



Towards an Australasian Paediatric SCI/D Registry
 ANZSCoS 2021 – Pre-Conference Workshop sponsored and facilitated by
 SpineCare Foundation
 Wednesday 27 October 2021 – 1:30PM - 4:30PM (AEDT)

In this workshop, notable speakers with extensive registry and dataset experience will share relevant learnings and offer recommendations for development of a Paediatric Spinal Cord Injury and Dysfunction (SCI/D) Registry.

It is proposed that a data repository specific to paediatric SCI/D would provide more comprehensive epidemiological data than currently available, enhance understanding of secondary complications and associated health service use, enable monitoring of trends over time and identification sub-sets for preventative campaigns, provide insight into treatment approaches and highlight areas of unmet need.

Facilitated discussion will engage all workshop participants to reach consensus on;

- Registry objectives and applications
- Core data + collection schedule
- Registry structure (e.g. state, national or Australasian)
- Formation of an Advisory Group

TIME (AEDT)	SPEAKER NAME	PRESENTATION TITLE
1330	Dr Adrienne Epps / Isabel Chapman Session Chair	Welcome, session introduction, objectives and anticipated outcomes of this workshop
1340	A/Prof Adam Scheinberg	Making Connections – using consumer, health professional and researcher perspectives to guide development of a national paediatric SCI register
1350	Prof MJ Mulcahey and Prof Larry Vogel	Longitudinal Monitoring of Outcomes in Children with SCI: Experience, Challenges, Opportunities and Priorities
1400	Dr Reidar P. Lystad	Examining trends of paediatric spinal cord injury using Australian admitted patient data collections
1410	Ms Tara Alexander	Collecting paediatric data in the national rehabilitation medicine integrated outcomes centre – AROC (Australasian Rehabilitation Outcomes Centre)
1420	Ms Suzanne Humphreys, Dr Nancy Thorogood	Lessons Learned from Developing and Managing the Rick Hansen SCI Registry
1430	Dr Allison Graham	Paediatric SCI – fact or fiction?
1440 -1450	Dr Adrienne Epps / Isabel Chapman Session Chair	Comments on previous presentations
1450 -1500	Short Break	
1500	Dr Sarah McIntyre	Learnings from developing the Australian Cerebral Palsy Register (ACPR) – we’re continually learning
1510	Dr Simon Paget	Learnings from patient registries for specialised interventions for cerebral palsy
1520	A/Prof Bonita Sawatzky	An international registry for adults with AMC - a novel methodology
1530 - 1630	Dr Adrienne Epps / Isabel Chapman	Questions & Answers / Facilitated discussion & actions – panel session with all live presenters, including A/Prof Peter New.

**Note all program timings are draft and subject to change.