ScotPHN report

Scottish Public Health Network (ScotPHN)

LONG-TERM CONDITIONS TOOLKIT 1: ACQUIRED BRAIN INJURY USING EPIDEMIOLOGY AND RESEARCH IN SERVICE PLANNING

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Preface

In 2012, when the Scottish Public Health Network (ScotPHN) published its *Health Care Need Assessment of Services for Adults with Rheumatoid Arthritis*[*], a number of people approached ScotPHN with suggestions for other health care need assessments relating to what we now refer to as 'long-term conditions'. Whilst ScotPHN was happy to consider such suggestions, it quickly became apparent that such project – if we followed the traditional approach to comprehensive health care need assessments – would be very labour intensive and may not really be that useful to those health and social care service planner and third sector agencies that had approached us.

After careful consideration and debate, we conceived the notion of preparing shorter, more focussed guidance documents which helped apply epidemiological and research evidence into service planning. We further though that these could build up – over time – into a service planning "toolkit". In discussion we felt that we could provide two products for each area – a written guidance and an accompanying spreadsheet that would allow local areas to generate a routine epidemiological "statement" that could be used, based on their own local population data. Whilst this latter aspiration has taken longer to develop than we had hoped, the first actual written service planning guidance note is now ready. Rather than wait for the spreadsheet to be ready, we felt it more helpful to make it available now.

The first area on which we were encouraged to develop service planning guidance was on acquired brain injury and we were very fortunate that Dr Brian O'Suilleabhain, a Public Health Consultant, volunteered to draw on his considerable expertise in working with the Brain Injury Service in NHS Lanarkshire and the Scottish Acquired Brain Injury Network, to develop the written component of the guidance. We are extremely grateful to him and to those who were generous with their comments and suggestions which helped shape the final document.

ScotPHN will seek to extend this "toolkit" as occasion arises, particularly working with our colleagues in public health who have special interests in, and expertise of, service planning and improvement. Do please feel free to contact us (see www.scotphn.net for details) with your thoughts on the approach and your suggestions for other long-term conditions for which we could develop guidance for service planning.

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[*] (Available at: http://www.scotphn.net/projects/rheumatoid-arthritis/)

1 The nature of acquired brain injury

Traumatic Brain Injury (TBI) is often used as the paradigm for Acquired Brain Injury (ABI) and will be in this report but other causes need to be recognised as resulting in similar consequences for the individual affected (1). Haemorrhage into or around the brain can occur spontaneously or after trauma; hypoxic brain injury can occur in association with a temporary cardiac or respiratory arrest, choking, drowning or drug overdose; and infective brain injury can result from encephalitis or a brain abscess. Stroke is not considered in this paper because separate dedicated services exist for this condition.

The most widely used index of injury severity is the Glasgow Coma Scale (GCS), which classifies injuries in to mild, moderate, or severe based on the duration of unconsciousness and post-traumatic amnesia after the injury, as in table 1.

Table 1: Glasgow Coma Scale.

	Duration of unconsciousness	Post-traumatic amnesia duration	GCS score	Outcome
Mild injury	Less than 15 minutes	Less than 24 hours	13-15	Usually make a complete recovery but some exceptions
Moderate injury	15 minutes – 6 hours	1-7 days	9-12	Recovery is likely but may be protracted
Severe injury	More than 6 hours	More than one week	1-8	Considerable risk of death and survivors will often have significant disability.

The Glasgow coma scale is useful to predict early morbidity and mortality but it only offers a crude indication of the likely longer-term effects. Even a minor or moderate injury as classified on the GCS can lead to significant long-term problems. Therefore the Glasgow Outcome scale is widely used to describe the outcomes of acquired brain injury in populations (see table 2).

Table 2: Glasgow Outcome Scale

Death	
Vegetative state	The patient never speaks nor makes any psychologically meaningful response, not even obeying simple commands or uttering simply words. The patient my open their eyes or make reflex movements but there is no behavioural evidence of cerebral cortex function.
Minimally conscious	A state of partial consciousness with eye-opening, periods of wakefulness and sleep, and the ability to follow simple instructions or respond appropriately to people or events.
Severe disability	The patient is conscious but dependent on another person for some activities during every 24 hour period. There may be marked

	physical disability or dysphasia alongside some cognitive deficits; for some the main deficits are cognitive and they are physically well.
Moderate disability	The person is independent but clearly disabled on account of memory problems, personality changes or some physical disability.
Good recovery	The person is able to participate in normal social life and capable of returning to work. The person may still have some evidence of deficits but is clearly better than someone with a moderate disability.

The disabilities resulting from brain injury are potentially significant leading to physical disability, communication problems, emotional and behavioural problems and difficulties with thinking, reasoning and memory. Because people with TBI often develop a number of different problems, there can be considerable personal and financial costs to them and their families, including long-term unemployment, family breakdown, mental health problems, substance misuse and suicide. Through the Scottish National Managed Clinical Network for Brain Injury the following five scenarios have been developed to describe the most common composite mix of problems that brain injury patients are likely to experience (2).

Scenario A: An individual who has no significant physical impairment and is sufficiently orientated to be discharged home from hospital but has persisting cognitive impairments.

Scenario B: A patient who is medically stable but has mixed physical and cognitive impairment without major behavioural issues. He requires assistance with some physical activities and because of mixed cognitive and language difficulties needs some supervision in activities of daily living.

Scenario C: An acutely behaviourally disturbed individual person who, because of cognitive and communication impairment, is unco-operative with ward staff, attempts to leave hospital and can be aggressive to staff.

Scenario D: Persisting challenging behaviour in a person who is aggressive to staff but lacks cognitive capacity to comply with the staff or go to the community.

Scenario E: An individual in a vegetative state or a minimally conscious state. Medically stable but requires nursing care for all needs and has been in this state for some weeks.

Scenarios A and B as described above constitute the most common mix of problems that brain injury patients are likely to experience, while scenarios D and E are relatively rare. Brain injury can impact on the family and closest friends of the patient, often to a dramatic extent. While the brain injury patient may experience minimal direct suffering on account of a lack of insight, the family and carers may be faced with supporting somebody that bears little resemblance to their pre-morbid nature in terms of behaviour, personality, and functioning.

2 The epidemiology of acquired brain injury

This epidemiology section focuses largely on the published literature because routinely collected NHS data has many limitations in relation to brain injury - particularly in respect of errors in coding, variations in coding practice in different areas, the quality and timeliness of the raw clinical information on which coding is based, double counting and case inflation. Also it is uncertain how many people might experience disability after an acquired brain injury, where they did not seek medical attention or get admitted to hospital. For these reasons this epidemiology section focuses largely on the studies in the literature on the outcomes for patients that get admitted to hospital for an acquired brain injury. There is some research evidence to suggest that around 300 people per 100,000 population in Scotland get admitted to hospital each year for a traumatic brain injury (3). Based on the methodology used in the SNAP report, it seems reasonable to add an additional 10% to allow for other causes of acquired brain injury, thus giving an overall hospital admission rate of around 330 per 100,000 population per year. Through the Scottish Acquired Brain Injury Network (SABIN) a review of services across Scotland was conducted in 2013-14, which resulted in an estimate of 22 per 100000 population needing transfer to neurosurgery or neuro-intensive care each year; the other 308 per 100,000 population approximately are mainly admitted to hospital for observation, managed of behavioural and other issues, and to start hospital-based rehabilitation (4).

Some robust and detailed epidemiological studies have been conducted in Glasgow on the outcome after hospital admission with a head injury (3), (5), (6). The initial cohort was identified following hospital admission between February 1995 and February 1996 and subsequent reports have charted progress at intervals; the most recent report describes the outcomes at 12-14 years post-injury. The researchers found that around 90% of hospital admissions were for mild head injuries (GCS 13-15), around 5% for moderate head injuries (GCS 9-12) and 4% for severe head injuries (GCS 1-8). Approximately 50% of the people that were followed up in each category of head injury (mild, moderate or severe) were found to have a disability at one year. However because admission for a mild injury is much more common this group accounted for by far the highest numbers with disability. Around one third of patients were lost to follow up in this study and assuming that most of these are well and have made a good recovery the researchers estimated that between 100 and 150 people per 100,000 will develop a brain injury related disability per year, based on those that are admitted to hospital.

The researchers followed up a proportion of the patients admitted to hospital to assess their status at one year post-injury and the findings are summarised in table 3.

Table 3: Outcome at one year post-injury for those admitted to hospital with a brain injury

Severity of head injury	Dead/PVS	Severe disability	Moderate disability	Good recovery
Mild injury	8%	20%	28%	45%
Moderate injury	16%	22%	24%	38%
Severe injury	38%	29%	19%	14%
Total	11%	21%	25%	43%

The contents of table 3 suggest that around 20% of all patients admitted to hospital for a brain injury will have a severe disability after one year. If the hospital admission is assumed to be 330 per 100,000 population, it is expected that severe disability would affect around 65 per 100,000 population. However in this study it is assumed that most of the 30% of patients that are lost to follow up are likely to be well and have made a good recovery. This suggests that a more accurate estimate of severe disability and need for structured multi-disciplinary rehabilitation at around 45 per 100,000 in the Glasgow area. The need for structured multi-disciplinary rehabilitation in other parts of Scotland is likely to be somewhat lower than this on account of a lower prevalence of social, economic and behavioural factors that might predispose people to disability after a brain injury (co-existence of substance misuse, mental health or physical health problems).

A survey of care homes in Glasgow in 2,000 concluded that around 5 people per 100,000 population were resident in care homes or a similar setting for an acquired brain injury. Changes to national and local policies since that time would suggest that the figure is likely to be lower than this in 2015 (7).

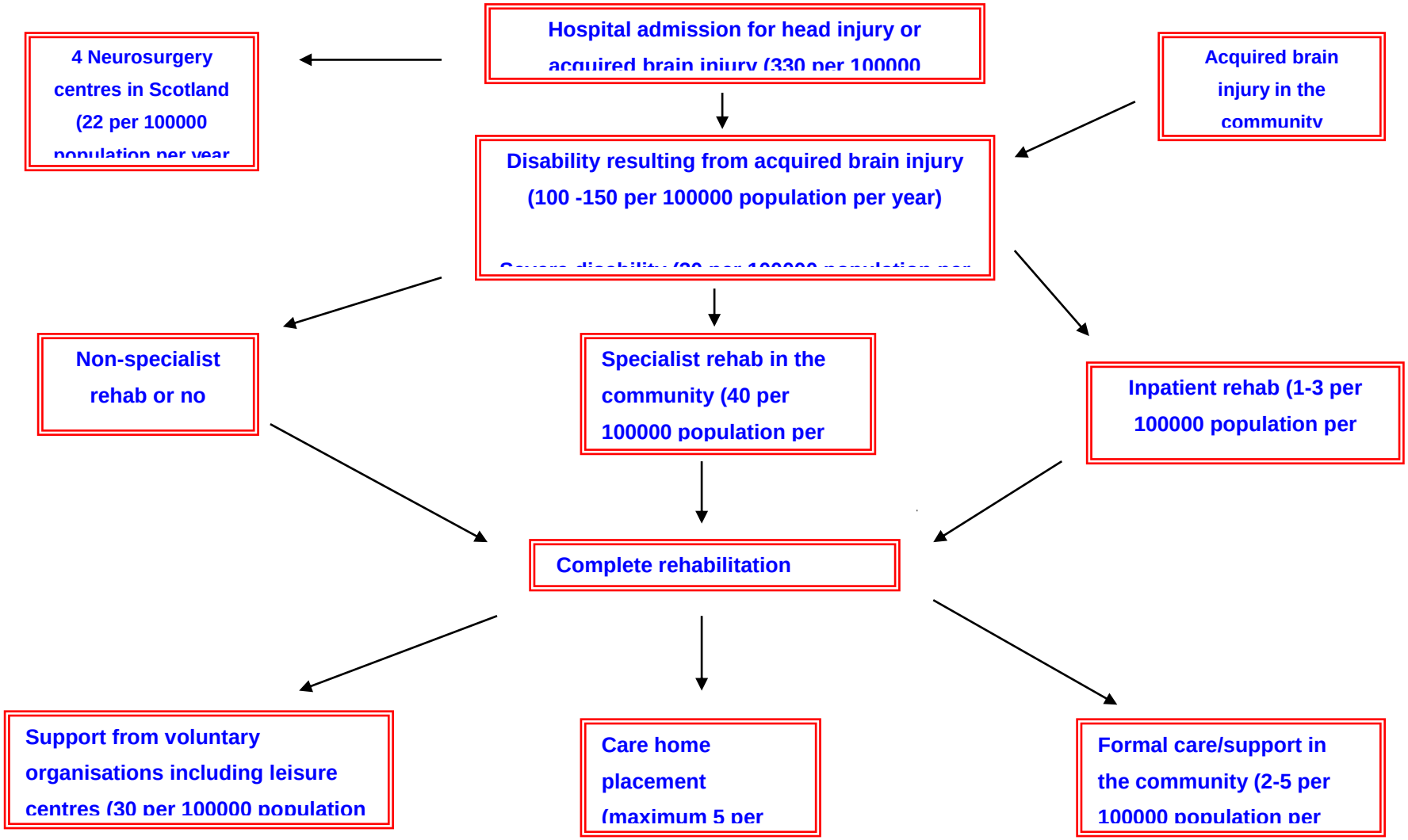
3 Services for people with Acquired Brain Injury

An overall pathway for brain injury patients is summarised in Figure 1. It is based on the pathway developed by the British Society for Rehabilitation Medicine (8) and the outputs of a service mapping exercise that was conducted through the Scottish Acquired Brain Injury Network (SABIN) in 2009 and updated more recently (9). Many patients with a significant brain injury will attend Accident and Emergency, after which they will either be sent home with advice, be referred to an outpatient clinic for review, be referred for some community-based rehabilitation, or be admitted to hospital for observation. Once in hospital the patient may be referred to neurosurgery to be considered for an intervention before discharge to the community (with or without community-based rehabilitation) or to an inpatient rehabilitation facility. During or after rehabilitation the patient may receive support through social work (day care, home care package, care home) or through voluntary agencies that offer a variable range of support services depending on where the patient lives. There are some care home centres that specialise in the care of people with complex problems such as brain injury (Leonard Cheshire, Capability Scotland etc). Many areas also offer an assessment and signposting service for patients that develop new symptoms related to a previous head injury or for patients that never received any initial treatment for their head injury but develop significant problems at a later stage. Most brain injury services develop close links with related services that patients will often need such as mental health, addictions and neurology.

All board areas in Scotland provide A&E services, beds on a hospital ward, community-based multi-disciplinary rehabilitation (generic or specific to brain injury), access to social care services, and some voluntary agency support. There are four dedicated neurosurgery facilities in Scotland located at the Southern General hospital in Glasgow, the Western General hospital in Edinburgh, Aberdeen Royal Infirmary and Ninewells hospital in Dundee - all boards in Scotland have some access to these. All boards also offer uni-disciplinary AHP services that can often manage patients with mild or moderate disability related to a brain injury. Some boards offer generic inpatient rehabilitation facilities or even a specific neuro-rehabilitation inpatient facility that usually involves input from a consultant in rehabilitation medicine and a multi-disciplinary team. There are also three dedicated brain injury inpatient rehabilitation centres in Scotland located at Murdostoun Castle in Lanarkshire, the Astley Ainslie Centre in Edinburgh and the Robert Ferguson Unit in Edinburgh (mainly for patients with challenging behaviour related to a brain injury). SABIN has published a set of service standards that cover all aspects of the brain injury patient pathway and apply to most of the services listed above (2).

Figure 1 describes a generic pathway for acquired brain injury treatment and rehabilitation that is based on the above description of services in Scotland. The estimates of need at each stage of the patient pathway are based on the findings of the epidemiology section in this paper and a review of service usage data in Glasgow and Lanarkshire in the period from 2012 to 2014. There were challenges involved in getting some of this data, particularly in relation to estimating the use of voluntary organisations and formal care/support in the community where only approximate numbers are available.

Figure 1 - GENERIC PATHWAY FOR ACQUIRED BRAIN INJURY REHABILITATION



4 The cost of brain injury rehabilitation

A short analysis of service costs and throughput of patients in Lanarkshire and Glasgow has helped to give an approximate cost per brain injury patient that is offered specialist rehabilitation in the home/community setting or as an inpatient (national brain injury rehabilitation centre). This analysis was carried out in 2015 and largely relates to the calendar year 2014. Typically a brain injury client offered rehabilitation in a community setting or in their own home over a period of four to six months is estimated to cost between £2,000 and £4,000; this crude estimate is obtained simply by dividing the service annual budget by the number of clients seen in one year. A more complex brain injury patient offered rehabilitation as an in-patient in a national brain injury rehabilitation centre for a period of 3-12 months can be expected to cost between £35,000 and £40,000 on average; the small number of more complex patients requiring neuropsychiatric input at the Robert Ferguson Unit would cost a lot more than this. It is uncertain what the average cost would be for a brain injury patient that receives in-patient rehabilitation on the rehabilitation ward at their nearest acute hospital or community hospital or the cost for a patient that receives a mix of inpatient and outpatient rehabilitation in this setting.

There is some uncertainty about the average costs attached to providing social care support in the home or another community setting, largely because the intensity and duration of these care packages will vary hugely depending on the complexity of disability and care needs that the clients will have. For similar reasons it is challenging to provide a meaningful average figure for clients that spend a significant period of time in a care home or another institutional setting.

5 The supporting evidence base

The evidence base is more established in relation to the acute management of brain injury through the initial visit to A&E, hospital admission for observation, neurosurgical intervention and any follow up through outpatients or a dedicated head injury clinic. The evidence is well summarised in SIGN guideline 110 and supports most of the interventions that are routinely delivered in hospitals across Scotland (10). However there are difficulties inherent in producing high quality rehabilitation studies by traditional methods on the subject of brain injury rehabilitation. The treatments involved are complex and tailored to individual needs, involving teaching, behavioural change and environmental changes that are not universal in nature nor easily randomised in a research setting. The goals associated with successful treatments will vary from one individual to the next, so that the use of outcomes measures that are simple to measure for research will not be comprehensive or even necessarily illustrative of what the intervention has delivered. Also brain injury rehabilitation is sometimes delivered by multiple disciplines working synergistically, meaning that quality appraisal becomes more complicated. For this reason there are few randomised controlled trials on the effectiveness of brain injury rehabilitation and the observational studies carried out rarely control for selection bias. Most studies are small case series, reflecting the individual nature of rehabilitation interventions and the challenges of using a more complex study design. This limits the generalizability of the findings of a study to the wider community of brain injury patients and limits the ability to draw conclusions about cause and effect.

SIGN 130 was launched in March 2013 but few strong recommendations appear in the guideline on account of the above limitations with evidence in this field (11). Both inpatient rehabilitation and community-based rehabilitation are considered to be more beneficial to patients than not receiving either of these interventions and it is recommended that these be delivered by a specialist multi-disciplinary team. Some specific interventions are also endorsed such as cognitive behavioural therapy for those with anxiety symptoms, strategies to help manage identified cognitive deficits, and interventions for spasticity, seizures and other recognised complications of brain injury.

In relation to cost-effectiveness of brain injury rehabilitation, the prospective study of Worthington et al 2006 is based on 101 patients admitted to BIRT inpatient rehabilitation units in Birmingham, Leeds, York, and Milton Keynes (12). The study concluded that the lives of patients improved a lot after rehabilitation and also that the costs of inpatient rehabilitation were exceeded by the huge cost savings that resulted in terms of reduced need for care and support for the rest of that person's life. The cost savings were calculated by comparing care needs before and after rehab and they adjusted the costs to allow for inflation and discounting; they also subtracted the costs of the inpatient rehab. This study was prospective so they recruited patients as they were admitted to BIRT units and followed them up. However there are a few limitations with this study as follows:

1. Some patients may have recovered a bit over time in any case even without any rehab so their care costs would reduce anyway. This study had no control group so did not adjust for this.
2. They included informal, family-provided care and costed this at an hourly rate so the actual savings to the public sector budget would be less than what is stated here.
3. The patients were all severely disabled and needed inpatient rehabilitation and therefore do not reflect the totality of patients affected by brain injury.
4. BIRT was both service provider and the commissioner of the research.

In spite of the above limitations the study concluded that the average savings from inpatient rehab amounted to between £70 and £150 per day, between £25K and £50K per year and up to around £1million over a person's lifetime. This is achievable if the person is admitted for rehab within 12 months of their injury. Delays to admission after injury reduce the effectiveness of rehab and the cost savings are only half as much if the delay is around 2-3 years.

6 Conclusions

Brain injury is a complex condition that can have unpredictable long-term effects on a person depending on the nature of the injury, the medical history of that person and their exposure to other wider economic and social factors. While the evidence of effectiveness and cost-effectiveness is not as robust as for some other conditions, there are sound reasons for this, and the expert consensus is that treatment and structured multi-disciplinary rehabilitation is likely to be effective, especially for those with severe disability after their brain injury.

An estimate of the numbers needing intervention at each stage of the patient pathway is provided in Figure 1; these numbers are based on experience in Glasgow and Lanarkshire and the numbers needing intervention are likely to be lower in other parts of Scotland.

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