



# LONG TERM PATIENT OUTCOMES DATA COLLECTION USING REGISTRIES Victorian State Trauma Registry

**Dr Belinda Gabbe and Prof Peter Cameron**

Prehospital, Emergency and Trauma Unit  
School of Public Health and Preventive Medicine, Monash University



School of Public Health & Preventive Medicine





## Overview

1. Considerations for using registries to measure population outcomes
2. Introduction to the Victorian State Trauma Registry (VSTR)
3. Validation studies and methodological questions
4. Current data collection methodology
5. Brief summary of 12-month outcomes
6. Summary and directions for the future



# Challenges for measuring longer term outcomes

Stakeholder relevance

Resource limitations

Broad spectrum of injury regions and severities

- Proxy
- Instrument specificity

Retrospective assessment of pre-injury status

All age groups

Population monitoring

- Not a research project
- >2000 patients per year



Gabbe et al. *Acad Emerg Med* 2005;12:751-8



# Victorian State Trauma Registry



# Victorian context



- 5.36 million people
- Routine data collection systems
  - VAED
  - VEMD
  - Deaths/Coroners
  - **Victorian State Trauma Registry (VSTORM)**
  - Victorian Orthopaedic Trauma Outcomes Registry (VOTOR)
- Integrated, inclusive trauma system





## Victorian State Trauma Registry (VSTR)

- Statewide, population-based
- All major trauma
- **Opt-off consent**
- Government tender
  - Comprehensive reporting
- Integrated into the trauma system



<http://www.health.vic.gov.au/trauma/trauma-rep0701-0606.pdf>



## Definition of major trauma

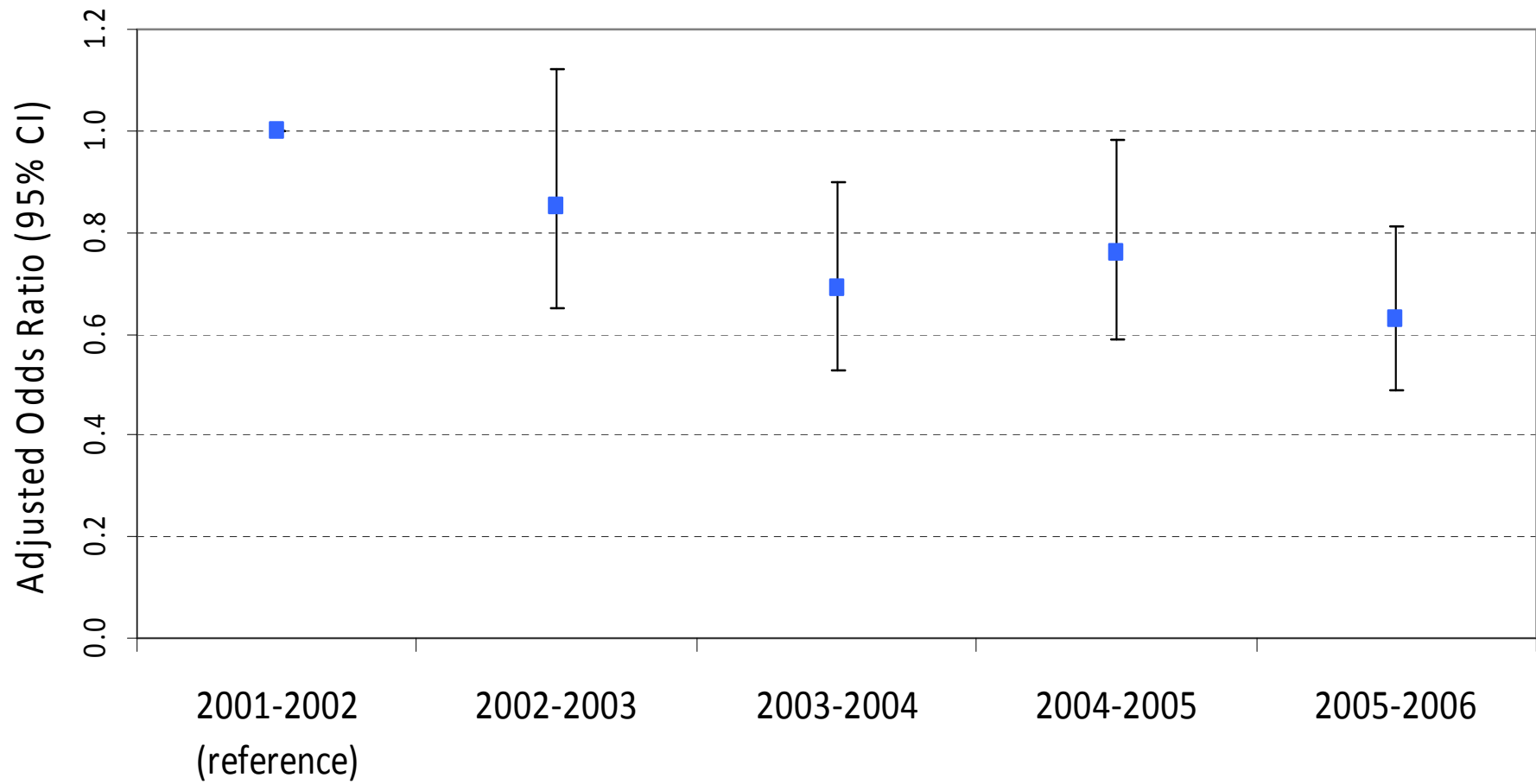
- Death following injury
- ISS>15
- Admission to ICU>24 hours, requiring mechanical ventilation
- Urgent surgery



## Data collection

Patient details	Gender, age, preferred language, fund source, contact details
Pre-hospital data	Indicators, observations, mode of transport, etc.
Injury event details	Cause, place, intent, type and activity at the time of injury
Injury diagnosis	ICD-10 AM, AIS, ISS
Injury management	ICU, Procedures and operations
Key indicator data	Length of stay, discharge destination, in-hospital mortality

# Adjusted risk of mortality (ISS>15)





## VSTORM Approach

- Implemented a brief follow-up at adult Level 1 centres\*
- Validation studies
  - MMMT
  - VOTOR
  - Nested cohort study
  - Paediatric Outcome Study in Trauma (POST)



\*Gabbe et al. *J Trauma* 2006;61:1393-9



## Methodological questions and validation

- Which functional instrument?
- Can we measure pre-injury health status and disability?
- Can we collect information about readmission from the patient?
- Which HRQOL/health status instrument?
- Which time points?

Gabbe et al. *Ann Surg* 2008;247:854-9

Gabbe et al. *J Orthop Trauma* 2007;21:223-228

Gabbe et al. *Aust Health Review* 2007;31:628-632

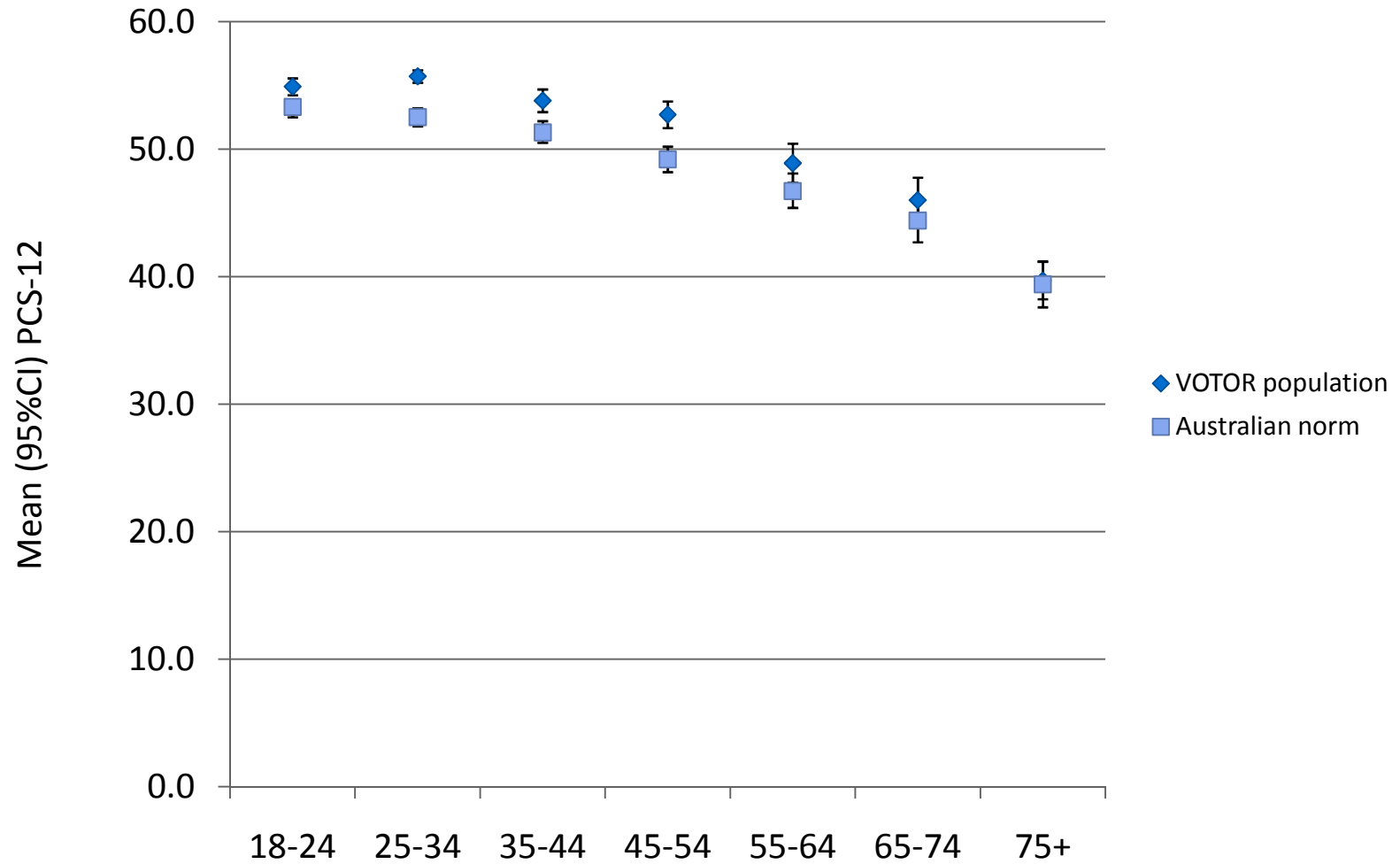
Williamson et al. *Arch Phys Med Rehab* (in press)



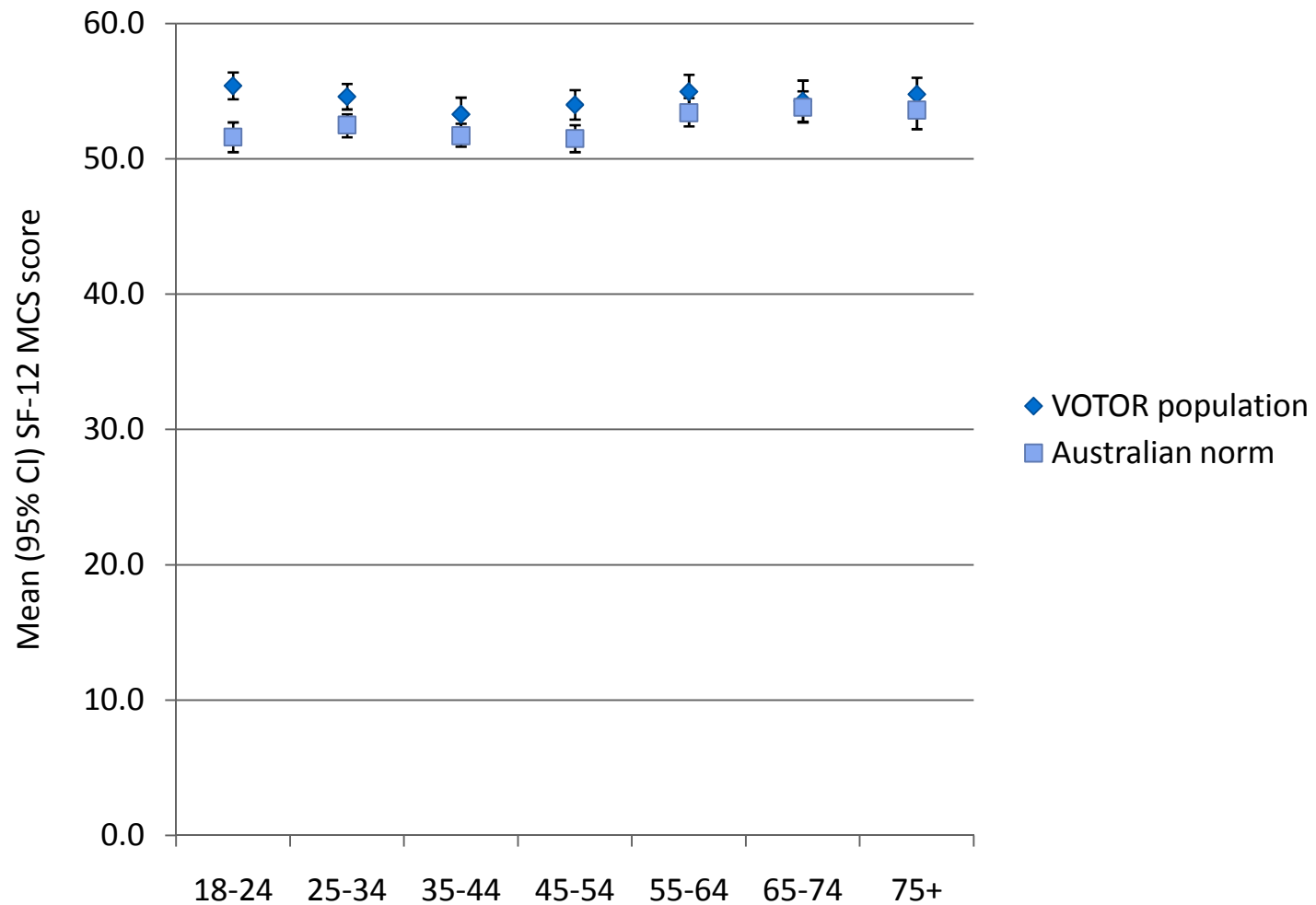
# MMMT Project - results

Instrument		Prediction	Alternate form reliability	Sensitivity	Responsiveness
GOS		-	+++	-/++	+++
GOS-E		-	+++	-/+++	+++
Modified FIM	Loco	-	+	++/+	-
	Feed	-	+++	+/-	-
	Exp	-	++	-/-	-
Modified FIM		-	++	+/-	+
FIM total		++	na	+++/-	+
FIM motor		+++	na	+++/-	+
FIM cognitive		-	na	-/-	-

## Pre-injury physical health scores (PCS-12)



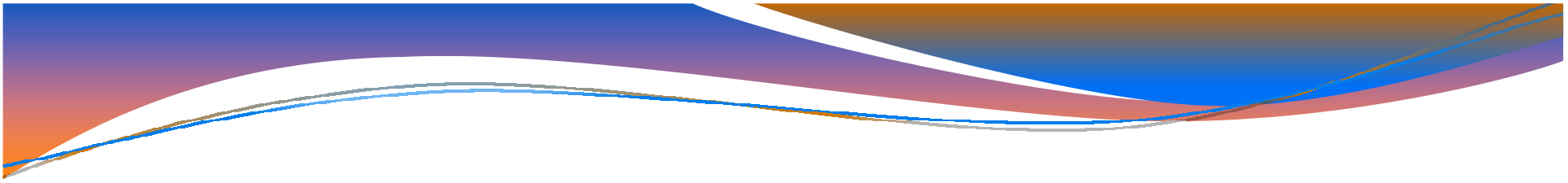
# Pre-injury mental health scores (MCS-12)



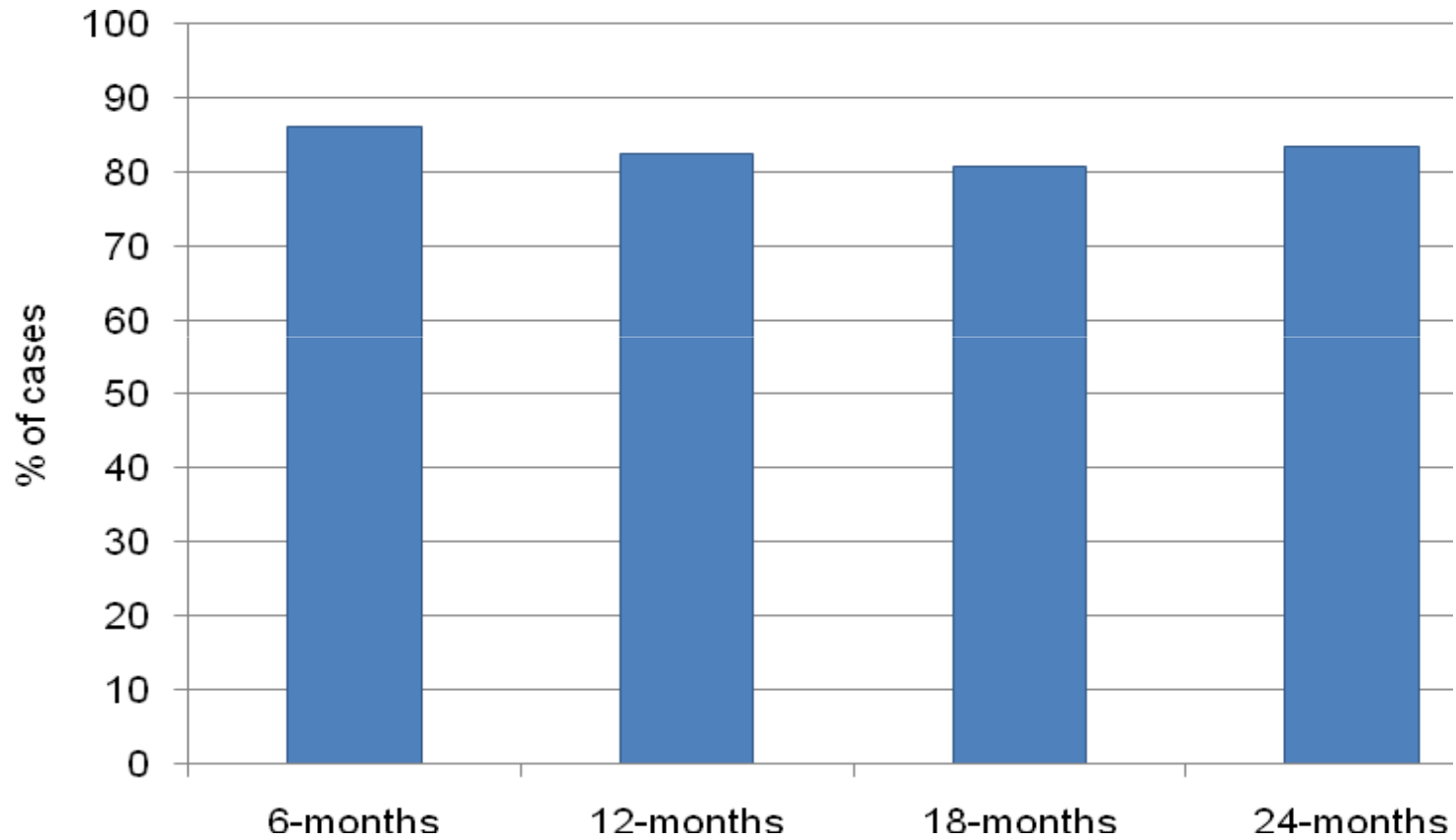


## Pre-injury disability - agreement

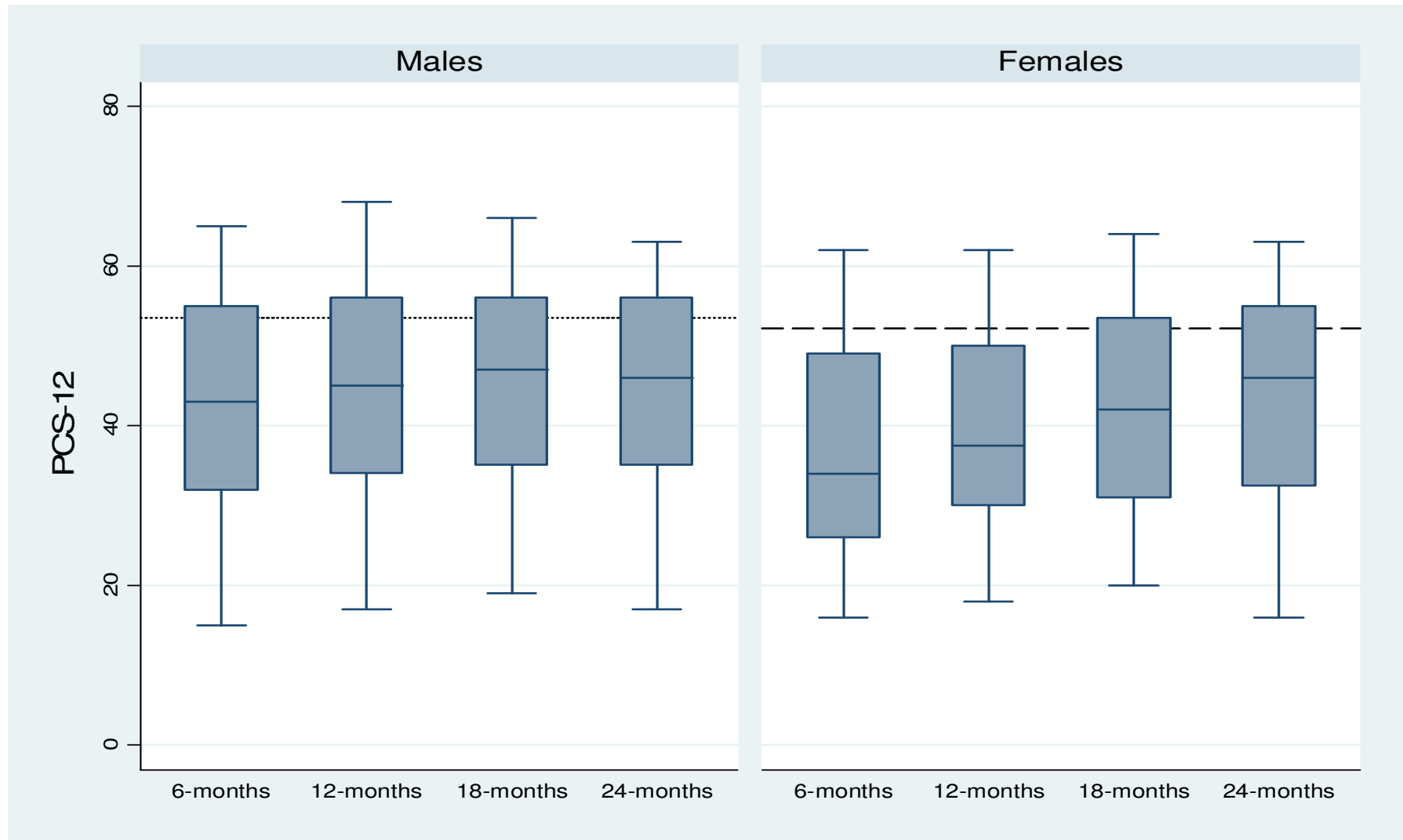
<b>Comparison</b>	<b>Baseline vs. 6 months</b>	<b>Baseline vs. 12 months</b>	<b>6 months vs. 12 months</b>
Agreement (%)	78.4	79.0	83.0
Agreement $\pm$ one category (%)	93.4	92.9	94.1
Under-estimation compared with previous time-point (%)	11.9	7.9	6.9
Over-estimation compared with previous time-point (%)	9.7	13.1	10.0



# Follow-up rates

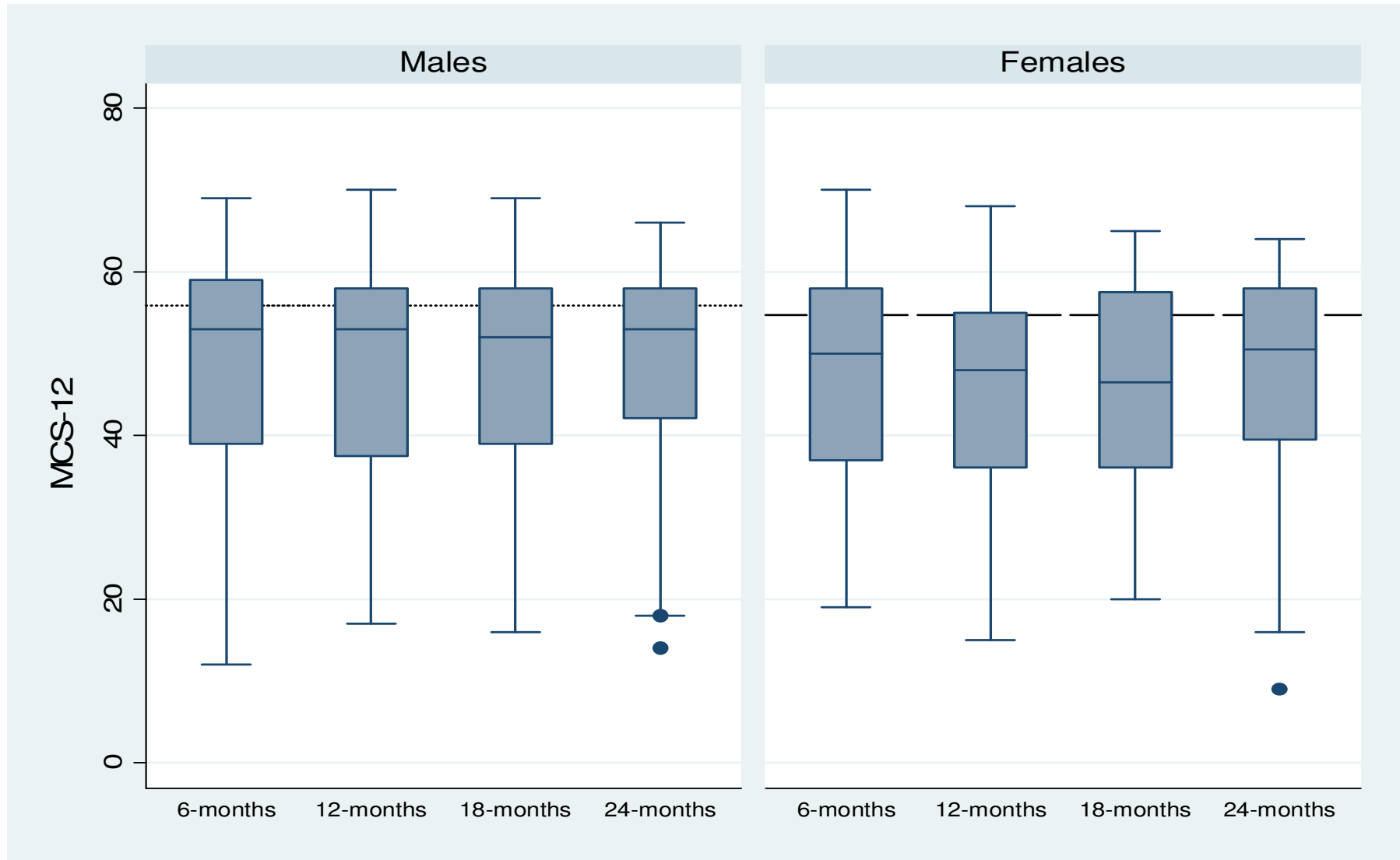


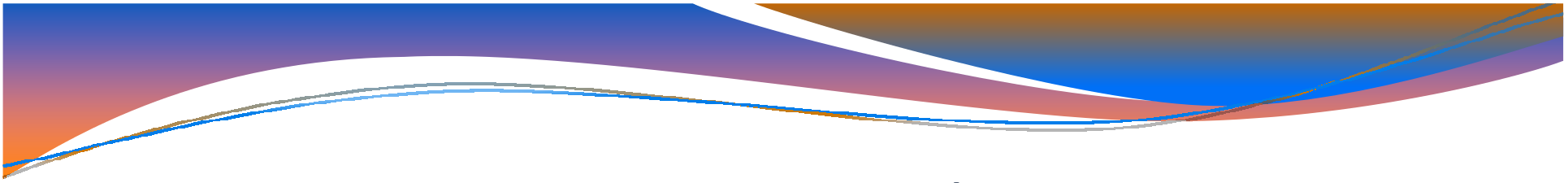
# Physical health (PCS-12)



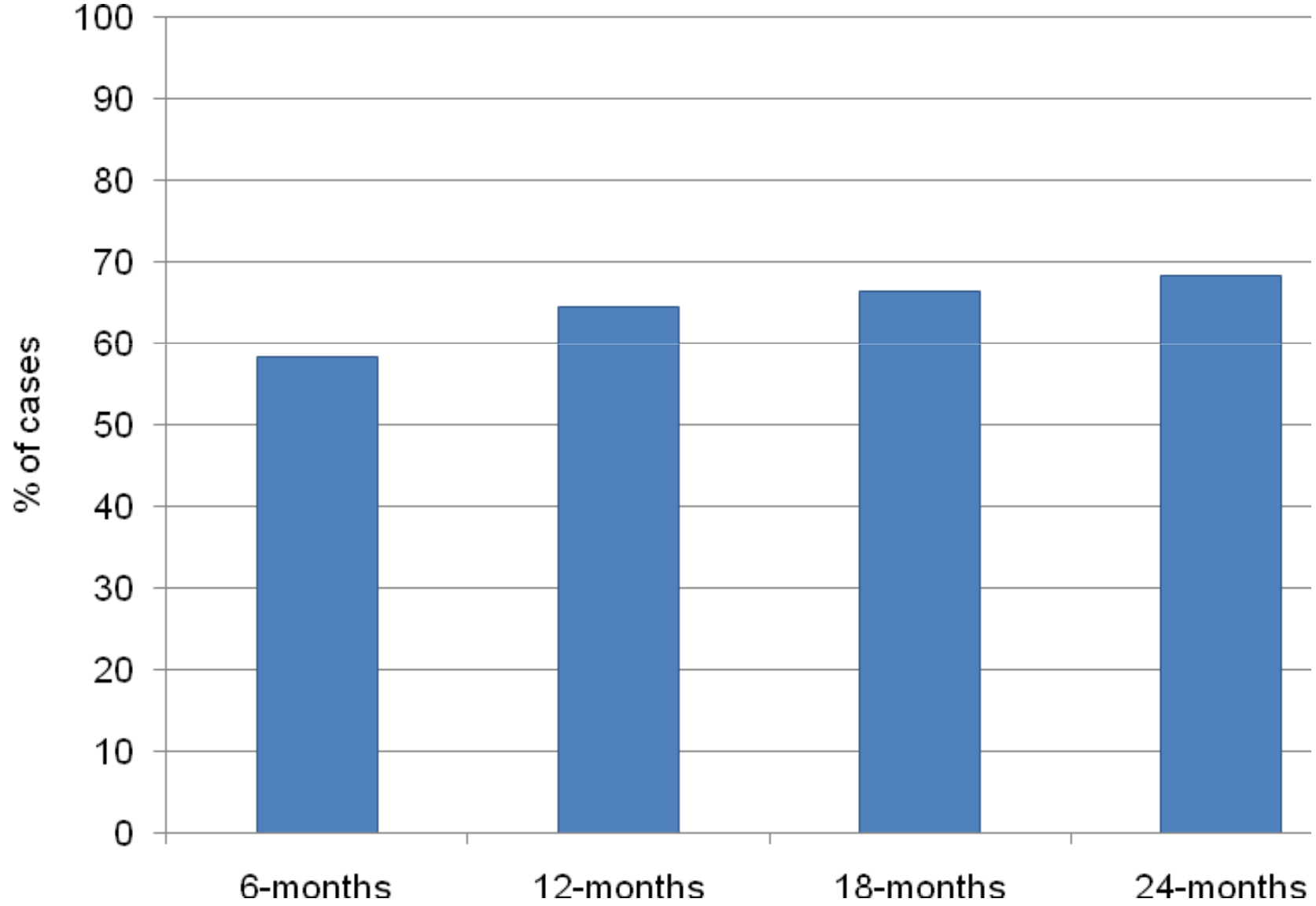


## Mental health (MCS-12)





# Return to work





## Outcome Data Collected – since July 2006

### Proxy

- Living status
- Pre-injury demographics
- Self-reported disability (Global Questions)
- GOSE (Functional measure)
- Return to work and work disability

### Patient

- Living status
- Pre-injury demographics
- Pain (NRS)
- Self-reported disability (Global Questions)
- GOSE (Functional measure)
- SF-12 (Health status measure)
- Return to work and work disability



## Outcome Data Collection

- Centralised location
- Standardised telephone interview
- Trained staff
- Integrated with orthopaedic registry



# Interviewers

- Mostly medical, dentistry and physiotherapy students in later years
- None of the instruments require specific qualifications or formalised training
- Patients difficult at times
  - Not uncommon for a patient to be distressed or suicidal
  - Significant clinical or life experience needed to cope
- Paid on an hourly rate
  - Expectation of  $\geq 2$  interviews per hour
  - Paid around \$23/hour



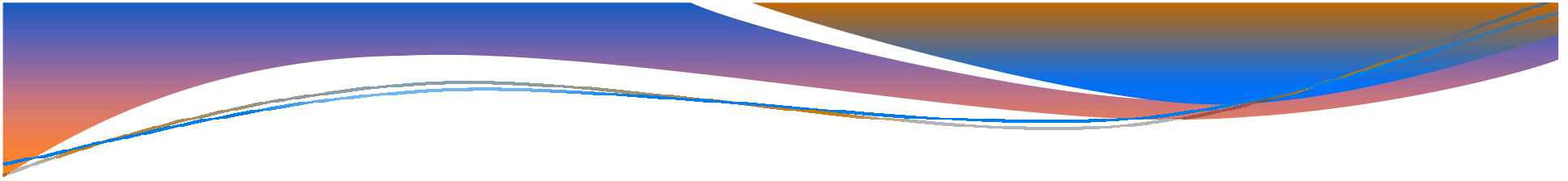
## Timing of interviews

- **Elderly**
  - Interviews during working hours
- **Young and working age**
  - Interviews in evening and weekends



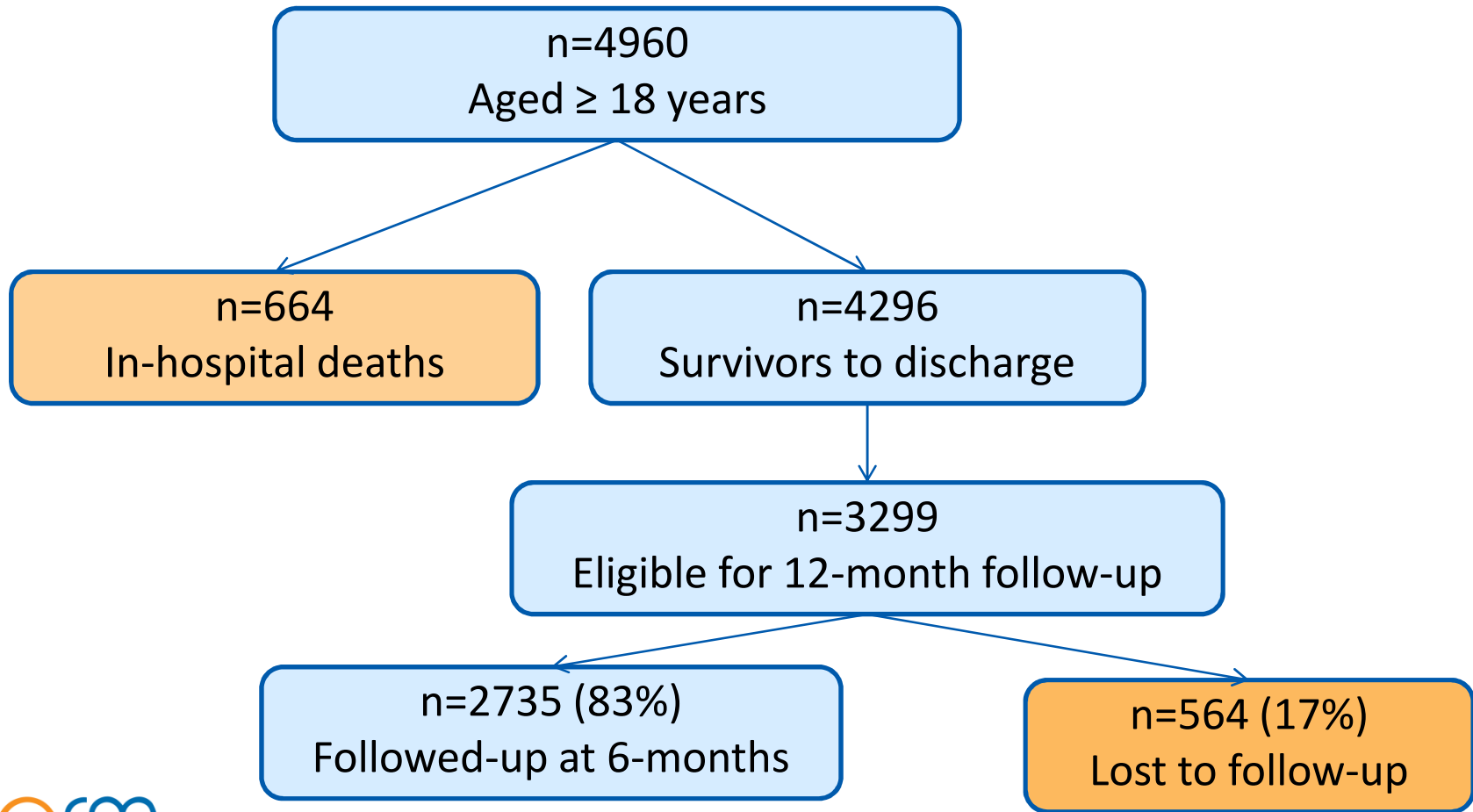
## Follow-up procedures

- **Attempt to contact 4 times at different times of day**
- **Try next of kin if difficulty contacting patient**
- **Capacity to designate a patient lost to follow-up limited to 3 staff members**
  - Checks through phone book, hospital administration, etc



## 12-month outcomes of major trauma patients

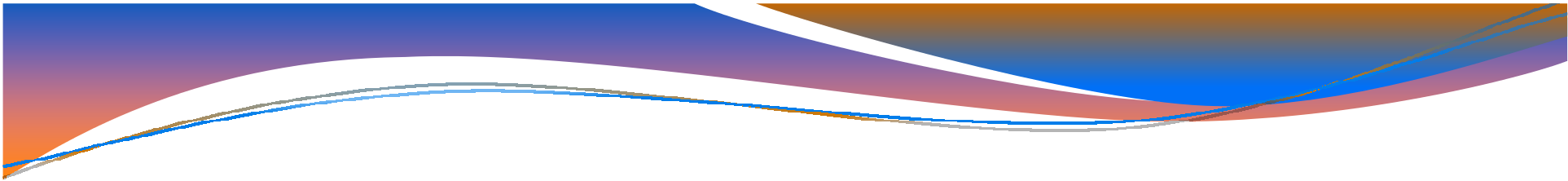
# October 2006 – December 2008



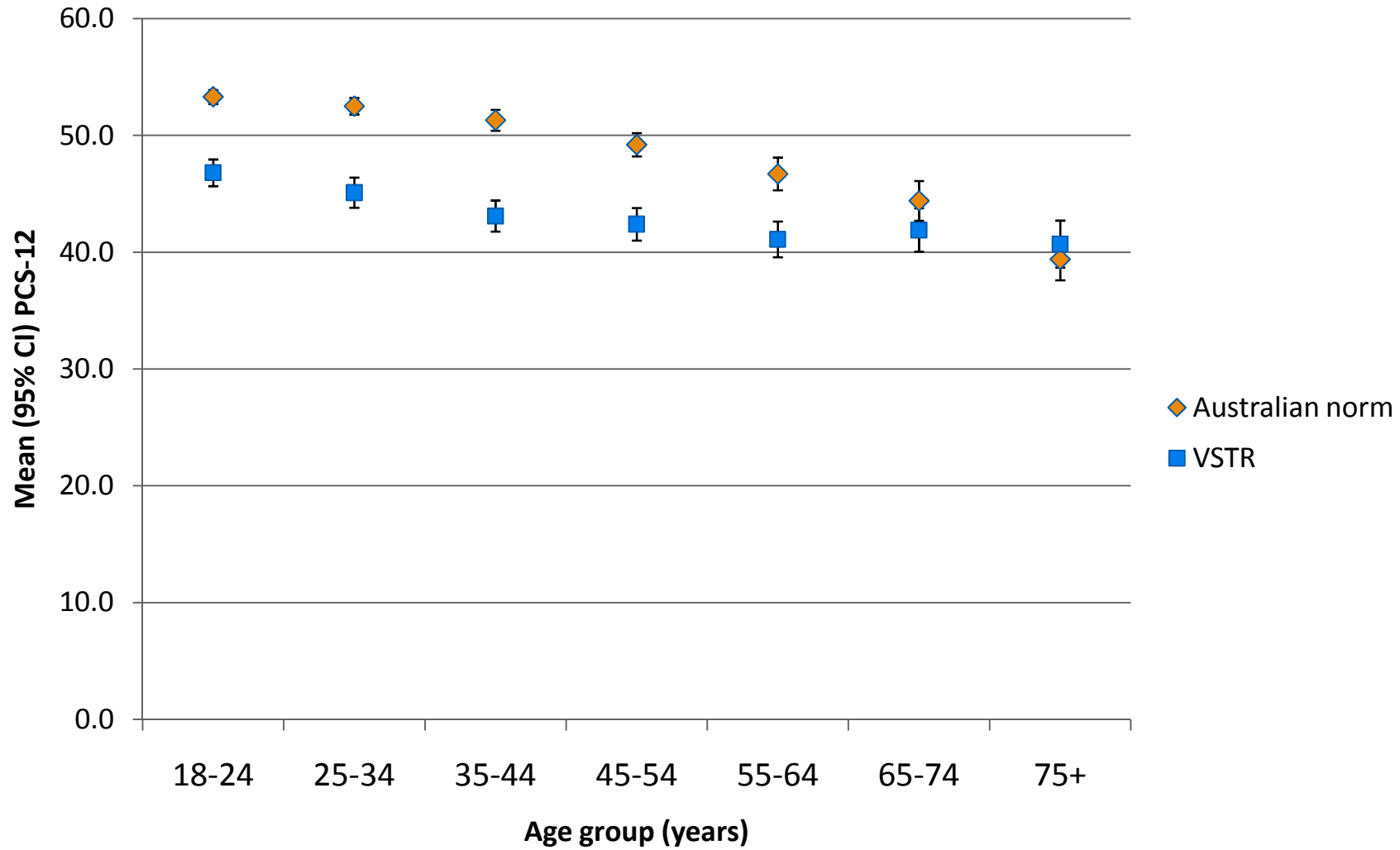
•84% at 6-months – 90% with  $\geq 1$  time point

## Profile of patients

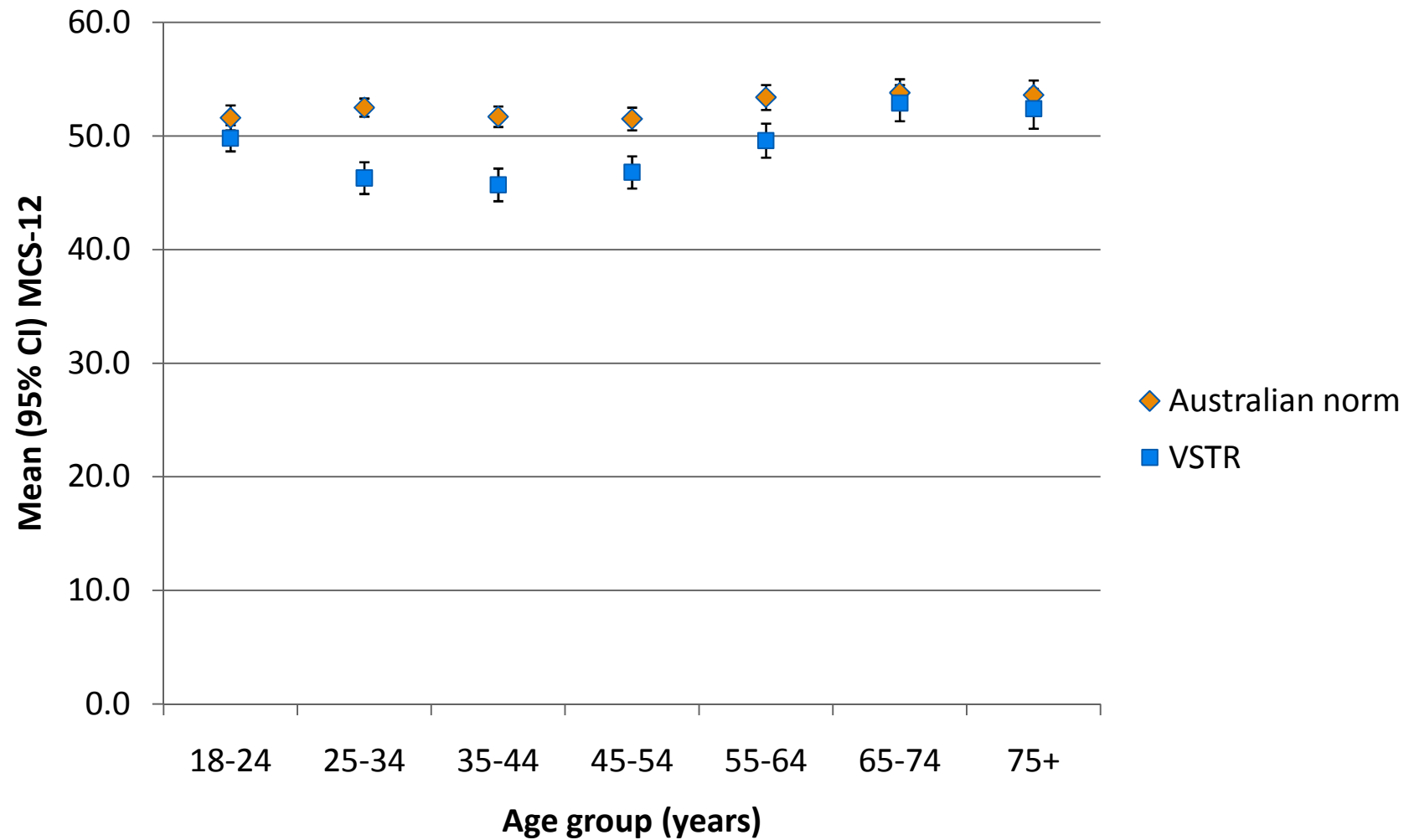
Variable	Responders (n=2735, 83%)	Non-responders (n=564, 17%)
Age (mean (SD))	48.4 (21.7)	40.8 (18.5)
Male (%)	78.9	72.9
Road trauma (%)	49.7	41.6
Unintentional (%)	88.8	73.1
ISS (median (IQR))	20 (17-26)	19 (16-25)
Injury profile (%)		
Orthopaedic injuries only	28.9	23.8
Head and other injuries	25.5	21.3
Isolated head injury	24.2	23.1
Isolated chest/abdominal injuries	7.3	12.2
Spinal cord injury	2.2	2.8
Other injuries	11.9	16.8



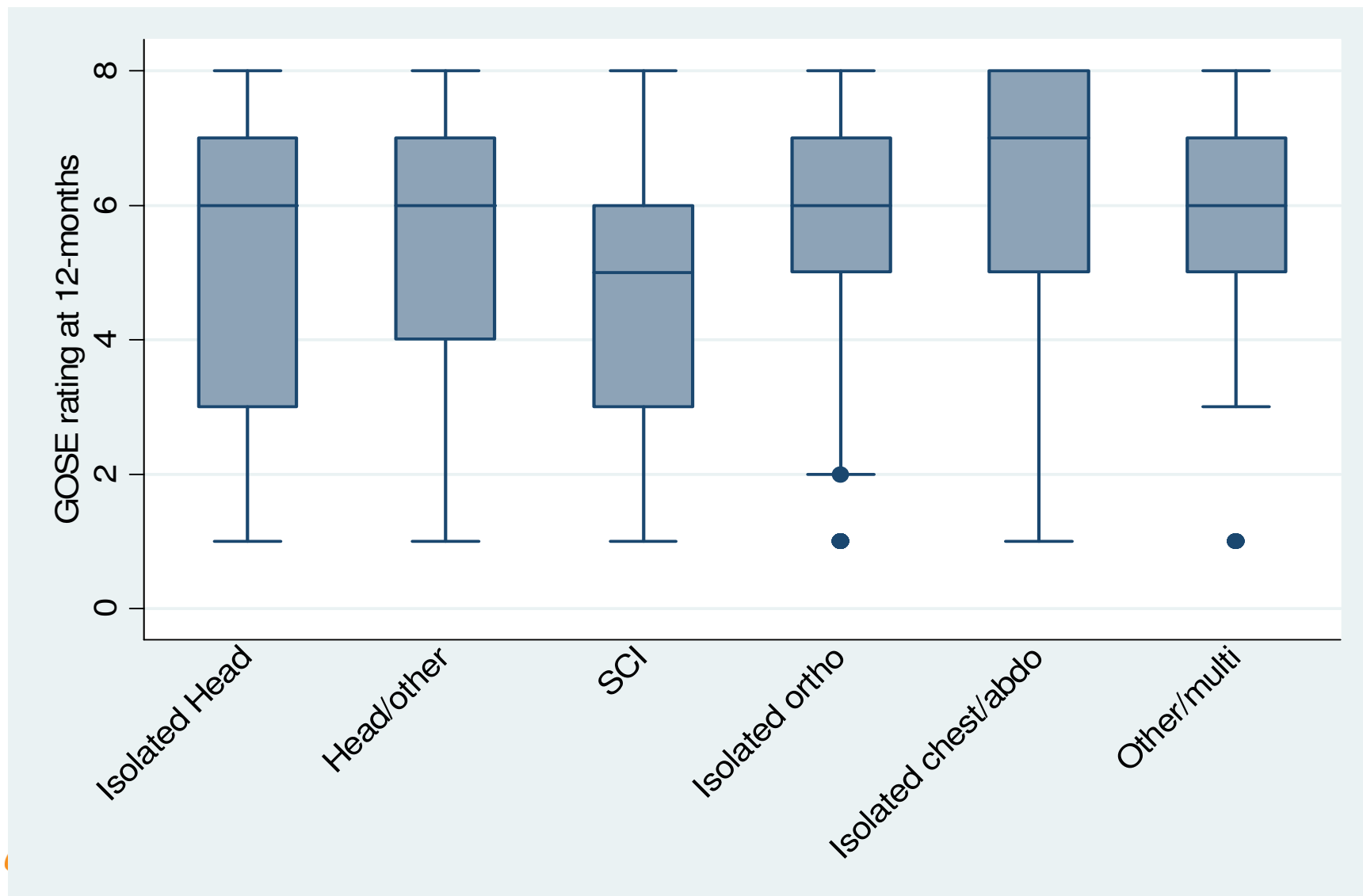
# Physical health scores at 12-months

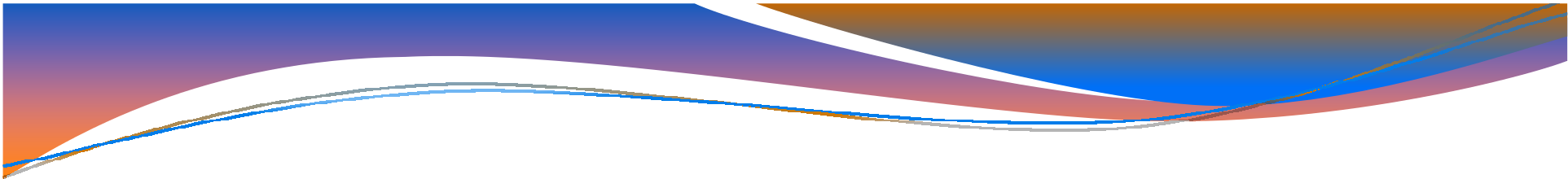


# Mental health scores at 12-months

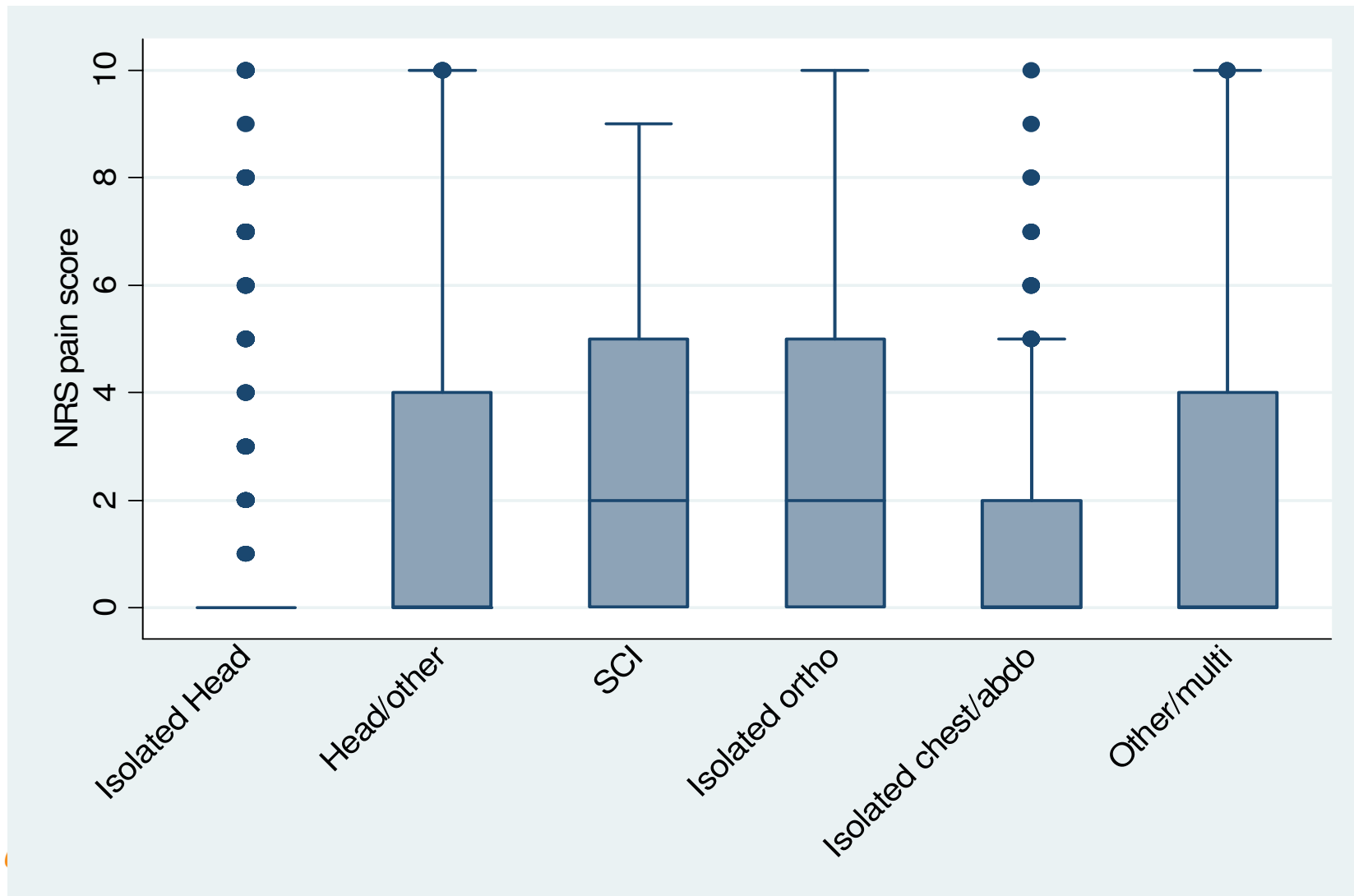


## Functional outcomes at 12-months



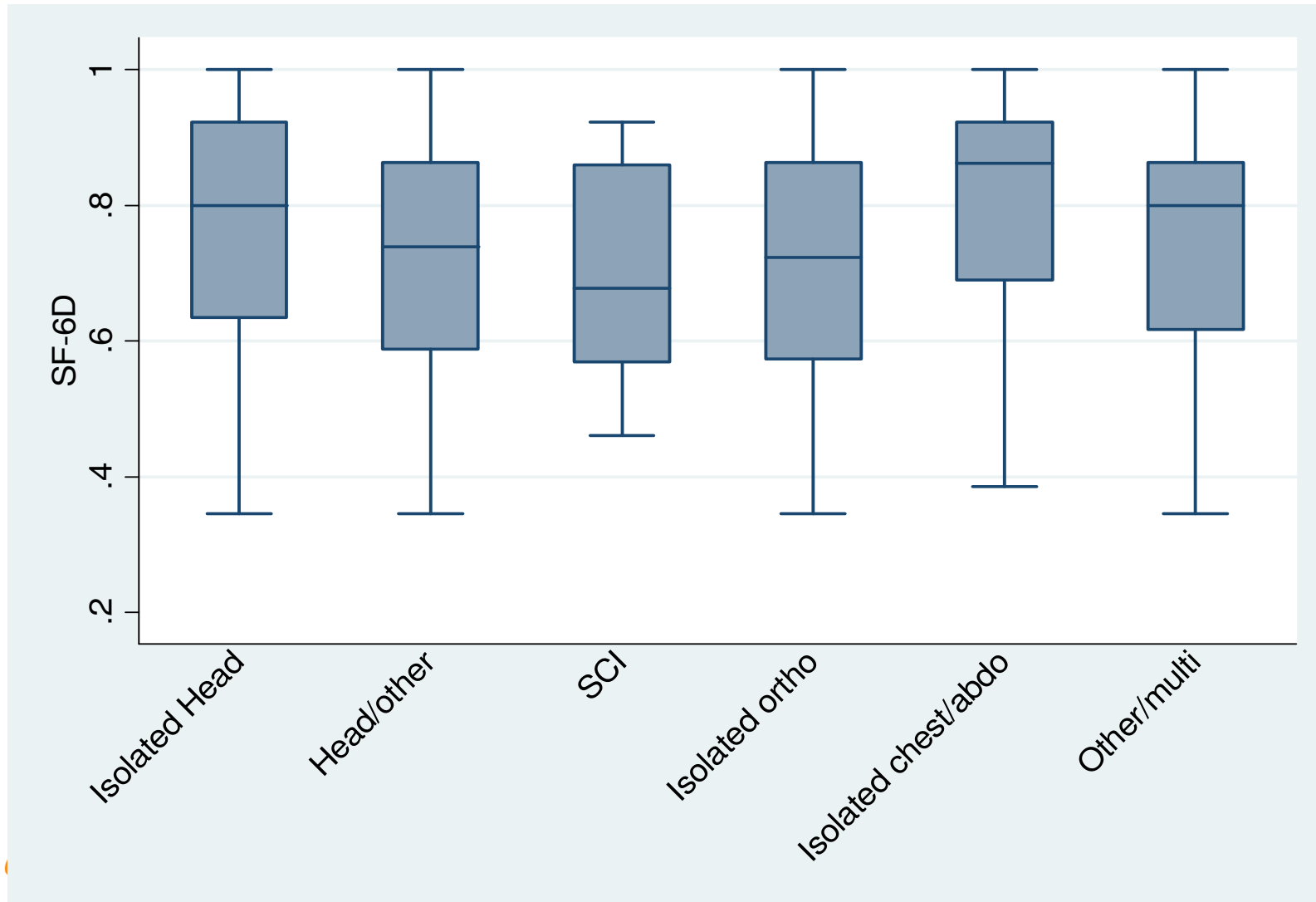


# Pain at 12-months





## SF-6D at 12-months





## Return to work or study

Injury group	Working prior to injury (%)	Returned to work (%)
Isolated head injury	43.8	72.2
Head and other injuries	65.7	57.9
Spinal cord injury	74.2	37.2
Orthopaedic injuries only	71.6	69.2
Isolated chest/abdominal	67.0	79.0
Other/multi-trauma	71.3	67.3



# What have we learned?

## What worked?

- Telephone interview
- Staged follow-up
- GOSE
- SF-12
- Evening/weekends

## What didn't work?

- Mail-out
- Reliance on health status as primary outcome measure
- FIM, modified FIM
- AQoL
- Pre-injury status in hospital



## Benefits

- Population-based monitoring of a complex patient group
- Relatively inexpensive
- Very good follow-up rates
- Will enable comparisons across time, across patient groups
- Identification of patients at risk of poor outcome
- Potentially drive improvements in delivery of acute and rehabilitation care



## What are the alternatives?

- Sample
  - Representative sample difficult
  - Complex patient group
- Use data from compensation systems
  - $\approx 50\%$  compensable and care is different for this group
- Use data from rehabilitation settings
  - $\approx 30\%$  of major trauma patients are admitted to inpatient rehabilitation centres



## Where are we going?

- Population-based follow-up paediatric major trauma
- Addition of 24-month post-injury time point
- Addition of the EQ-5D
- Establishing risk-adjustment models for non-fatal outcomes
- Linkage with compensable data
- GBD2005 and international comparisons



## Acknowledgements

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**TRANSPORT  
ACCIDENT  
COMMISSION**

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A Victorian  
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## Further questions?

[belinda.gabbe@med.monash.edu.au](mailto:belinda.gabbe@med.monash.edu.au)

[peter.cameron@med.monash.edu.au](mailto:peter.cameron@med.monash.edu.au)

