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

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Funded by NHMRC, Transport Accident Commission, State Government of Victoria



#### Rationale

- Worldwide shortage of population data to inform understanding of nonfatal 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)



#### UK

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#### Australia

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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)

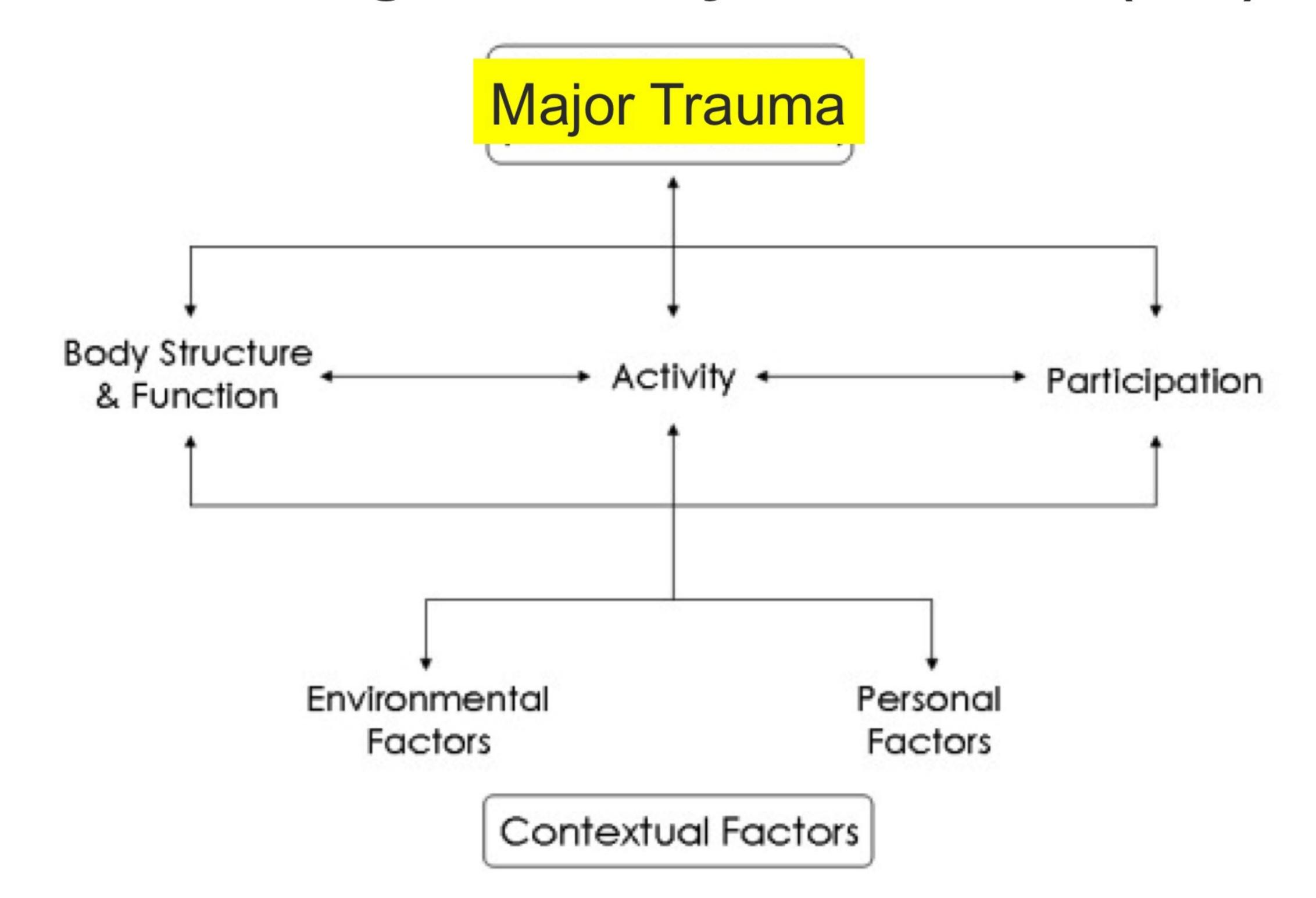


#### Results

- 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)



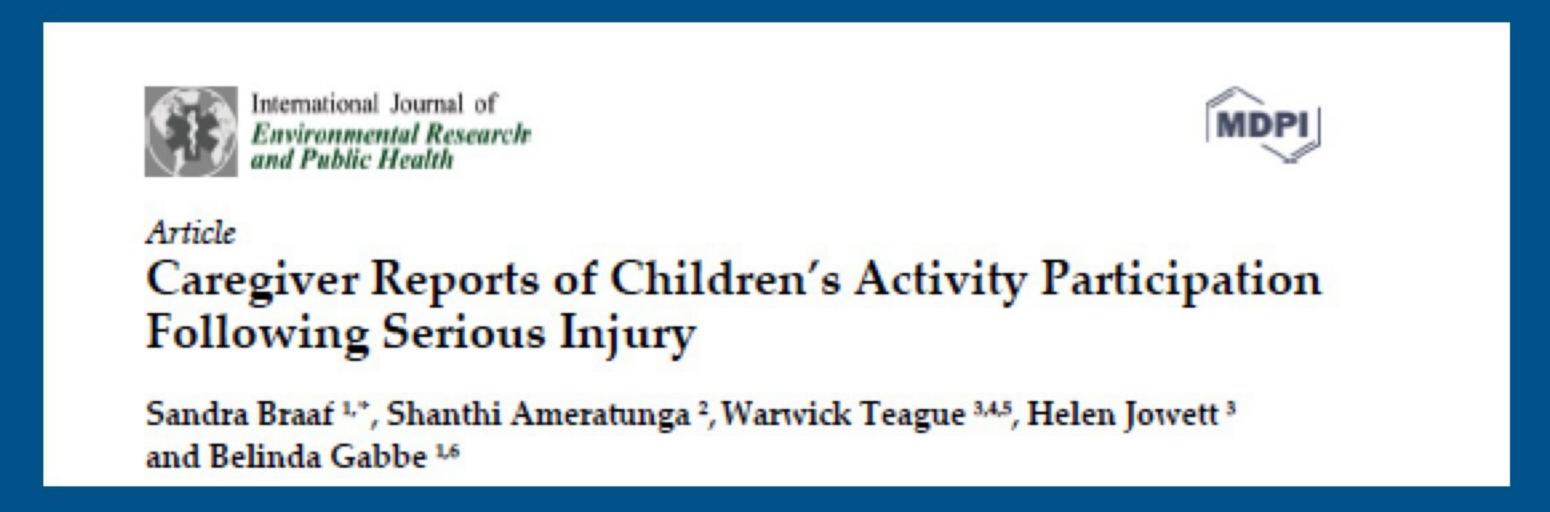
# Implications for Practice and Research

- 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



## Acknowledgements

- Participants and funders
- Project team led by Prof Belinda Gabbe
- Publication (open access): Braaf, Ameratunga, et al. Caregiver Reports of Children's Activity Participation Following Serious Injury. International Journal of Environmental Research and Public Health 2016; 13: 652



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