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

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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

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

Definition of major trauma

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

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

## MMMT Project - results

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Prediction</th>
<th>Alternate form reliability</th>
<th>Sensitivity</th>
<th>Responsiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>GOS</td>
<td>-</td>
<td>+++</td>
<td>+/-</td>
<td>+++</td>
</tr>
<tr>
<td>GOS-E</td>
<td>-</td>
<td>+++</td>
<td>+/-+++</td>
<td>+++</td>
</tr>
<tr>
<td>Modified FIM</td>
<td>Loco</td>
<td>-</td>
<td>+</td>
<td>+/+</td>
</tr>
<tr>
<td>Loco Feed Exp</td>
<td>-</td>
<td>+++</td>
<td>+/-</td>
<td>-</td>
</tr>
<tr>
<td>Modified FIM</td>
<td>-</td>
<td>++</td>
<td>+/-</td>
<td>+</td>
</tr>
<tr>
<td>FIM total</td>
<td>++</td>
<td>na</td>
<td>+++/-</td>
<td>+</td>
</tr>
<tr>
<td>FIM motor</td>
<td>+++</td>
<td>na</td>
<td>+++/-</td>
<td>+</td>
</tr>
<tr>
<td>FIM cognitive</td>
<td>-</td>
<td>na</td>
<td>+/-</td>
<td>-</td>
</tr>
</tbody>
</table>
Pre-injury physical health scores (PCS-12)

Mean (95%CI) PCS-12

VOTOR population
Australian norm

18-24 25-34 35-44 45-54 55-64 65-74 75+

40.0 50.0 60.0
Pre-injury mental health scores (MCS-12)

VOTOR population
Australian norm
## Pre-injury disability - agreement

<table>
<thead>
<tr>
<th>Comparison</th>
<th>Baseline vs. 6 months</th>
<th>Baseline vs. 12 months</th>
<th>6 months vs. 12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agreement (%)</td>
<td>78.4</td>
<td>79.0</td>
<td>83.0</td>
</tr>
<tr>
<td>Agreement ± one category (%)</td>
<td>93.4</td>
<td>92.9</td>
<td>94.1</td>
</tr>
<tr>
<td>Under-estimation compared with previous time-point (%)</td>
<td>11.9</td>
<td>7.9</td>
<td>6.9</td>
</tr>
<tr>
<td>Over-estimation compared with previous time-point (%)</td>
<td>9.7</td>
<td>13.1</td>
<td>10.0</td>
</tr>
</tbody>
</table>
Follow-up rates

- 6-months: 90%
- 12-months: 80%
- 18-months: 70%
- 24-months: 60%

% of cases
Physical health (PCS-12)
Mental health (MCS-12)

The diagram shows box plots for male and female mental health scores (MCS-12) across 6, 12, 18, and 24 months. The scores are represented on the y-axis, and the time points are on the x-axis. The box plots indicate the distribution of scores with the central line representing the median, and the boxes showing the interquartile range. The whiskers extend to show the range of the data, excluding outliers. The outliers are marked with individual points.

- **Males**: Scores appear to be consistently distributed across the time points with no significant trend or pattern.
- **Females**: Scores also show a consistent distribution with similar trends as males, but with slight variations at different time points.

The overall pattern suggests stable mental health scores with minor fluctuations over the 24-month period.
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 ≥ 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

n=4960
Aged ≥ 18 years

n=664
In-hospital deaths

n=4296
Survivors to discharge

n=3299
Eligible for 12-month follow-up

n=2735 (83%)
Followed-up at 6-months

n=564 (17%)
Lost to follow-up

84% at 6-months – 90% with ≥ 1 time point
## Profile of patients

<table>
<thead>
<tr>
<th>Variable</th>
<th>Responders (n=2735, 83%)</th>
<th>Non-responders (n=564, 17%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean (SD))</td>
<td>48.4 (21.7)</td>
<td>40.8 (18.5)</td>
</tr>
<tr>
<td>Male (%)</td>
<td>78.9</td>
<td>72.9</td>
</tr>
<tr>
<td>Road trauma (%)</td>
<td>49.7</td>
<td>41.6</td>
</tr>
<tr>
<td>Unintentional (%)</td>
<td>88.8</td>
<td>73.1</td>
</tr>
<tr>
<td>ISS (median (IQR))</td>
<td>20 (17-26)</td>
<td>19 (16-25)</td>
</tr>
<tr>
<td>Injury profile (%)</td>
<td>Orthopaedic injuries only</td>
<td></td>
</tr>
<tr>
<td></td>
<td>28.9</td>
<td>23.8</td>
</tr>
<tr>
<td></td>
<td>Head and other injuries</td>
<td>25.5</td>
</tr>
<tr>
<td></td>
<td>24.2</td>
<td>21.3</td>
</tr>
<tr>
<td></td>
<td>Isolated head injury</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7.3</td>
<td>12.2</td>
</tr>
<tr>
<td></td>
<td>Isolated chest/abdominal injuries</td>
<td>2.2</td>
</tr>
<tr>
<td></td>
<td>Spinal cord injury</td>
<td>11.9</td>
</tr>
<tr>
<td></td>
<td>Other injuries</td>
<td>16.8</td>
</tr>
</tbody>
</table>
Physical health scores at 12-months
Mental health scores at 12-months

- **Mean (95% CI) MCS**

- **Age group (years)**

- **Australian norm**

- **VSTR**
Functional outcomes at 12-months

- GOSE rating at 12-months
- Isolated Head
- Head/other
- SCI
- Isolated ortho
- Isolated chest/abdo
- Other/multi
Pain at 12-months

- Isolated Head
- Head/other
- SCI
- Isolated ortho
- Isolated chest/abdo
- Other/multi

NRS pain score

0 2 4 6 8 10
SF-6D at 12-months
### Return to work or study

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

- Peter Cameron & John McNeil
- Mimi Morgan, Andrew Hannaford, Ann Sutherland & Sue McLellan
- Steering Committee
- Data collectors and trauma coordinators at all participating hospitals
- All follow-up staff
- The VSTR is funded and approved by the Department of Human Services and TAC
This project is proudly supported by the Transport Accident Commission
A Victorian Government initiative

Victoria
The Place To Be
Further questions?

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