

Patient priorities for brain health equity in traumatic brain injury: A priority-setting initiative using the PROGRESS-Plus framework

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Introduction

- Traumatic brain injury (TBI) is an injury caused by an external force
- People's outcomes differ based on social characteristics (Fig.1)
- It is unknown what people with TBI and other interest groups think about the role of social parameters in brain health outcomes
- This knowledge is important for person-centered rehabilitation

Objective

- To ask people with TBI and other interest groups to rank their priorities on social parameters that matter most to them

Methods

- We followed a step-wise prioritisation process (Fig. 2)

Identifying interest holders

- People with TBI
- Their families
- Researchers
- Clinicians
- Community orgs

Survey distribution

- Importance of social parameters
- Integration in policy, research, practice
- Needed resources

Team distribution

- Brain Injury Canada
- Patient partners
- Researchers
- Academics
- Clinicians

Ranking ideas

- Survey responses
- Feasibility
- Impact

Fig. 2: Steps in knowledge translation priority setting

Results

Top three priorities set by patients and other interest groups (Fig. 3)

PROGRESS-Plus	Top parameters (average score)	Rated as top parameter by:
Place of residence	Homelessness (3.74)	
	Housing insecurity (3.71)	
Race, ethnicity, culture, language	Language (3.16)	
	Race (2.89)	
Occupation	Access to benefits (3.75)	
	Work status (3.38)	
	Workplace health/safety (3.49)	
Gender, sex	Sex at birth (3.03)	
	Gender (2.99)	
Religion	Spirituality (2.77)	
	Religious beliefs (2.62)	
Education	Level of formal education (3.12)	
Socioeconomic status	Income level (3.37)	
	Wealth and assets (2.94)	
Social capital	Trust in relationships (3.56)	
	Community participation (3.35)	
	Social network size (3.35)	
Plus	(Dis)ability (3.68)	
	Exposure to assault/abuse (3.46)	
	Age (3.36)	

Person with TBI

Family member/friend

Researcher

Healthcare professional

Staff/leader in TBI organization

Person selecting more than 1 group

Fig. 3: Weighted ratings of PROGRESS-Plus parameters by patients and other interest groups

Results, continued

- Quotes from research participants on their priorities and solutions
- "I think including people with brain injury in conversations is an ideal place to start..."*
- "Professionals - to focus on...social factors as part of initial assessment, to consider social goals as part of rehabilitation plans, to address social needs..."*
- "We need a database that shows...resources for families and caregivers so that these can be offered right away..."*

Discussion

- Differences in prioritization across groups calls for reflection and action to ensure patients' priorities drive research, policy, and practice priorities
- Why do patients priorities matter the most? Because patients are the reason the healthcare system exists
- Rehabilitation at its core is patient-centered.

References

- Mollayeva T, et al. Traumatic brain injury: sex, gender and intersecting vulnerabilities. Nat Rev Neurol. 2018 Dec;14(12):711-722.
- Cochrane Methods Equity. PROGRESS-Plus.
- Tylinski Sant'Ana T, et al. "Gender matters": the development of infographics to raise awareness and promote gender-transformative care in traumatic brain injury. Brain Inj. 2025 Mar 21;39(4):300-311.

Infographics

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