

Appendix A

Objectives for future research on traumatic brain injury in New Zealand

In the process of developing this guideline, the Guideline Development Team identified a number of research gaps where there was insufficient research. For future guideline updates the Guideline Development Team recommends that the following research areas be considered. These are necessarily broad. The order does not reflect a priority ranking.

1. Quantifying the incidence of TBI in New Zealand (ie, new cases)

Currently there is insufficient information to establish the incidence of TBI in New Zealand, particularly at the mild end of the spectrum, ie, being able to distinguish between cases that are initially ‘suspected TBI’ but don’t meet the criteria for ‘definite TBI’ as described in this guideline. Within this problem, there are sub-problems around populations at high risk on the basis of age, gender, ethnicity, geography and comorbidities (such as mental health disorders, drug and alcohol misuse). The proportions of people with severe, moderate and mild TBI need to be accurately established for efficient service delivery.

2. Burden of TBI in New Zealand

What is the impact of TBI for individuals (and their families and carers) with TBI of different severity and demographic and other characteristics in New Zealand? This will require comprehensive case ascertainment and follow-up over long enough periods to measure important outcomes. One question that needs to be specifically addressed is whether outcomes are as bad as those measured in the 2000 Thornhill study⁴ (rates of disablement of around 45% at one year even for people with mild TBI).

3. The effectiveness of specific interventions for people with TBI

There are very many of these that are not adequately tested. The systematic design of appropriate studies and testing of interventions would be of international significance.

4. The effectiveness, timing and content of assessments for people with TBI

One specific issue is around assessments of people with mild TBI. Is a policy of early, simple assessment (eg, using computerised cognitive screening assessments) followed, where necessary, by more comprehensive assessment, more efficient and/or more effective, than the current policy of delayed, moderately comprehensive assessment using mild TBI clinics?

5. The experience of TBI for people and their carers

There is remarkably little known about how people cope with the effects of TBI. The same applies to carers. Qualitative research could help to clarify some of these issues and make a difference to the way services are delivered.

6. Children and young people with TBI

It is clear from the TBI guideline that there are many areas where there is simply no information specific to children and young people with TBI. This absence of good information applies to all of the points above and specific research in this group needs to be considered.

7. Appropriate tools and measures for use with people with TBI in New Zealand

Although there may need to be specific work on the psychometric properties of some tools, utility needs considerable attention. Which tools, when and for what purpose?

8. Measurement of performance of TBI services in New Zealand

The ability to identify services that are delivering good outcomes and those that are struggling should allow for a process of quality improvement over time. This would allow a move away from reliance on measures of process as a proxy for performance.