

Scottish Acquired Brain Injury Network

Paediatric Best Practice Statements, 2018

NOTE

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.



**Paediatric
Acquired Brain Injury
Best Practice Statements**

**Scottish Acquired Brain Injury National
Clinical Network, NHS Scotland 2018**



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Target Audience NHS managers and service commissioners, NHS staff, partner organisations, service users, family and carers.

Description Acquired Brain Injury in Children and Young People: Best Practice Statements

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Paediatric Acquired Brain Injury (ABI) Best Practice Statements

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1. Introduction

1.1 Background to the NHS Scotland Acquired Brain Injury National Managed Clinical Network

The Scottish Needs Assessment Programme (SNAP) report (2000) and progress report (2003) published recommendations in relation to Acquired Brain Injury (ABI) services; including increased strategic service organisation and the creation of National Managed Clinical Networks (NMCNs) to develop and improve care pathways, service accessibility and information provision for professionals and patients.

The NHS Scotland Acquired Brain Injury NMCN (known as SABIN) was established in 2006, with a remit to improve the quality of NHS healthcare for patients with ABI across Scotland. SABIN is led by a Steering Group, linking a network of service-user, carer and professional members (across health, voluntary, local authority, education and research agencies). More details can be found on the SABIN website (www.sabin.scot.nhs.uk).

In line with SNAP report recommendations, SABIN aims to improve access to quality services for children and adults living with ABI across Scotland, promoting best practice and continuous service improvement. The network published standards for Traumatic Brain Injury in Adults in 2009. The current standards Best Practice Statements were developed by a Paediatric Short Life Working Group, under the direction of the SABIN Steering Group.

1.2 Scope of the Paediatric Acquired Brain Injury Best Practice Statements


The scope of this document is to outline NHS clinical service Best Practice Statements for paediatric ABI. These Best Practice Statements provide direction regarding the level of performance that service users and their families can expect from NHS Scotland paediatric ABI services. This is not a clinical guideline, and the reader is directed to relevant clinical guidelines published elsewhere. The target audience for the document includes healthcare planners and commissioners, NHS professionals working with children and young people with a diagnosis of ABI, as well as other agencies working in partnership with NHS healthcare services. The Best Practice Statements are in line with aims of current Scottish Government strategy, aiming to deliver quality healthcare services to people living with long-term conditions in Scotland (e.g. Improving Care Pathways for Long Term Conditions, 2010; the NHS Scotland Healthcare Quality Strategy, 2010).

1.3 Definition of Paediatric Acquired Brain Injury

For the purposes of this document, Paediatric ABI is defined as “damage to the brain that was sudden in onset and occurred after birth and the neonatal period. It is thus differentiated from birth injuries, congenital abnormalities and progressive or degenerative diseases affecting the central nervous system” (SNAP report, 2000). This definition is adopted by Scottish ABI clinical guidelines (SIGN 130, 2013), and is directly relevant to a paediatric group; allowing inclusion of traumatic (physical injury of sudden onset and severity which require immediate medical attention) and non-traumatic (injuries to the brain not caused by an external physical force to the head, e.g. infection, tumour, hypoxic, vascular, toxic and/or metabolic) mechanisms of injury while differentiating the definition from injury to the brain during birth and early childhood, and congenital abnormalities such as cerebral palsy. Furthermore, this definition is operationally useful in addressing service Best Practice Statements, since children and young people sustaining ABI have similar service needs (Forysth & Kirkman, 2012; McKinlay et al, 2016). The term “paediatric” is used throughout the document as a short-hand reference for NHS services provided for children or young people up to the age of 16 years (although many community NHS services will continue to provide services to young people through transition up to 18 years).

1.4 Rationale for Paediatric Acquired Brain Injury Best Practice Statements

There is now widespread appreciation that children require dedicated services, because they are physiologically, psychologically and developmentally distinct from adults (Better Health, Better Care, 2009). Recent Scottish clinical guidelines and best practice statements (SIGN 130 Rehabilitation of Acquired Brain Injury in Adults, 2013; Traumatic Brain Injury in Adults: Standards, SABIN, 2009) have taken



care not to apply evidence from adult ABI research findings to paediatric populations. Instead, these publications highlight the need to consider paediatric groups in the context of paediatric evidence, legislation and service systems. There is greater potential to improve health and well-being outcomes through the application of age-appropriate interventions delivered by staff trained in the care of children. Services should be flexible, timely, holistic, integrated, child-centred and sensitive to the service-user's changing needs (Department of Health, 2004, ABI NSF for Children, Young People and Maternity Services). It is important to develop Paediatric ABI best practice statements as distinct from those for adults to enhance suitable clinical pathways (the process of the care provided) across rapid developmental periods, addressing (1) age-appropriate service needs from pre-school to mature teenage years; (2) the potential for emerging brain impairment across developmental stages; (3) the architecture of paediatric service provision; (4) the importance of school inclusion and early vocational experiences in long-term rehabilitation; and (5) the need for planned transition to adult services.

For children and young people living with ABI, attention must be paid to relevant developmental and societal roles within family and school systems, as well as age-appropriate peer socialisation and community participation. Child protection legislation*, Getting It Right for Every Child across school years, early vocational support, and transition services must all be considered. ABI is often not identified on acute (emergency) admission, but emerges through family report at longer-term follow-up, with persistent concerns regarding physical, cognitive, emotional and behavioural changes in functioning following original injury or illness. Importantly, ABI is identified as a change in developmental trajectory for a young person, previously developing normally. Difficulties may only emerge as later developmental stages in that trajectory are reached, revealing increasing academic and social-skills gaps between those with paediatric ABI and their peers (Anderson et al, 2005; Babikian & Asarnow, 2009). Cognitive difficulties most commonly affect executive function, attention, speed of processing and working memory which are normally anticipated to mature across teenage years in relation to increased white matter growth and prefrontal cortex connectivity (Nagy et al, 2004; Crone, 2009). The potential for difficulties to emerge years after original diagnosis, has led to proposed models of service delivery which advocate clinical follow-up over developmental trajectories (Chevignard et al, 2009; McKinlay et al, 2016), but this has rarely happened in service provision. There is evidence that a significant proportion of children and young people may be missing out on referral to rehabilitation services, even in moderate to severe ABI cases (Lodh et al, 2016). Transitional processes in neurodisability have also been identified as poorly developed (Action on Neurology, 2005; Transition: Getting It Right for Young People, 2006). It is important that those children and young people who require ongoing rehabilitation have co-ordinated plans that include early identification of transitional needs.

1.5 Incidence of Paediatric Acquired Brain Injury

Paediatric ABI results from a wide range of diagnoses, and often emerges over time, making prevalence estimates challenging. The Best Practice Statements provide recommendations for further data collection, standardised severity assessment, patient information provision and record-keeping; which may all contribute to improved incidence rate reporting, identification of service needs and improved care pathways for follow-up.

1.5.1 Traumatic causes of ABI

Traumatic Brain Injury (TBI) is the most frequent and well documented cause of ABI. It requires emergency hospital admission and management. A recent Information and Statistics Division (ISD) based study (Shivaji et al, 2014) indicates an annual rate of 488.24 children per 100,000 population (aged 0 to 14 years) admitted to hospital after head injury. Scotland has a higher rate of head injury incidence than other European countries, indicating a greater public health challenge.

It is important to identify the severity of head injury during acute admission to determine if an injury to the brain is suspected, to indicate prognosis and the potential need for follow-up. There is a great deal of evidence showing that original injury severity measured via specific and standardised methods is predictive of long term outcome. For this reason, severity of injury should be measured via standardised assessment of level of consciousness (Glasgow Coma Scale (GCS)) and Post Traumatic Amnesia (PTA), and recorded

in medical records and discharge reports. The majority (>90%) of 'head injury' admissions are for minor head injury, for which most children will be discharged home without ill effect. There is increasing public health awareness about minor head injury and concussion, particularly during repeated sports injury; and there are specific child guidelines published by the Scottish Government to provide information for children injured during school or club sports participation (Sports concussion: If in doubt, sit them out, 2014). A minority of children and families will report persistent post concussive symptoms following mild TBI, usually associated with psychosocial factors (Yeates et al, 2010; Ryan et al, 2016). These children should initially be followed up through their GP and local services. Moderate-severe TBI (as determined by depressed GCS scores and/or longer PTA) remains one of the largest causes for long-term disability in the paediatric age group, resulting in many future years of disability and service need. The service challenge is in providing appropriate information for all discharges, and in identifying those who may need ongoing follow-up, review and/or rehabilitation.

1.5.2 Non-Traumatic Causes of ABI

Childhood arterial ischaemic stroke in the UK was recently estimated as occurring in 1.60 per 100,000 of the general population each year (Mallick et al, 2013). The annual incidence of non-traumatic coma in the UK has been reported as 30.8 per 100,000 children (aged up to 16 years) (Wong et al, 2001). In considering all causes of ABI, a recent review by Forsyth & Kirkman (2012) estimated that 1300 children in the UK sustain an ABI resulting in significant neurological impairment every year (including diagnoses of TBI, childhood stroke, infection, hypoxia and brain tumours). These Paediatric ABI Best practice statements acknowledge the lack of accurate information regarding the prevalence (number/ rate) of childhood survivors of ABI living with sequelae and recommendations include improved data collection of the incidence of diagnoses associated with ABI, as well as identifying the service needs of this population in Scotland.

1.6 Outcomes and Rehabilitation after Paediatric Acquired Brain Injury

ABI often results in complex physical, mental, social and vocational needs continuing for many years after diagnosis, and services must identify and improve appropriate pathways of care and increase service accessibility (SNAP report, 2000; National Service Framework for Long Term Conditions, 2005). There is a tentative, but growing evidence base for the effectiveness of cognitive, behavioural and psychosocial rehabilitation interventions, highlighted by the publication of recent systematic reviews (Catropa et al, 2012; Gordon & DiMaggio, 2012; Ross et al, 2011; Rohling et al, 2009; Laatsch et al, 2007; Ylvisaker et al, 2007; Anderson & Catropa, 2006). Due to the range of potential outcomes after paediatric ABI, intervention should be multidisciplinary, and involve longer-term community follow-up, as well as inter-agency and inter-disciplinary working (across NHS, Local Authority and Voluntary Agencies). The heterogeneity (diverse range) of the ABI population means that an individualised and tailored approach is required. The involvement of the whole family in the rehabilitation process, as well as community-based interventions within home and school environments, increases intervention effectiveness (Braga et al, 2005; Hickey et al. 2016). Although some initial evidence-based recommendations can be made, there is an ongoing need for quality research to draw conclusions on intervention effectiveness.

1.7 Paediatric Acquired Brain Injury Care Pathways

The development of appropriate care pathways involves consideration of available general and specialist expertise, the availability of resources across agencies and geography and the needs of the individual service user and their family. It is recognised that ABI specialist services are often provided at a national level, and that there are differences in service structures and provisions across NHS Boards, partly due to geography and population distribution. The current Best Practice Statements aim to ensure that pathways across local, regional and national specialist services are developed and audited, and that where services exist quality care is delivered.

Children with ABI may initially present (be reported) through different services (ranging from Accident & Emergency to the family General Practitioner). The Best practice statements therefore need to address a broad range of potential pathways for a paediatric ABI service-user (patient) (as well as age at diagnosis/ service entry). There may be no “typical” pathway, but a co-ordinated individualised planned pathway for a child/young person through existing services.

Children and young people with complex ABI presentations sometimes fall between service gaps, and their needs must be considered on an individual basis in partnership with relevant services; for example where specialist ABI services do not exist or where the main presenting difficulties may most appropriately be addressed by Child and Adolescent Mental Health Services (CAMHS) or Learning Disability services. This has been identified in other published Best Practice documents (Northern Ireland Health & Social Care Board’s Regional Acquired Brain Injury Implementation Group; Brain Injury: Service Best practice statements and Quality Indicators, 2010; Service provision for children and young people with acquired brain injury: Practice recommendations, McKinlay et al, 2016). Where provision is made by non-specialist services, their objectives may include increasing access to appropriate ABI training and specialist consultation for the local workforce. Key principles from these service frameworks are recognised within the current document, including the need for a coordinated integrated holistic approach and partnership working (Children and Young People’s Mental Health: A Service Framework for Promotion Prevention and Care, 2005; The same as you?, 2000). These themes are in line with quality requirements outlined within the National Service Framework for Long Term Conditions (2005).

2. Best Practice Statements Development Process

2.1 SABIN Paediatric Best Clinical Practice Statement Short Life Working Group

Under the direction of the SABIN Steering Group, the Paediatric Best Practice Statement Short Life Working Group developed the Best Practice Statements, following NHS Quality Improvement Scotland (NHS QIS) methodology. The Short Life Working Group membership and details of the wider consultation group comprising multiagency contributors, can be found in Appendix 1.

The process of statement development involved service mapping of existing NHS services across Scotland, review of existing best practice statements and guidelines, consideration of key stages in the patient pathway, development of draft statements, and a process of peer review by relevant stakeholders. The peer review process included multidisciplinary draft consultation across Scotland in face-to-face review meetings, and feedback from a parent focus group (detailed in Appendix 1). Analysis of professional and service-user feedback was incorporated into the final document.

2.2 Existing Best Practice Statements/Guidelines

The group reviewed published Scottish, UK and international best practice statements and guidelines related to ABI and TBI, for both adult and paediatric populations. The following publications were considered:

- ABI National Managed Clinical Network NHS Scotland (2009): Traumatic Brain Injury in Adults Standards.
- British Society of Rehabilitation Medicine (2009): BSRM Best Practice Statements for Rehabilitation Services Mapped on to the National Service Framework for Long-Term Conditions.
- Child Brain Injury Trust (2008): Lost in Transition; A Family's Guide to Coping with Change Following Childhood Acquired Brain Injury.
- Child Brain Injury Trust (2005): Scotland's Invisible Children: Acquired Brain Injury Revealed.
- Department of Health (2004): Acquired Brain Injury, National Service Framework for Children, Young People and Maternity Services. Department of Health, December 2004.
- Department of Health (2005): National Service Framework for Long Term Conditions. Department of Health, March 2005.
- Northern Ireland Health & Social Care Board's Regional Acquired Brain Injury Implementation Group. Brain Injury: Service Best Practice Statements and Quality Indicators (2010).
- Northern Ireland Health & Social Care Board's Regional Acquired Brain Injury Implementation Group. Acquired Brain Injury Pathway for Children & Young People (2010).
- National Institute for Health and Clinical Excellence Guideline 176 (2014): Triage, assessment, investigation and early management of head injury in infants, children and adults.
- New Zealand Guidelines Group (2007): Traumatic Brain Injury: Diagnosis, Acute Management and Rehabilitation.
- Royal College of Physicians & British Society of Rehabilitation Medicine (2003): Rehabilitation after Acquired Brain Injury. National Clinical Guidelines.
- Scottish Intercollegiate Guidelines Network 46. Early management of patients with a head injury (2000). (Available from <http://www.sign.ac.uk/guidelines/fulltext/46/index.html>)
- Scottish Intercollegiate Guidelines Network 130. Brain Injury Rehabilitation in Adults (2013). (Available from <http://www.sign.ac.uk/pdf/sign130.pdf>)

- International Brain Injury Association’s World Congress (IBIA) special interest group, McKinlay et al, 2016. Service provision for children and young people with acquired brain injury: Practice recommendations.
- Social Care Institute for Excellence (2009): Think Child, Think Parent, Think Family: a Guide to Parental Mental Health and Child Welfare.
- Stroke in Childhood: Clinical Guidelines for Diagnosis, Management and Rehabilitation (2004) Paediatric Stroke Working Group, Royal College of Physicians.

2.3 Best Practice Statement Development Process

The current Best Practice Statements were developed based on NHS Quality Improvement Scotland (QIS): Standards for Clinical Governance & Risk Management (2005) guidance. NHS QIS standards are designed to be clear and measurable, based on appropriate evidence, and written to take into account other recognised standards and best practice clinical guidelines. The current document was developed following this NHS QIS guidance. Each statement follows the same format, including a title and a description of the level of performance to be achieved. A rationale section provides the reasons, with reference to the relevant evidence base, on why the statement is considered important. Quality criteria state evidence, which determine how a statement might be achieved. Some criteria are essential, so it is expected that they will be met wherever a service is provided. Other criteria are desirable in that they are being met in some parts of the service, and demonstrate levels of quality that other providers of a similar service should strive to achieve. The criteria are numbered for ease of reference and the numbering is not a reflection of priority.

3.0 Best Practice Statements for Paediatric Acquired Brain Injury (ABI)

Statement 1:	<p>Organisation of Care for Children and Young People with Acquired Brain Injury (ABI):</p> <p>In each NHS Board the needs of children and young people with Acquired Brain Injury (ABI) are identified and met by quality services, which are integrated, planned and managed through governance and delivery structures.</p>
Statement 2:	<p>Acute Management for Children and Young People with Suspected Acquired Brain Injury (ABI):</p> <p>All children with suspected ABI who require emergency admission receive timely and accurate medical assessment and management.</p>
Statement 3:	<p>Post-Acute Inpatient Rehabilitation of Paediatric Acquired Brain Injury (ABI):</p> <p>Designated multi-disciplinary teams (MDTs) provide comprehensive inpatient assessment and rehabilitation for paediatric ABI, involving a high level of family participation within a goal-based rehabilitation programme. Patient pathways into inpatient rehabilitation are clear, and planned discharge to community services is co-ordinated and integrated.</p>
Statement 4:	<p>Outpatient Follow-up and Community Rehabilitation: Outpatient follow-up and ongoing community rehabilitation is provided as close to home as possible for the child/young person affected by ABI, through an MDT and interagency approach involving social and educational services.</p>
Statement 5:	<p>Information for Children, Young People, Families and Carers:</p> <p>Children and young people with ABI and their parents /carers are enabled and supported to take part in decision-making through access to high quality information in accessible formats, taking account of developmental stage and communication abilities.</p>
Statement 6:	<p>Transition to Adult Services:</p> <p>For all young people with ABI who require ongoing service input, there is a clear transitional pathway (route) from paediatric services to relevant adult services.</p>

Statement 1: Organisation of care for children and young people with Acquired Brain Injury (ABI)

In each NHS Board the needs of children and young people with acquired brain injury (ABI) are identified and met by quality services, which are integrated, planned and managed through governance and delivery structures.

Rationale:

Leadership and accountable governance structures are required to plan, design and deliver person-centred, clinically effective, safe, equitable, and timely services. Joint working partnerships between patients, families, healthcare professionals, and other agencies enhance the delivery of quality services. Specialist rehabilitation services should be planned and co-ordinated through networks.

References: 1 - 15

Essential criteria:		Examples of evidence:
1.1	There is a named lead clinician and senior manager with responsibility for the planning, audit and review of paediatric ABI services, who is a member of, or reports to the NHS Board.	Recognised lead person for paediatric ABI. Remit in job description. Reporting arrangement.
1.2	The NHS Board has a current strategic plan for paediatric ABI in partnership with Local Authority and Voluntary agencies.	Joint strategic plan for ABI (including paediatric ABI) which is documented, dated and has timescales for review.
1.3	The NHS Board collects and collates data on incidence and activity at all points in the patient pathway and is able to demonstrate how this data has been used to plan and co-ordinate service provision. There are appropriate Information Services Division read-codes to record incidence.	Incidence and activity data available and referred to in the strategic or service plan.
1.4	Formal partnerships are established between NHS Boards, Local Authorities and other providers of services to children and young people with paediatric ABI to determine strategy and commission services.	Interagency group established to include: <ul style="list-style-type: none"> • remit • minutes • implementation plan
1.5	There is a range of public and patient/family/carer involvement in the planning of paediatric ABI services. NHS boards gather patient perceptions and personal experience of care, and use that information to make improvements to care.	Reports from public/patient involvement events and consultation.

1.6	All NHS boards have a named professional lead who is responsible for the care of that patient, ensuring that patients are assessed and, if appropriate, referred for further ABI assessment and rehabilitation.	Named professional lead e.g. ABI nurse specialist.
1.7	<p>A set of core competencies for staff providing services to children and young people with ABI is established.</p> <p>Education and training needs (of staff providing services to children and young people with ABI) are identified and addressed via personal and professional development plans. This includes both specialist and general services.</p>	<p>Training needs assessment reports.</p> <p>Regular brain injury awareness and training programmes.</p> <p>Induction modules/ programmes.</p>

Statement 2: Acute Management for Children and Young People with Suspected Acute Brain Injury (ABI)

All children with suspected ABI who require emergency admission receive timely and accurate medical assessment and management.

Rationale:

Early recognition of ABI and timely intervention and management improves outcome and helps to identify those who require medical follow-up.

References: 5, 6, 16 - 27

Essential criteria:

Examples of evidence:

2.1	<p>A Glasgow Coma Scale (GCS) score (including Total GCS and detailed breakdown of Eye, Motor and Verbal response scores) should be recorded at the earliest opportunity, by both paramedics and on admission to Accident and Emergency (A&E). GCS is a standardised measure which is predictive of long term outcome.</p> <p>GCS should be monitored and recorded at frequent intervals, and always be assessed and recorded prior to transfer or discharge.</p>	<p>Paramedic records.</p> <p>GCS recording and monitoring in A&E records.</p> <p>GCS provided in all written transfer and discharge summaries.</p> <p>Emergency Department cards evidence/patient records.</p>
2.2	<p>In the case of traumatic causes of Head Injury, and in accordance with SIGN 110 and NICE 176, assessment of Post Traumatic Amnesia (PTA) should be undertaken at regular intervals by an appropriately trained physician using a brief, standardised and reliable 'bed-side' assessment of orientation and anterograde memory (loss of memory after incident). PTA is a standardised measure which is predictive of long term outcome.</p> <p>PTA (or abbreviated PTA for younger children) should always be assessed and recorded in the patient record prior to transfer. Patients within PTA should not be discharged.</p>	<p>A&E PTA assessment protocol.</p> <p>Administration and recording of PTA in medical notes using standardised measures (e.g. Westmead PTA Scale or the Children's Orientation and Amnesia Test).</p>

<p>2.3</p>	<p>Clinical Guidelines should be used to guide assessment and intervention led by acute care consultants. Published clinical guidelines are continually reviewed and updated and are based on the best current evidence.</p> <p>The guidelines should be used in a flexible manner that is sensitive to an individual child/ young person and their neurological status, and the expertise and resources of the local acute care department.</p> <p>Where there are indications of non-accidental trauma, child protection proceedings must be instigated in line with Getting it Right for Every Child (GIRFEC) framework and relevant child protection guidance.</p>	<p>Local acute care protocols based on best evidence and published clinical guidelines are person centred and applied flexibly.</p> <p>Guidelines directly relevant to acute care and paediatric ABI include those on head injury, stroke, brain tumour and meningococcal disease (References: 16-20).</p>
<p>2.4</p>	<p>Transfer to tertiary centres: Where a child/ young person has a significantly depressed level of consciousness (GCS<13) and/or they require paediatric intensive care, paediatric high dependency or specialist care that is not available locally, supervised retrieval for transfer to the nearest regional/ national neuroscience/ paediatric inpatient centre/ specialist children's hospital should be arranged in a timely manner.</p>	<p>Local protocols for defined assessment criteria and agreements for transfer to regional neurosciences centres.</p>
<p>2.5</p>	<p>Following resolution (completion) of emergency care treatment, children with a known ABI should be assessed and transferred to clinical services appropriate to their needs for further management (including where required, inpatient multi-disciplinary rehabilitation teams or equivalent).</p>	<p>Protocol for transfer to on-going care for those patients with rehabilitation needs.</p> <p>Multi-Disciplinary Team Rehabilitation service description (including remit and personnel requirements)</p>
<p>2.6</p>	<p>Where a minor injury to the head is identified (i.e. GCS 15/15, no loss of consciousness, no PTA) it is recognised that there is a negligible risk of ABI.</p> <p>Children should be discharged from A&E following examination (including GCS and PTA recording) and an appropriate period of observation.</p> <p>The content of a head injury advice leaflet (including expected recovery and common early symptoms) should be discussed fully with children and their family/carers, before being given to them to keep. It should include appropriate local contact details in case of ongoing symptoms (in accordance with SIGN 110 and NICE 176). Leaflets should advise parents to return to their doctor/A&E with any concerns</p>	<p>Protocol for discharge following minor head injury.</p> <p>Recording of GCS and PTA in medical records prior to discharge.</p> <p>Head injury leaflets available in A&E - Appendix 4 provides an example of good practice: SABIN Minor Head injury Leaflet.</p>

2.7	<p>Acute Care discharge paperwork and recommendations for follow-up: A written discharge summary with details of attendance at A&E, GCS and PTA is delivered to the child's GP.</p> <p>This should clearly state the assessments undertaken, interventions initiated, whether there were any concerns relating to the possibility of an ABI, and any recommended follow-up.</p>	<p>A&E discharge protocol.</p> <p>Written discharge summary in hospital medical records provided for any onward inpatient/ outpatient consultants and the child's GP.</p>
2.8	<p>Follow-up After Hospital Discharge: All children and young people with a depressed level of consciousness (GCS<13) during admission, should be invited for neurosurgical review within three months of discharge, as identified and recorded on acute care/hospital discharge.</p>	<p>Identification of patients for review after discharge.</p>

Desirable criteria:

2.9	<p>Patients with minor/ mild head injury concerned about persisting symptoms are reviewed by their GP or other relevant medical contact (such as those detailed on local discharge leaflet) within two weeks of discharge.</p> <p>Children with reported emotional or learning difficulties which are considered unrelated to ABI should be referred, in a timely way, to relevant services (such as CAMHS and/or Educational Psychology).</p>	<p>Protocol for on-going care of patients with minor or mild head injury who fail to make expected progress (including referral to other services).</p> <p>Service description. Referral procedure.</p>
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Statement 3: Inpatient Rehabilitation of Paediatric Acquired Brain Injury (ABI)

Designated multi-disciplinary teams (MDTs) provide comprehensive inpatient assessment and rehabilitation for paediatric ABI, involving a high level of family participation within a goal-based rehabilitation programme. Patient pathways into inpatient rehabilitation are clear, and planned discharge to community services is co-ordinated and integrated.

Rationale:

A coordinated MDT approach allows multidimensional assessment of physical, emotional, cognitive and behavioural sequelae (condition as a result of previous disease/injury), and improves outcome following paediatric ABI. Family participation improves outcome. Goal-based programmes allow greater patient and family participation in achieving outcomes, and allow staff and families to identify progress.

Effective discharge facilitated by a comprehensive MDT approach, involving the child/young person and their family, ensures appropriate hospital follow-up, continuing community care and educational support. Clear referral pathways allow for timely assessment and seamless progression between acute, inpatient and community services.

References: 5 – 7, 22, 28 – 38

Essential criteria:

Examples of evidence:

3.1	There is a clear referral pathway to the inpatient neurorehabilitation service.	<p>Established written service description, clear referral pathway and referral criteria.</p> <p>Information leaflets for referrers including referral criteria.</p> <p>Written information available for child/ young person and family/ carers (see Statement 5 for more detail about information for service-users).</p>
3.2	Assessment for neurorehabilitation occurs at the earliest possible point (and within two weeks) of a patient being deemed medically stable even where there may be ongoing acute care needs (see Statement 2.5).	<p>Procedure for assessment.</p> <p>Audit of time between referral and assessment.</p>

<p>3.3</p>	<p>Inpatient neurorehabilitation MDT includes the following members with training, knowledge and skills relevant to paediatric ABI:</p> <ul style="list-style-type: none"> • Consultant Paediatric Neurologist/ Consultant in Paediatric Neurodisability/ Equivalent Specialist Paediatrician • Nurse specialist • Physiotherapist • Occupational Therapist • Speech and Language Therapist • Clinical Neuropsychologist and/or Clinical Psychologist • Hospital Outreach Worker/ Case Manager/ Key Worker (titles and professional background may vary depending on local protocols) <p>With consultation access to a full range of clinical specialities and identified external/joint working agencies e.g. Paediatric Liaison Psychiatry, Orthotics, Ophthalmology, Audiology, Hospital Outreach Teaching Service, Wheelchair Services, Hospital Social Worker, Dietetics, Discharge liaison nurse, as well as community Social Services, Education and Local Authority services, and Third Sector organisations.</p>	<p>Service profile.</p> <p>Job plans and job descriptions.</p> <p>Developed Hospital Outreach Worker/Case Manager/Key Worker role with job profile.</p> <p>Staff personal development plans.</p> <p>Training programmes.</p>
<p>3.4</p>	<p>Rehabilitation:</p> <ul style="list-style-type: none"> • Is put in place within five working days of completion of assessment • Is goal-directed, and evidence-based. • Addresses the developmental stage and needs of the child • Addresses physical, emotional, behavioural and cognitive rehabilitation needs of the child • Is individualised and tailored to the needs of the child and their family/ carers • Directly involves “hands-on” and shared participation from parents, carers and other family members • Adopts appropriate equipment • Provides information for and encourages participation from the individual, family, education, charity and third sector organisations and care/ social work • Invites feedback and service user involvement from children, young people and families 	<p>Evidence of goal setting including involvement of patient, parents and carers.</p> <p>Evidence of outcome measures and service user satisfaction measures at admission and discharge.</p> <p>Evidence of benchmarking against clinical guidelines – service audit.</p>
<p>3.5</p>	<p>Care environment: Children and young people are cared for in age-appropriate environments, with consideration of their age and developmental stage.</p>	<p>Children across the age range are provided for in settings with developmentally appropriate facilities, considering infant, child and teenage needs.</p>

3.6	<p>All children/ young people with ABI will be considered for a neuropsychological consultation as an inpatient (and for neuropsychological assessment at follow-up see Statement 4.3).</p> <p>Advice and management strategies are shared with patient, family and all appropriate agencies during the discharge process, including Educational Psychology and Schools.</p>	<p>Referral pathway for Clinical Neuropsychology consultation during inpatient stay.</p> <p>Clinical Neuropsychologist as integrated member of MDT – job profiles, MDT service description.</p>
3.7	<p>All children will be reviewed by the hospital neurorehabilitation service within three months of coordinated discharge.</p> <p>A process of ongoing review and consultation provision to community services (health, education, third sector and care) is clearly documented in the patient record with copies for relevant professionals (with patient and family consent) and copies/ written summaries to the family wherever appropriate.</p>	<p>Written policy.</p> <p>Patient record and written discharge report to GP and community paediatrician.</p>
3.8	<p>Hospital Discharge Planning: Discharge is facilitated by a comprehensive MDT approach, coordinated by the ABI nurse/relevant key worker, inviting all relevant parties (including education, social work, community health and relevant third sector services) to discuss and implement transition of care from inpatient to community settings, with the use of Getting it Right for Every Child (GIRFEC) paperwork and procedures.</p>	<p>Discharge protocol and planning minutes.</p> <p>Locally agreed GIRFEC paperwork and procedures recorded.</p> <p>Minutes from Child or Young Person's Planning Meeting/ Child's Plan.</p> <p>Inpatient and local MDT pathways.</p>
3.9	<p>Hospital Outreach Worker/ Case Manager/ Key Worker role: There is a designated member of the inpatient MDT to coordinate the discharge process. This will include the early assessment of discharge needs, including the child/ young person's home environment and anticipated community follow-up.</p>	<p>Hospital Outreach Worker/ Case Manager/ Key Worker role with job profile.</p> <p>Named lead discharge co-ordinator.</p>
Desirable criteria:		
3.10	<p>The hospital outreach team member attends all GIRFEC meetings within the first year post-discharge, and where necessary provides longer-term consultation and advice in the home and community setting.</p>	<p>GIRFEC paperwork, including Child's Plan.</p>

Statement 4: Outpatient Follow-up and Community Rehabilitation

Outpatient follow-up and community rehabilitation is provided as close to home as possible for a child/ young person affected by Acquired Brain Injury (ABI), through an MDT and interagency approach involving social and educational services.

Rationale:

ABI is a lifelong condition. Children and young people affected may have significant on-going needs which can impact on their participation and attainment in education, social interactions, behaviour and activity of daily living skills. Participation in education is integral to ongoing rehabilitation following paediatric ABI. Involvement of the child/ young person and their families and carers in the rehabilitation process improves outcomes. In Scotland, the Children and Young People (Scotland) Act 2014, the Getting it Right for Every Child (GIRFEC) framework and the Education (Additional Support for Learning) (Scotland) Act 2004 underpin interagency support given to children and young people and ensure that the child/ young person is at the centre of ongoing plans.

References: 2, 5 – 7, 36, 39 – 46

Essential criteria:

4.1 For patients with significant ABI (GCS<13) and persisting symptoms, ongoing rehabilitation is provided by a community MDT service, led by a consultant paediatrician with training and expertise in ABI. MDT staff should include:

- Clinical Psychology/ Clinical Neuropsychology
- Occupational Therapy
- Speech and Language Therapy
- Physiotherapy
- Clear integrated working and joint working (in line with local policy) with education, social care and third sector organisations.

The community MDT may be a specialist ABI rehabilitation team, Community Child Health or Child Development Centre, and in some cases within the local community Child and Adolescent Mental Health Services (CAMHS) or Learning Disability CAMHS.

In local geographical areas where expertise in managing specific aspects of ABI is not available, services should be available with clear referral pathways to specialist/ tertiary units e.g. assessment and consultation from inpatient/ specialist MDT.

Examples of evidence:

Local service profile.

Local care pathways.

Job plans and job descriptions.

Staff personal development plans.

Training programmes.

Links with charity/ third sector service providers.

Referral letters, discharge letters, rehabilitation profiles/ plan.

4.2	Named person or lead professional (if required) to arrange and record further child/ young person planning meetings using GIRFEC.	GIRFEC review paperwork, including Child's Plan
4.3	<p>All children/ young people with ABI will be considered for outpatient referral for neuropsychological assessment or consultation.</p> <p>Formulation and management strategies are shared with patient, family and all appropriate agencies, including Educational Psychology and Schools.</p>	<p>Referral pathway for Neuropsychological assessment.</p> <p>Clinical Neuropsychologist as integrated member of MDT - with job profiles and MDT service description.</p>
Desirable criteria:		
4.4	<p>Community rehabilitation programmes:</p> <ul style="list-style-type: none"> • Are goal-directed and evidence-based • Address the developmental stage and needs of the child • Address the physical, emotional, behavioural and cognitive rehabilitation needs of the child • Are individualised and tailored to the needs of the child and their family/ carers • Directly involve parents, carers, and other family members • Provide information for and encourage participation from the individual, family, education, charity and third sector organisations and care/ social work • Invite feedback and service user involvement from children, young people and families 	<p>Evidence of goal setting including involvement of patient, parents and carers.</p> <p>Evidence of outcome measures and service user satisfaction measures at admission and discharge.</p> <p>Evidence of benchmarking against clinical guidelines – service audit.</p>
4.5	Outcomes should be recorded at regular reviews using standardised measures relevant to paediatric ABI (encompassing cognitive, emotional, behavioural and physical progression following rehabilitation, and linking this with diagnostic and brain injury severity data).	Valid and Reliable standardised measures are adopted across health board areas to allow comparison of long-term outcomes as well as effectiveness of interventions.

Statement 5: Information for Children, Young People and Families

Children and young people with ABI and their parents/ carers are enabled and supported to take part in decision-making through access to high quality information in accessible formats, taking account of developmental stage and communication abilities.

Rationale:

Effective information sharing is an integral part of high quality healthcare. It can:

- Support the patient and their parents / carers in making informed decisions
- Enable continuity, clear communication and shared decision-making
- Support and involve the family in the rehabilitation process, which improves outcomes
- Act as a reminder to the individual, family or carers of what they have been told
- Increase patient and family potential to access, understand and engage in rehabilitation. All of which can be achieved when information is presented in an age and stage appropriate way and in a variety of formats. The provision of information to the patient/ parents/ carer must allow for age and stage of development, communication difficulties, cognitive impairment or emotional disturbance.

References: 2, 5 – 7, 16, 21, 36, 37, 43, 47 – 57

Essential criteria:

5.1 Patients and their families are central to rehabilitation and are actively engaged with appropriate training, information and support to participate in inpatient and outpatient rehabilitation activities and processes.

Patients and their families/ carers have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals.

Examples of evidence:

Involvement of family in child/ young person's planning meeting.

Written and spoken information and training regarding ABI and rehabilitation processes.

Active involvement of families in ward and outpatient care programmes and in setting and reviewing rehabilitation goals.

<p>5.2</p>	<p>Information (written, audiovisual and verbal) is appropriately accessible through each stage of a child/ young person's journey (and development), and is tailored to the individual patient's needs. Information is provided in a variety of formats and at various points in the pathway. This may include relevant outpatient review discussions and written reports, community rehabilitation information packs, and/ or GIRFEC paperwork, as relevant to the child's ongoing service needs.</p> <p>Information provided may include strategies on how to cope with commonly presenting symptoms after ABI, how to seek further help (for the full range of ABI symptoms) from NHS, Social Services (including welfare rights) and other organisations, including support networks, advocacy services, outreach services, self-help groups, voluntary, local third sector, charitable and community services.</p> <p>The written information is age-appropriate and tailored to the patient and family's needs and communication abilities.</p>	<p>A&E leaflet provided on discharge (Appendix 4). Minutes from child/ young person's planning meeting at discharge is provided to the family.</p> <p>Information pack. Patient information folder (rehabilitation service).</p> <p>Large print, accessible language, visually accessible, and translated leaflets.</p> <p>Website based information in visual, audio and video formats available. Child's plan from ongoing child/ young person's planning meetings in the community setting.</p> <p>Community Rehabilitation Goal folder and information pack.</p> <p>Discharge process audit.</p> <p>Information packs, leaflets and posters from a variety of agencies are provided during consultations and are easily accessible within GP Surgeries, NHS outpatient departments and wards.</p>
<p>5.3</p>	<p>Patients and their families have access to an appropriately trained paediatric healthcare professional during the immediate period after discharge. This may vary depending on individual circumstances, but may include a specialist Paediatric Liaison/ Outreach Nurse, Community or Hospital Paediatrician or relevant Therapist.</p>	<p>Patient information leaflet/ information pack discussed with child/ young person and their family.</p> <p>Discharge process audit.</p>

5.4	Information is made available to parents and carers regarding supports for carers, and relevant referral pathways for their own health and mental health where relevant.	<p>Information provided regarding the importance of self-care for carers.</p> <p>Families directed to accessible leaflet and internet information on carer support from other local agencies.</p> <p>Parents directed to GP for information on own self-care.</p>
Desirable criteria:		
5.6	Feedback on information given to patients, families and carers should be sought on a regular basis, and information packs updated.	<p>Service user audit and feedback.</p> <p>Dated and version details included on information packs and leaflets.</p> <p>Website based information with dated updates.</p>



Statement 6: Transition to Adult Services

For all young people with Acquired Brain Injury (ABI) who require ongoing service input, there is a clear transitional pathway (route) from paediatric services to relevant adult services.

Rationale:

A planned transitional pathway from paediatric to adult services ensures the provision of age-appropriate services and care environments, and improves clinical, educational and social outcomes for teenagers and young adults. Supported transition allows young people to be engaged in informed decision-making regarding their own development, health and well-being. This process should maximize a young person's independence and enhance engagement in their future partnership (relationship) with healthcare professionals.

References: 1, 2, 7, 22, 41, 42, 51, 52, 57 - 65

Essential criteria:

6.1 All children and young people with ABI and ongoing rehabilitation needs have an individualised plan that includes plans for transition to adult services; with consideration of health care and wider service needs.

Young Person's care plan includes transition planning from age 14 onwards and no later than 12 months before a young person leaves education. Some young people may appropriately move into adult services once they have left secondary school (age 16 years). For others, it may be appropriate to have a longer transitional period, and to be supported by paediatric services into late teenage years.

Transition should be planned and managed according to the best practice guidance described in the Department of Health's Transition: Getting it right for young people.

Examples of evidence:

All young people with ABI and ongoing rehabilitation needs have an individualised plan following GIRFEC processes with actions, outcomes, timescales and responsibility recorded.

Child's Plan with evidence of invitation of transitional/ adult service professionals to child/ young person's planning meetings.

<p>6.2</p>	<p>Transition should involve a period of preparation for the young person and their family, including appropriate provision of information (see Statement 5.4) to aid decision making on available choices. This should include an MDT meeting with family and carers, with a key named person taking responsibility for the transition.</p> <p>This may also include consideration of: Appropriate adult services within both local and national settings Good practice guidelines regarding consent and confidentiality in relation to information provision and decision-making for young people and their families</p>	<p>Written information on available services.</p> <p>Written information on independent advocacy.</p> <p>Signposting to information on Power of Attorney</p>
<p>Desirable criteria:</p>		
<p>6.3</p>	<p>Follow-up and monitoring should be provided by relevant paediatric services during a period of transition, until a young person is established in the appropriate adult oriented service.</p>	<p>Minutes of adult service planning meetings with evidence of invitation of paediatric service professionals.</p> <p>Joint clinics with adult services/ dedicated teenage clinic times and settings.</p> <p>Follow up review and reports provided by paediatric services.</p>

Appendix 1: Working Group Membership and Consultation Process

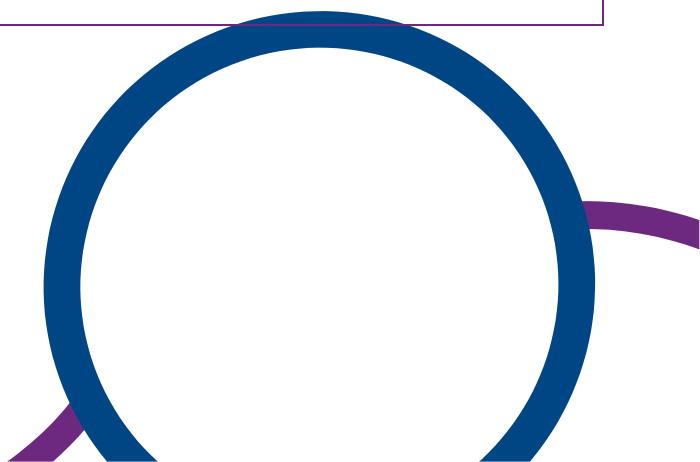
Paediatric ABI Best Practice Statements Short Life Working Group Membership

Ruth Sumpter (Chair)	NHS Lothian/NHS Greater Glasgow & Clyde	Consultant Clinical Psychologist
Linda Kerr Aileen Ferguson	NHS National Services Scotland	Programme Manager for SABIN
Susan Whyte	NHS Lothian	Programme Manager for SABIN
Alex Baxter	NHS Lothian	Consultant in Paediatric Neurodisability
Bruce Downey	NHS Grampian	Clinical Neuropsychologist
Jacqueline McPherson	NHS Lothian	Neurology Nurse Specialist
Kirsten Kernohan	NHS GG&C	Clinical Psychologist

Peer Review Contributions

SABIN Steering Committee Members	Committee Meeting Discussion: - 3rd July 2014	Distribution and feedback comments from committee members, including service user feedback.
Alan Carson, Steering Group Chair	Meeting and review: - 2nd July 2014	Discussion and feedback comments from committee chair.

<p>Multidisciplinary Team meetings to review drafts Service User and Carer focus group (through the Child Brain Injury Trusts (CBIT))</p>	<p>NHS GG&C Royal Hospital for Sick Children Glasgow – 16 February 2016</p>	<p>Physiotherapy, Clinical Neuropsychology, Clinical Psychology, Occupational Therapy, Community Paediatrician, Ward Charge Nurse, Rehabilitation Specialists, Neurology Consultants, Neurology Trainees, Liaison Psychiatry Nurse Specialist</p>
	<p>NHS Lothian RHSC Edinburgh – 3rd March 2016</p>	<p>Physiotherapy, Clinical Neuropsychology, Clinical Psychology, Occupational Therapy, Speech and Language Therapy, Hospital Outreach Teaching Service, Rehabilitation Consultant, Neurology Consultants, Child Brain Injury Rehabilitation Trust Case Worker, Neurology Nurse Specialist</p>
	<p>NHS Tayside RHSC Dundee 7th March 2016</p>	<p>Paediatric Neurology, Children's Specialist Palliative Care Nurse, Operations Manager, Specialist Nurse, Epilepsy Nurses, Associate Specialist Community Child Health, Associate Specialist Paediatric Neurodisability, Paediatric Neurology, Specialist Registrars, Consultant Paediatricians, SCNs, Community Paediatric Nurses</p>
	<p>NHS Grampian RHSC Aberdeen 26th May 2016</p>	<p>Clinical Neuropsychology, Occupational Therapy, Speech and Language Therapy, Paediatric Neurology Consultants, Consultant Paediatricians, Locum Consultant, Associate Specialists, Epilepsy specialist Nurse, Paediatric Specialist Trainees, Speciality Doctor, Child Health, ED Consultant</p>
	<p>NHS Highland Inverness 1st December 2016</p>	<p>Consultant Paediatrician, Physiotherapist, Speech and Language Therapist, Clinical Psychologists, Specialist Trainee, Community Paediatric Lead, Consultant in Rehabilitation (Adult Service), Senior Charge Nurse</p>
<p>Service User and Carer focus group (through the Child Brain Injury Trust - CBIT)</p>	<p>23rd June 2017</p>	<p>Parents and Service users were invited. Unfortunately, no children or young people were available to comment at this time, but a parent focus group provided comments which were incorporated into the document.</p>



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Appendix 4: Head Injury Discharge Leaflet



If any of the following signs occur you **MUST** either bring your child to the Accident & Emergency Department or contact your family doctor or NHS 24 immediately

- ✓ Increasing confusion (not knowing where they are, getting things muddled up)
- ✓ If your child is unusually drowsy DURING THE DAY or you cannot rouse him/her before you go to bed, or DURING THE NIGHT.
- ✓ If your child complains of a bad headache not relieved with paracetamol/Calpol®
- ✓ If your child vomits (being sick) more than once.
- ✓ Weakness of one or more limbs (arms or legs)
- ✓ Not seeing or breathing as well as usual
- ✓ Watery fluid or blood coming from the ear, nose or mouth
- ✓ If your child complains of any problems with his/her eyesight
- ✓ Has a seizure (fit) or has twitching of the face or hands
- ✓ Any behaviour not normal for your child



08454 242424

CONTACT NUMBERS

The aim of this leaflet is to give you information on how to care for your child following a minor head injury.

Is there anything I should look for?

Your child has suffered a Head Injury. Following this your child may complain of a sore head, therefore he/she will have to be observed carefully. During the first 24 hours after your child's accident, on returning home, try to keep your child resting quietly. A mild headache may be relieved by paracetamol.

When your child is sleeping you should arrange to check him/her for the first night at two-hour intervals to find out:

- Does he/she appear to be breathing normally?
- Is he/she sleeping in a normal posture?
- Does he/she make the expected response when you rouse him/her gently? e.g. Pulling up sheets, cuddling teddy bear

If you cannot satisfy yourself that your child is sleeping normally, he/she should be wakened fully to be checked.

Things you shouldn't worry about

Your child may feel other symptoms over the next few days which should disappear in the next two weeks. These include mild headache, feeling sick (without vomiting), dizziness, irritability or bad temper, problems concentrating or problems with their memory, tiredness, lack of appetite or problems sleeping.

If you feel concerned about any of these symptoms in the first few days after discharge you should bring your child to the Doctor.

If these problems do not go away after two weeks, you should bring the child to see the Doctor.

Appendix 5:

This appendix provides some simple examples of good practice, where local services have followed clinical and professional guidelines, and provided clear training, pathways, and/or patient information. These are examples, and do not constitute all the good practice that is already in place across NHS Scotland healthboards. Appendices are available on the SABIN website: <http://www.sabin-dev.scot.nhs.uk>

	Title	Example of:	Healthboard
5.1	Paediatric A&E triage proforma	Clear recording of GCS on emergency admission.	NHS Grampian
5.2	Discharge summary letter	Content of an acute care discharge letter, where information is provided clearly on GCS, PTA and other relevant predictors of long term outcome.	NHS GGC
5.3	ABI Integrated community Care Pathway	Local pathways for integrated care and rehabilitation after hospital discharge.	NHS Lothian
5.4	Case manager/ specialist ABI nurse job description	A paediatric ABI nurse specialist job description where the key role is as an ABI case manager/worker.	NHS Lothian
5.5	Local standards for transition	Clear communication of local good practice in transition for young people with long term conditions	NHS Highland

**Scottish Acquired Brain Injury National,
NHS Scotland 2018**

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