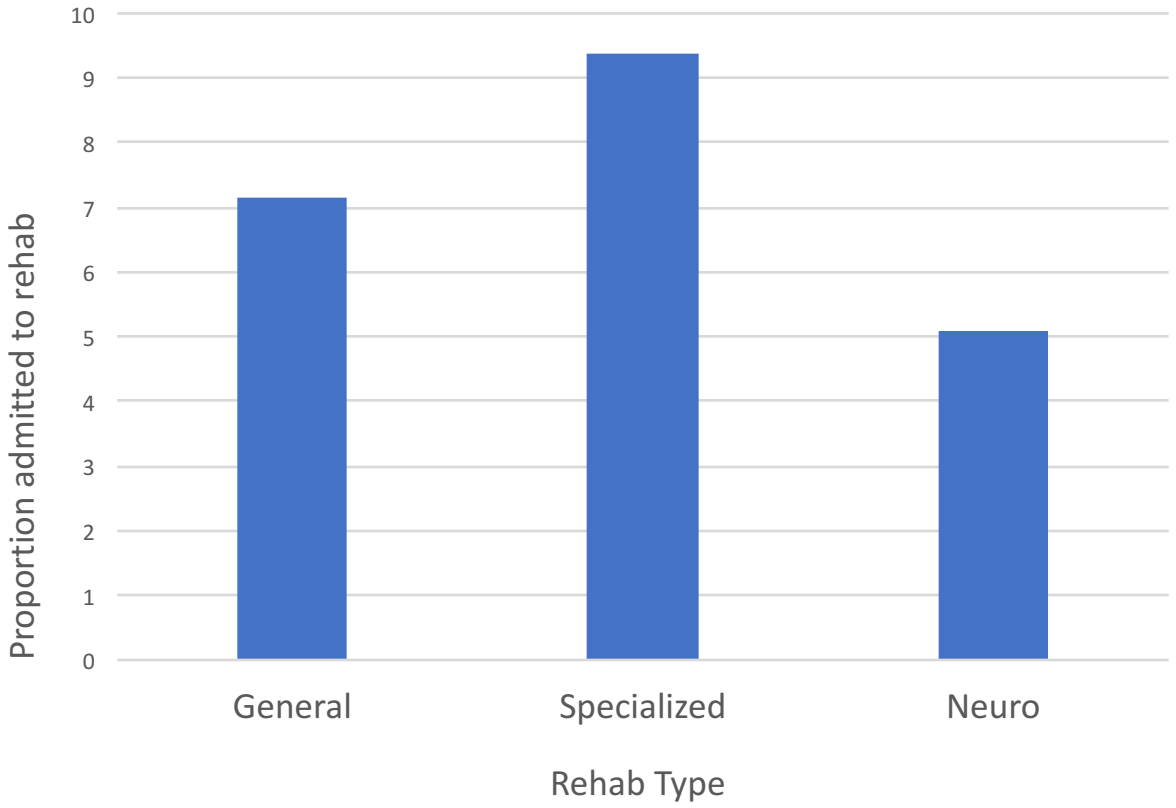
Incidence Rate of TBI: Champlain



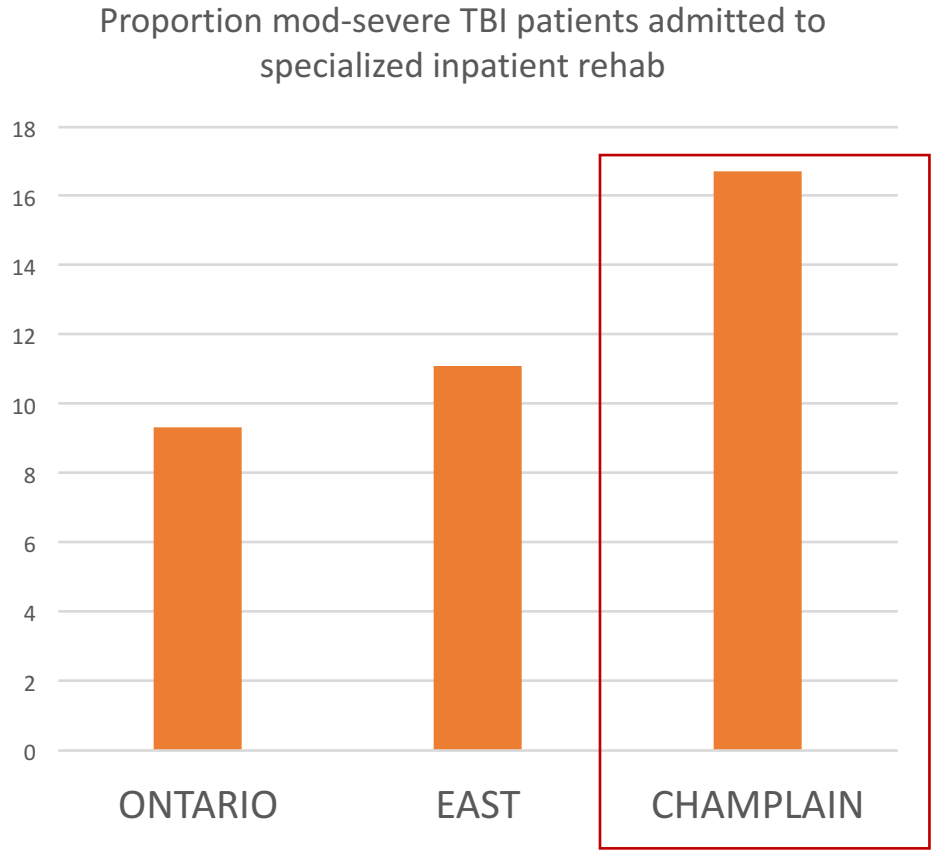
Access to Rehab (Mod-severe TBI)

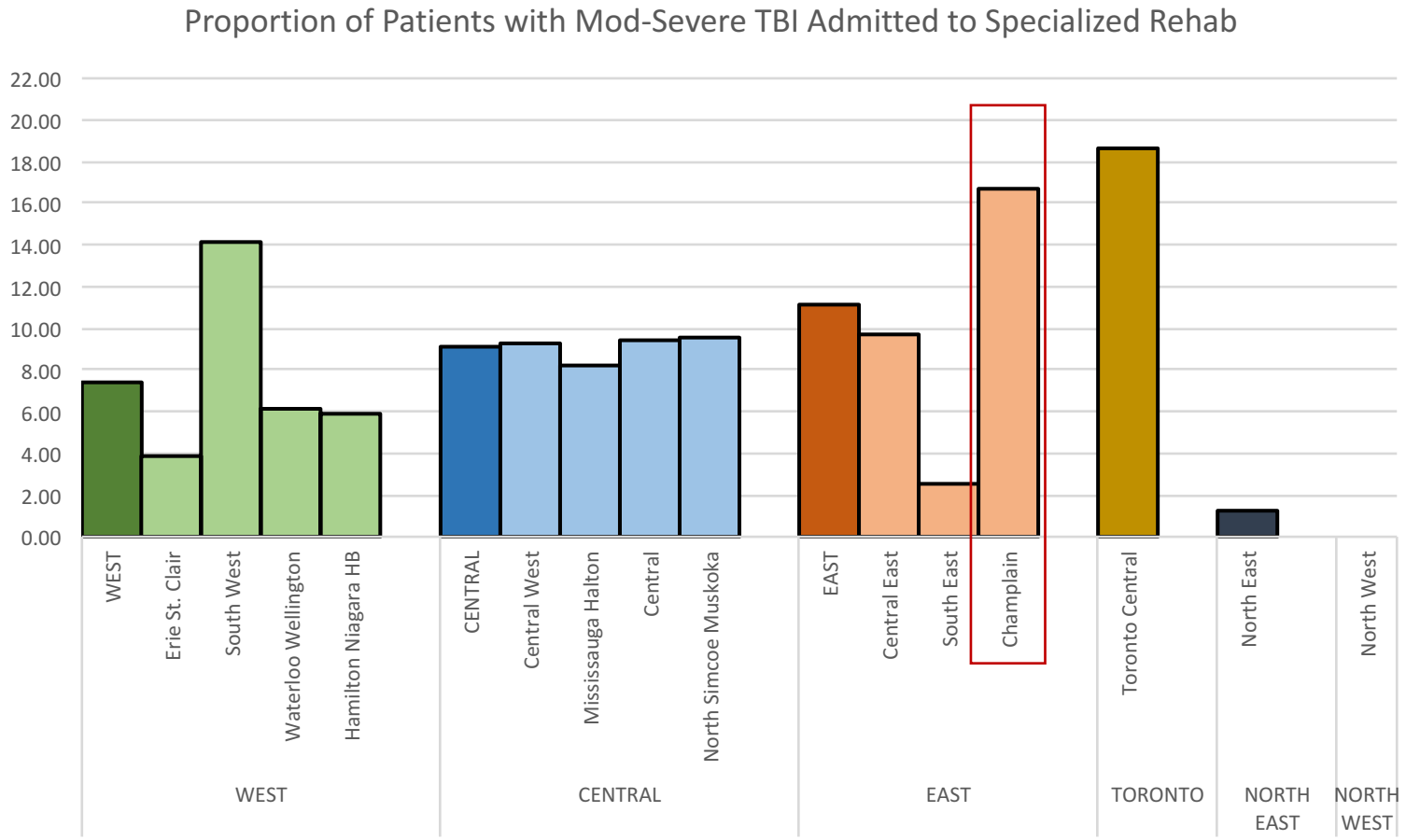


Only about 21% of people with mod-severe TBI access rehab within one year of their injury

- General Rehab – 7.14%
- Specialized Rehab – 9.37%
- Neuro Specialized Rehab – 5.07%

Access to Rehab - Champlain





Access to Rehab: A Focus on Older Adults

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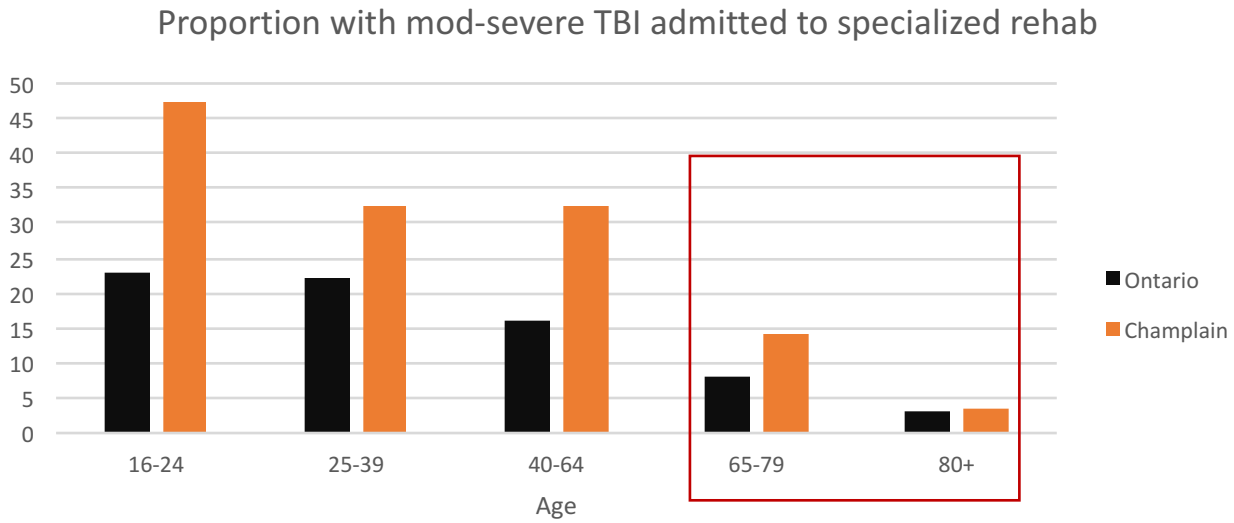
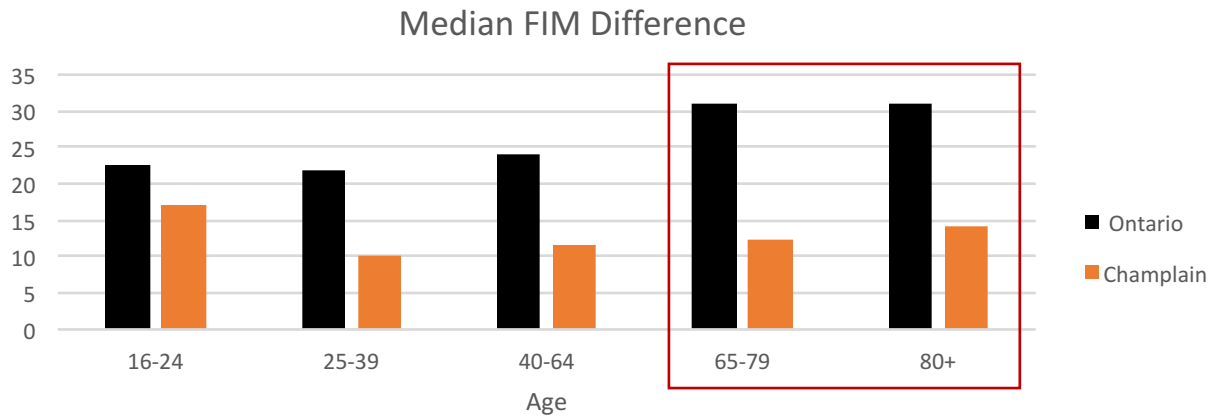


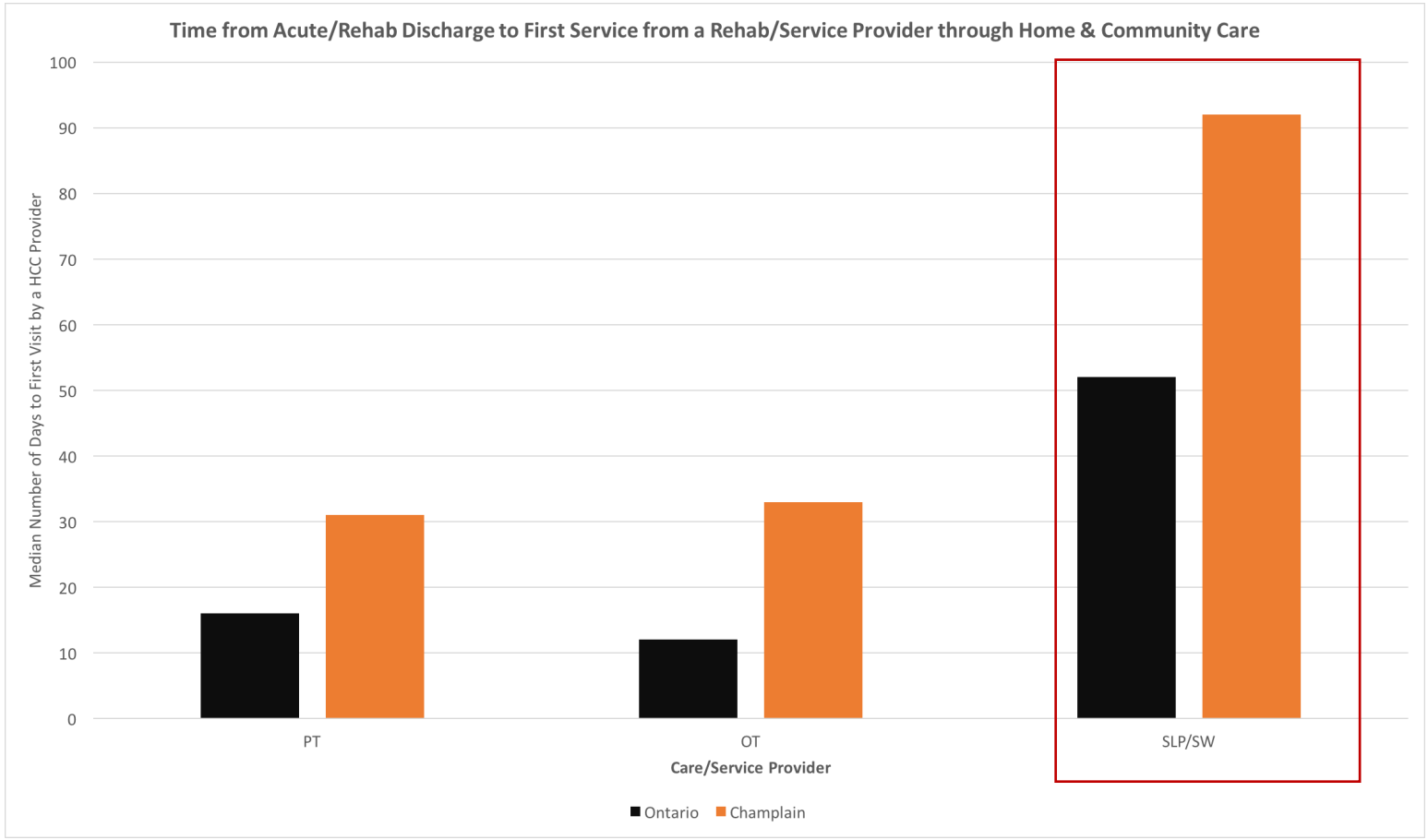


- Older adults (65+) access specialized inpatient rehab at a lower rate than any other age group, despite having highest incidence of severe injuries
- This is true at the provincial level and in Champlain

Despite making similar functional gains as younger patients, a smaller proportion of older adults are admitted to specialized inpatient rehab

Specialized TBI services are needed to support newly diagnosed seniors as well as people aging with TBI

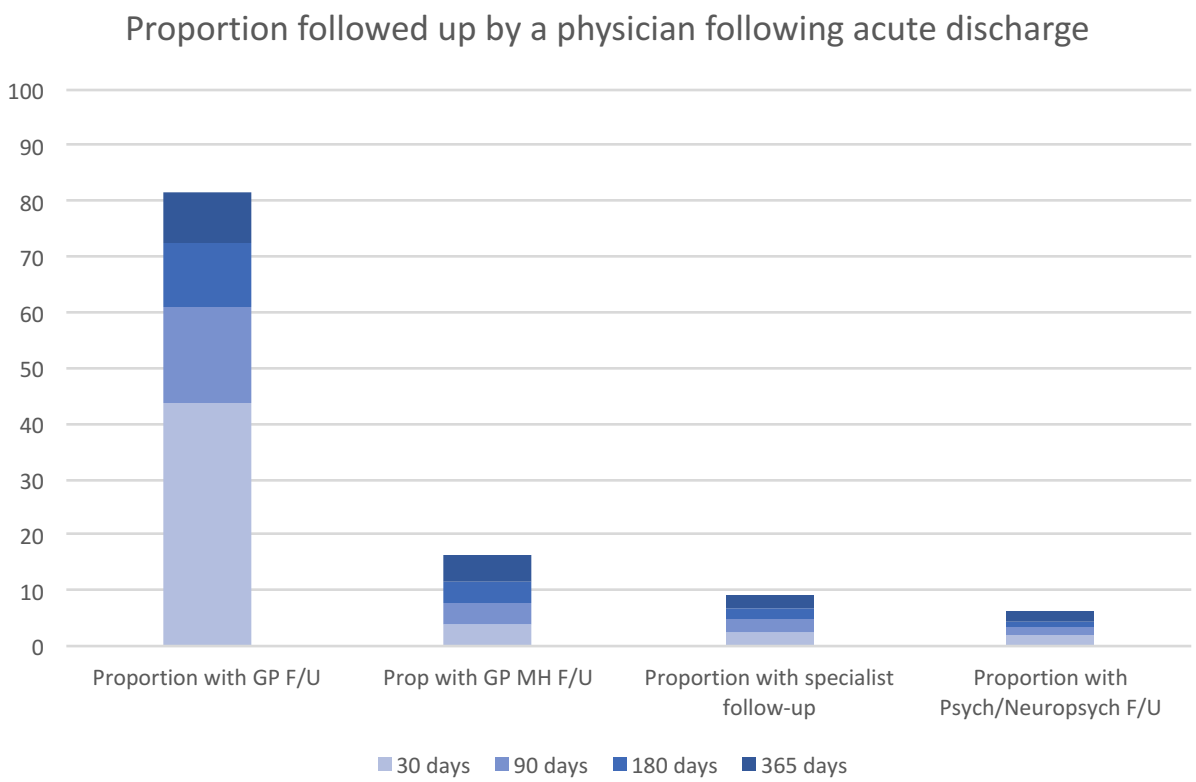
Time to First Rehab Provider Visit from Home and Community Care

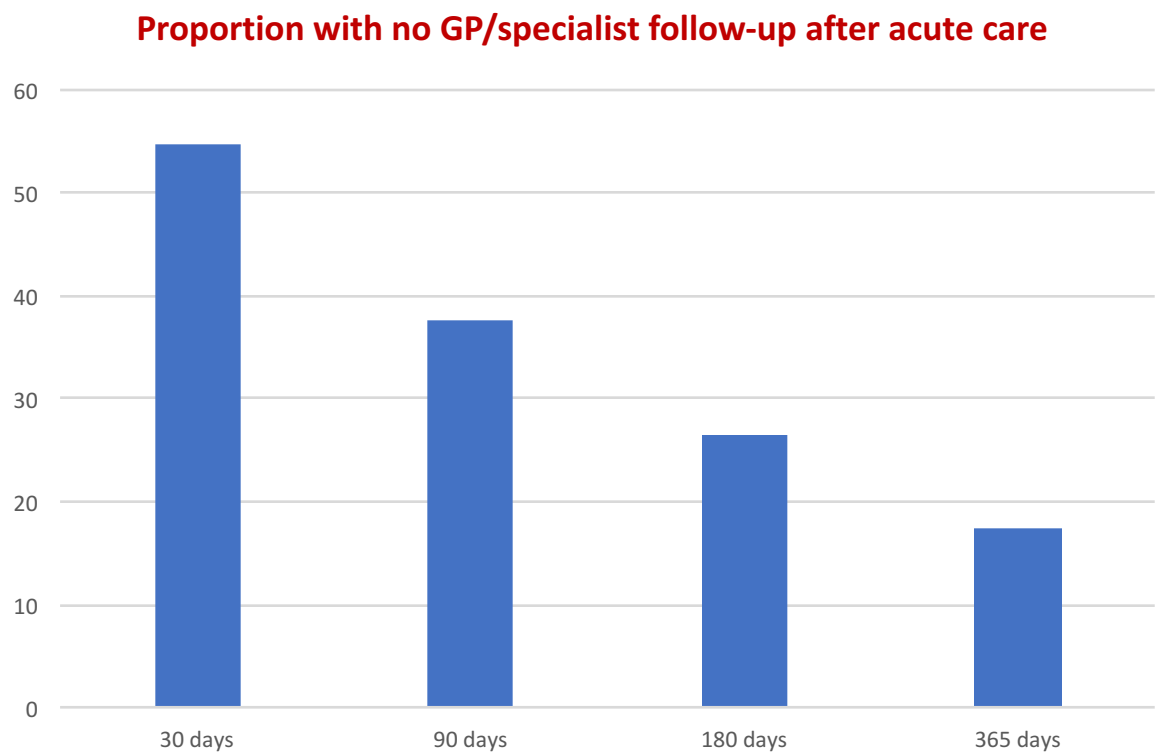


It takes roughly **2-4 weeks** to receive a visit from a physiotherapist or occupational therapist provided by Home and Community Care

It can take **3 months** to receive first SLP/SW visit

Physician Follow-up in Community





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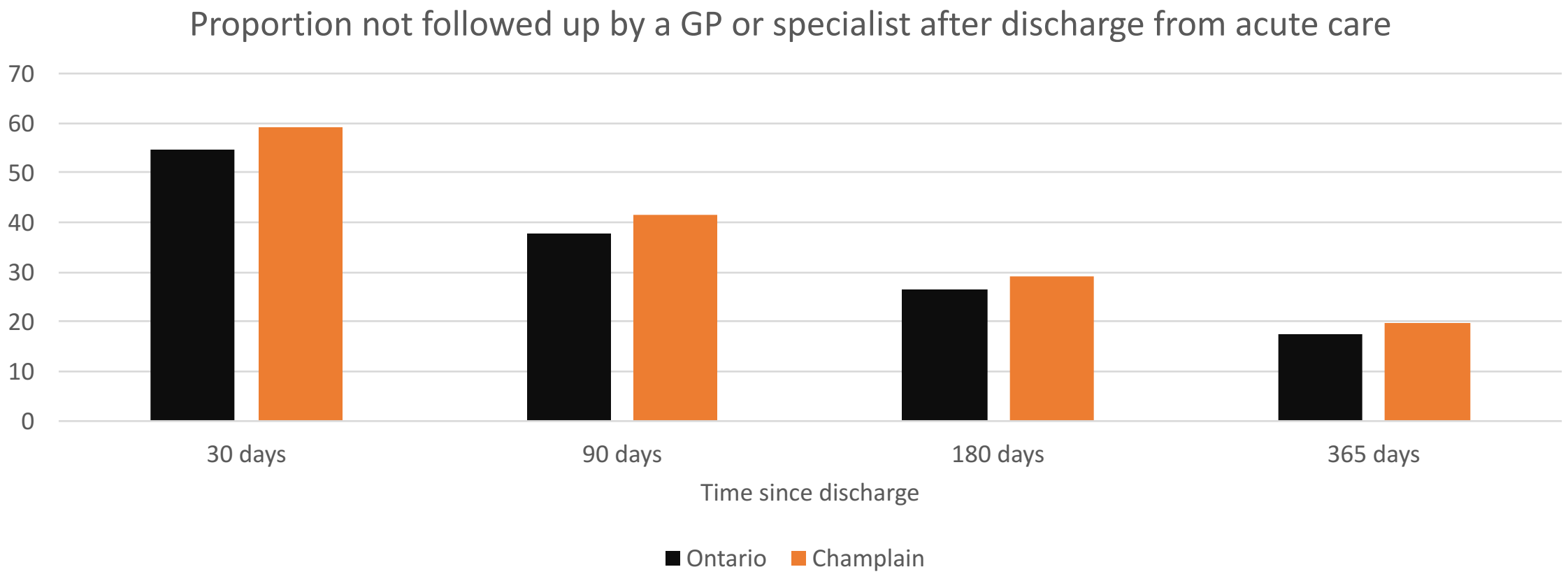
Physician Follow-up: Champlain



Discharge to non-rehab settings

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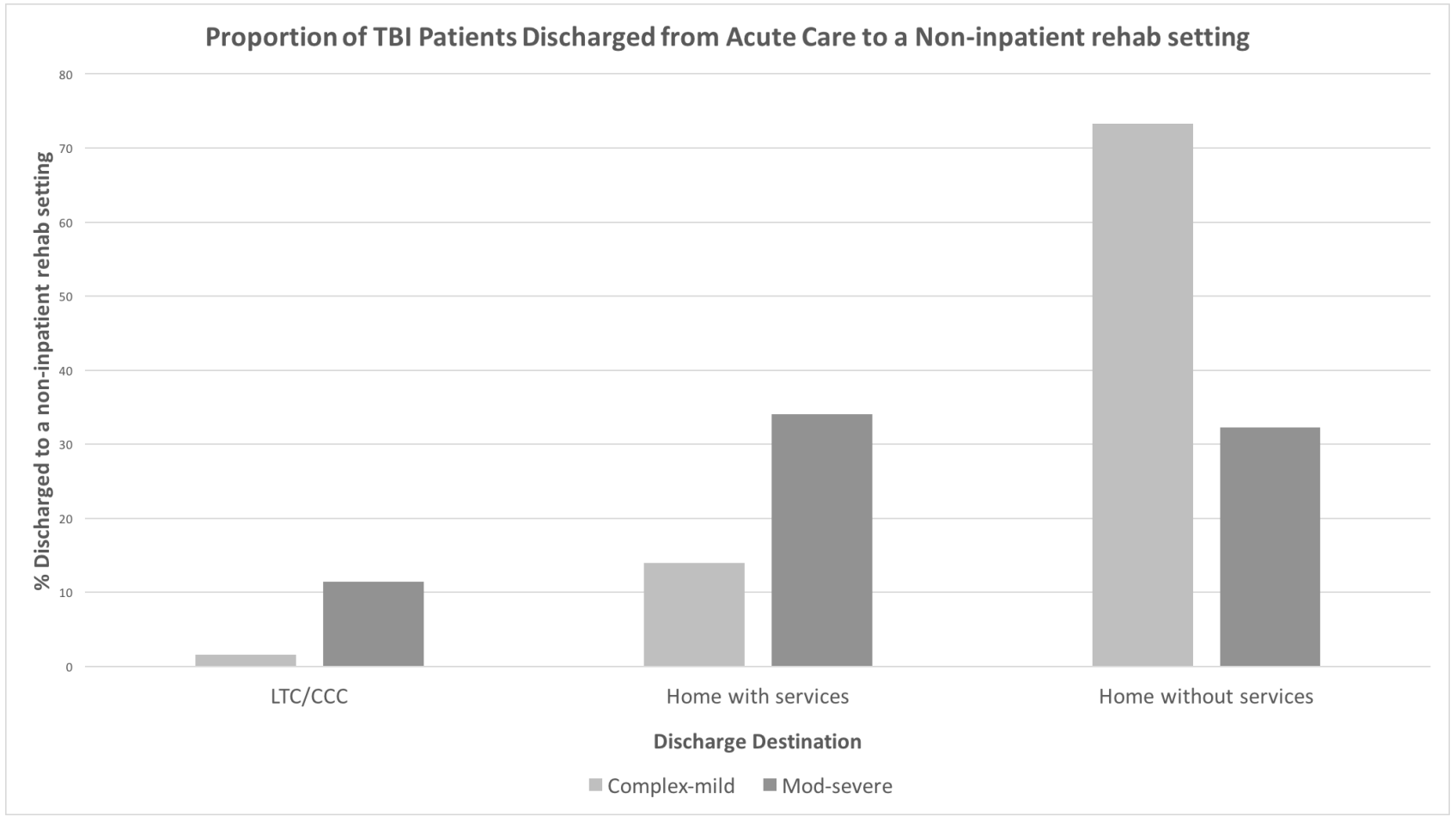

30% of people with mod-severe TBI are discharged home without services

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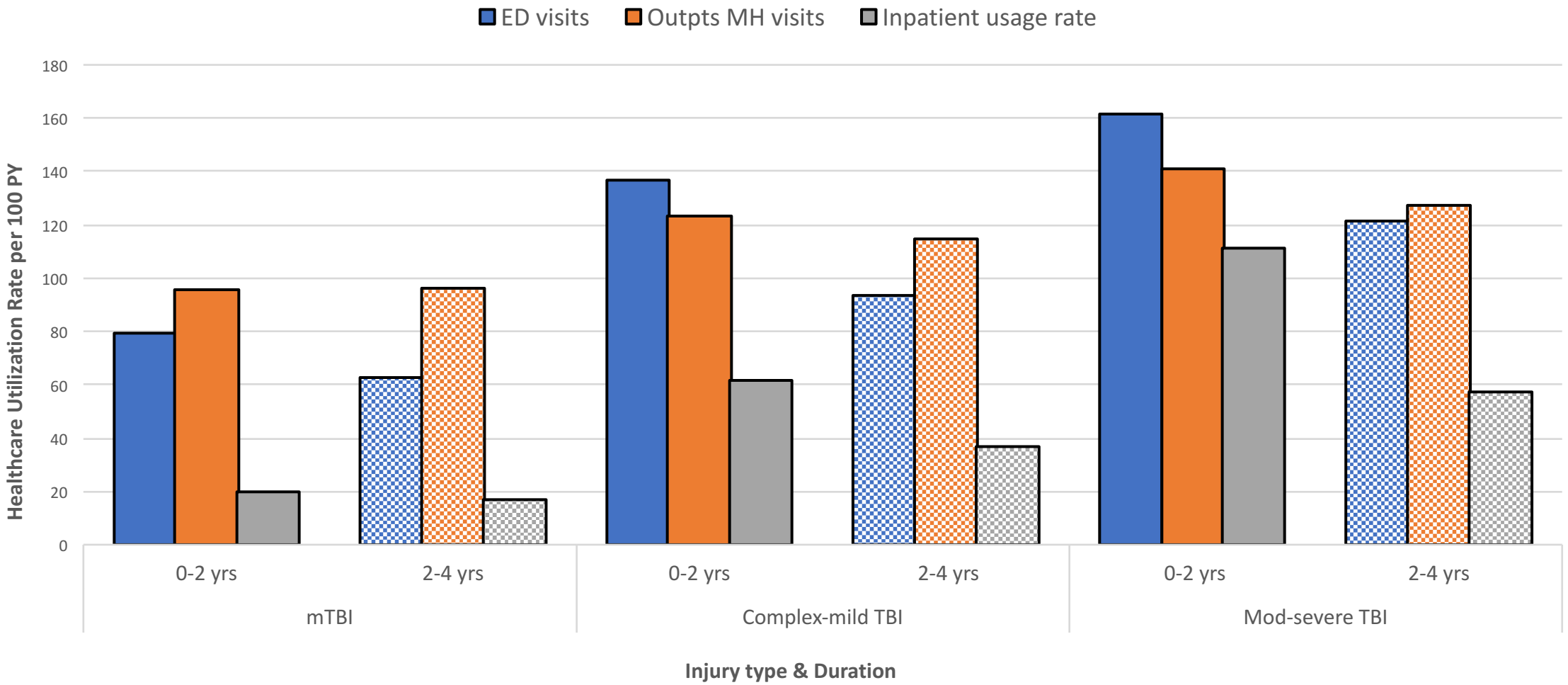
Healthcare Utilization



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Key Takeaways from Data

- TBI is a common condition in Ontario requiring ongoing care and support beyond acute and rehab stays
- Overall, there is a small percentage of people with TBI getting **specialized rehabilitation**, especially when it comes to older adults (65+) and people aging with TBI
- Once discharged to the community, there is a lack of consistent and timely follow-up and care (in general)
- There is a need to increase the availability of mental health supports and improve access to mental health services among people with TBI

Key Takeaways from Champlain Data

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No.	Indicator	Champlain 2020/21		East Region 2020/21		Ontario 2020/21	
5	**Median # of days (IQR: interquartile range) from TBI onset to admission to:**						
	a) general inpatient rehabilitation	14 (8-58)		9 (6-19)		11 (8-22)	
	b) specialized ABI inpatient rehabilitation	45 (26-63)		39 (19-59)		24 (12-44)	
6	**Median FIM change of:**						
	a) general inpatient rehabilitation	19.0		25.0		23.0	
	b) specialized ABI inpatient rehabilitation	15.5		23.0		27.0	
	Median FIM efficiency of:						
	c) general inpatient rehabilitation	1.0		1.3		1.3	
	d) specialized ABI inpatient rehabilitation	0.5		0.8		0.9	
7	**Median number of days (IQR: interquartile range) from acute care to first HCC visit for:**						
	a) physiotherapy	22 (8-75)		18 (7-52)		14 (6-49)	
	b) occupational therapy	18 (8-62)		13 (5-58)		10 (4-41)	
	c) speech language pathology/social work	18 (4-186)		38 (11-164)		63 (14-159)	
8	**Proportion of patients with TBI (%) discharged from acute care (no rehab) with a follow-up assessment within 30 days and 180 days by a:**	**30 days**	**180 days**	**30 days**	**180 days**	**30 days**	**180 days**
	a) GP/FP (any reason)	64.0	81.2	69.5	87.2	71.7	87.2
	b) GP/FP (mental health-related reason)	4.4	12.4	6.2	16.1	8.4	19.2
	c) Specialist (physical medicine, neurosurgeon, neurology)	31.2	58.0	25.7	51.5	22.2	44.3
	d) Specialist (psychiatry)	2.8	6.8	3.4	8.7	3.9	9.1
	e) No GP/FP or specialist follow-up assessment within 30 days	25.2	NA	22.7	NA	22.5	NA
9	**Proportion of patients with TBI (%) discharged from inpatient rehabilitation with a follow-up assessment within 30 days and 180 days by a:**	**30 days**	**180 days**	**30 days**	**180 days**	**30 days**	**180 days**
	a) GP/FP (any reason)	54.8	90.3	70.1	92.8	73.2	92.9
	b) GP/FP (mental health-related reason)	DS	29.0	6.2	23.7	9.50	26.8
	c) Specialist (physical medicine, neurosurgeon, neurology)	58.1	90.3	39.2	79.4	36.3	70.6
	d) Specialist (psychiatry)	0.0	DS	DS	10.3	3.9	13.2
	e) No GP/FP or specialist follow-up assessment within 30 days	DS	NA	16.5	NA	18.6	NA

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Data Gaps

- There are a lot of important data we still cannot collect due to siloed data systems and a lack of standardized data collection infrastructure
- The following are some major data gaps:
  - Care received in outpatient rehab
  - Care received outside of public funding
  - Tracking education provided to patient/family
  - Measuring Access (physical and financial) to services (distance, transportation, insurance, GP)
  - Tracking screening for Mental Health and Addiction services

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Supplemental Survey Findings

Survey of Publicly funded Rehab Centers – Key Messages

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- Limited provision of culturally relevant care
- Inconsistent tracking of patient goal achievement and satisfaction
- Limited Outreach services available
- **Little engagement of primary care providers**
- **Limited access to mental health/behavioural services**
- **Very little access for individuals aged 65+**

Survey of ABI Community Service Providers – Key messages

- Non-standardized data collection
- Funding & Resource availability
- Staffing and workload
- Lack of coordination between acute, rehab and community
- **Little engagement of primary care providers**
- **Limited access to mental health/behavioural services**
- **Very little access for individuals aged 65+**

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OBIA Impact Survey

- Most common mechanisms of injury:
  - Motor vehicle collisions, falls, sports, bicycling and “other causes”
- Mental health issues after injury were very common:
  - Depression was reported by 84.8% of respondents
  - Anxiety was reported by 85.2% of respondents
  - PTSD was reported by 53.8% of respondents
- Income level predicted access to services for both OHIP and non-OHIP funded services
  - Respondents in higher income brackets were more likely to access neuropsychologists, peer support, specialized physicians

Key Takeaways from Survey Data

- Better care coordination is needed across the care continuum
- Accessible and available mental health services are limited, despite this being a significant need for people with TBI
- Primary Care Provider involvement is inconsistent and follow-up is often limited
- There is a need for improved access to specialized services for older adults (65+)

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Future of Report Cards

- Report cards focused on **older adults** with TBI and people aging with consequences of the injury (65+)
- Special reports with data from the Workplace Safety Insurance Board and Insurance Bureau of Canada (address gaps in **community** data)
- Continue adding indicators and to the report cards to fill **data gaps**

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How you can stay in touch

- **Our contact information**
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Conclusions

- **To identify solutions to gaps in TBI care, we must start by asking the right questions**
- This is the overarching goal of the report card, which we hope to achieve by describing the landscape of TBI care, identifying gaps, and ultimately drive improvement in the system

Without data there appears to be no need for change

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Thank you!