Children surviving major trauma:
Restrictions in activities and participation 3 years post-injury

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Rationale

- Worldwide shortage of population data to inform understanding of non-fatal burden
- Non-fatal injury outcomes are multi-dimensional with impacts on the individual, their family and society
- Need data collected over an extended timeframe post-injury
- Few studies have collected data at multiple time points post-injury and many cease follow-up at 12 months
- Available data not sufficient to describe who recovers, how quickly they recover, whether treatment needs are met, and how needs change over time
RESTORE
(Recovery after Serious Trauma: Outcomes, Resource Use and Patient Experiences)

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Aims and Study design

- **Aims:** Explore restrictions in activities and social participation experienced by children 3 years following major trauma, as reported by their caregivers.

- **Study base:** Victorian Statewide Trauma Registry (population-based registry of all major trauma (ISS>12, ICU for >24 hours involving ventilation, urgent surgery)
  - 178 paediatric major trauma patients with a date of injury from 1 July 2011 to 30 June 2012

- **Study focus:** 44 injured children who survived to 3 years post-injury (most treated at state’s major trauma service)

- **In-depth qualitative (semi-structured) interviews of caregivers (most were parents)**
Results

- Nearly all had experienced some restriction in activities in and outside the home, with many having on-going problems.
- Many reported limitations in activities which had wide-ranging impacts on social participation, perceived quality of life, and independence.
- Experiences appeared to intersect with developmental stages, especially dependence on caregivers (pre-schoolers), school environment and social world (school-aged), and conflict and tensions with increasing independence (adolescence).
- Important interactions with physical and social environments – in terms of (missed) opportunities to play, learn, develop sense of competence and social networks – and varying manifestations of distress (behavioural in early years; depression/social withdrawal in later years).
- Significant sources of resilience and resourcefulness.
International Classification of Functioning, Disability and Health (ICF)

Major Trauma

Body Structure & Function

Activity

Participation

Environmental Factors

Personal Factors

Contextual Factors
Implications for Practice and Research

- Need for collaborative models of care across the trauma continuum, including post-discharge and longer term support
  - Children/young people, caregivers, teachers / schools, primary care / other health professionals

- Information and resources which are accessible that transcend issues of literacy, socio-economic/insurance status, and other sources of inequities (e.g., access to health care)

- Greater attention to environmental barriers and facilitators (physical, social and health services)

- Need to better understand perspectives of young people themselves as they negotiate transitions of many types

- Develop and implement models of care that transcend current silos of service delivery – and evaluations that assess effectiveness
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