National Services Division

Review of Scottish Acquired Brain Injury Network v1.1
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Executive Summary

The Scottish Acquired Brain Injury Network (SABIN) was set up in 2007. With evidence of inequity in service provision, its remit was to drive improvements in access and quality of services for children and adults with ABI.

This Review spans SABIN activity from 2007 up to 2017, and has gathered evidence from a wide range of Network sources, including views of stakeholders gathered through a survey and Strategic Planning Exercise.

The Expert Review Group (ERG) identified that SABIN had taken many steps to effect improvement in the provision of ABI care through the development of the evidence base. Of particular note was the production of a comprehensive service mapping exercise across Scotland, with findings used to inform the publication of standards for Traumatic Brain Injury in Adults and Paediatric Best Practice Statements.

In 2014, with evidence of ongoing variation in service provision across Scotland, SABIN led the development of a national service model that focuses on early identification and access to specialist ABI care and rehabilitation as a means to achieve optimal patient outcomes and cost effective service provision. SABIN proposals to pilot the model were endorsed by Scottish Government and NHS Boards and the Network is actively supporting a pilot project within NHS Lothian and Tayside.

The Review identified significant barriers that SABIN had encountered in providing demonstrable evidence of improvement. It highlighted in particular the lack of robust systems for national data collection and reporting, limited and patchy buy in to its work from local NHS Boards and a low strategic profile. However, it also noted emerging evidence that NHS Boards and SGHSCD recognise SABIN's key role in supporting the development of the major trauma services network, including a clinical pathway spanning pre hospital care through to rehabilitation and a national data set. This, together with the NHS Lothian and Tayside pilot project, presents SABIN with an unprecedented opportunity to address these barriers and achieve its improvement aims through effective collaboration with current strategic initiatives and developments.

The provision of education was also highlighted as a key area where SABIN adds value, most recently in delivery of an information website about ABI care aimed at non-specialist staff and a national conference with a focus on management of ABI in Emergency Departments.

On the basis of evidence of progress to date and of SABIN’s ongoing role in delivering key strategic policy aims, the ERG recommended continued designation of the network.
The ERG made a number of additional recommendations to enhance SABIN’s effectiveness and impact:

1. SABIN should revise its leadership model to include a Network Chair.

2. SABIN should repeat and update the service mapping exercise at regular intervals.

3. SABIN should focus on collaboration with current SG policy initiatives and strategic structures, including the Scottish Trauma Network, the Neurosurgery MSN and ABI model of care pilot, as a means to maximise its effectiveness in addressing barriers and achieving its objectives. To achieve optimal benefit of synergies between strategic aims and work programmes there should be reciprocal representation on respective Steering Groups.

4. SABIN should collaborate with the Neurosurgery MSN to develop a comprehensive national pathway that incorporates ABI and neurosurgery rehabilitative care, against which NHS Boards can be audited.

5. Access to robust and complete data is critical to SABIN success in enabling proposed improvements in ABI care; SABIN and NHS Boards should collaborate to explore options and ensure systems to collect, analyse and report ABI data meet requirements.

6. SABIN should design and deliver an education strategy that is based on current stakeholder needs.

7. SABIN should explore options to quantify potential cost savings associated with ABI care.

8. SABIN should ensure the key themes from the patient consultation and GP feedback inform future workplans.

9. SABIN should foster stronger relationships with NHS planners, including revision of its Steering Group membership to include representation from local/regional planning.

10. SABIN should work with NHS Boards to establish more effective two way communication between the Network and local planning and management systems.

The ERG also recommended that NHS Boards and other service providers be encouraged by Scottish Government to interact constructively and effectively with SABIN.
Section 1: Introduction

National Managed Clinical Networks (NMCNs) are recognised within NHS Scotland as effective vehicles for enabling service change and improvement. They are designated through national commissioning policy by National Services Division (NSD), as Commissioners, on behalf of NHS Boards and Scottish Government Health and Social Care Directorates (SGHSCD).

National commissioning policy and governance is well defined and underpinned by robust systems and processes. Through NSD, NMCNs are held to account for their performance in an annual cycle of performance management and reporting to NHS Boards and SGHSCD.

Following a review of national networks in 2011 the cycle incorporates progress against objectives agreed at designation as well as adherence to SGHSCD guidance on MCNs (CEL 29 (2012)) which was previously the remit of Quality Improvement Scotland (QIS). A short term legacy of bringing the QIS and NSD performance management systems together has resulted in a level of duplication in the current assessment criteria for SABIN. This will be addressed in the next forward planning stage of the cycle.

Since 2014, through NSD’s National Network Management Service (NNMS), all NMCNs are supported to fulfil their responsibilities within national commissioning policy and deliver against their work programmes. They are also included in a rolling, 3-5 year programme of independent reviews undertaken using standard NSD review methodology;

An expert review group (ERG) considers evidence from the network and its stakeholders to ascertain the extent to which the network:

- is adhering to the eight Core Principles set out in SGHSCD guidance on MCNs
- is achieving the objectives agreed at designation

The ERG analyse the findings to:

- draw conclusions on how well a network meets stakeholder needs and adds value to healthcare in Scotland
- make recommendations to NHS boards and SGHSCD through the National Specialist Services Committee (NSSC) on its future status and continuing central funding.

This report sets out the findings and conclusions reached by the ERG in relation to SABIN and presents its recommendations to NSSC for consideration.
Section 2: Network Overview

2.1 Rationale for Network Designation

In 2000, the Office of Public Health in Scotland included Acquired Brain Injury (ABI) as part of its Scottish Needs Assessment Programme (SNAP). It noted ABI was ‘a significant cause of morbidity and mortality in Scotland, encompassing damage to the brain’s physiology caused by an external force or pathophysical damage resulting from non-degenerative disease states.’

The SNAP report found that ABI services were poorly designed to meet patient needs, particularly in the case of children and adolescents, with the costs and burden of caring largely borne by patients, families and carers, with the help of the voluntary services. It highlighted a disproportionate numbers of ABI cases where the complexity of health and social needs reflected those in the community with chronic or progressive disabling neurological disorders.

The report contained ten recommendations for improving care for patients with ABI, including planning, care pathways, standards, information provision, advocacy, and access to services.

A subsequent review of progress in 2003 recommended a NMCN as a model to address ongoing issues for these patients, and in 2006 a proposal for the Scottish Acquired Brain Injury Network (SABIN) was approved within national commissioning processes with a remit to:

- Ensure patients are managed according to evidence-based, nationally-agreed procedures and protocols;
- Encourage multi-professional care;
- Enable provision of care for acquired brain injury in as cost effective manner as possible;
- Establish and maintain effective systems and processes to facilitate and provide evidence of continuous quality improvement (CQI) in the delivery of care;
- Promote equity of access and service delivery at the most appropriate point of contact (supported by agreed clinical standards and transparent service model);
- Engage with NHS managers and planners to support service development, improvement and redesign;

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1 Scottish Needs Assessment Programme (2000) Huntington’s Disease, Acquired Brain Injury and Early Onset Dementia, Glasgow, Office for Public Health in Scotland, available from http://www.scotphn.net/wp-content/uploads/2015/11/Huntington%C2%A6%C3%A9%C3%A4%C2%B0%C3%A4%C3%B3s_Disease_Acquired_Brain_Injury_and_Early_Onset_Dementia.pdf

Facilitate effective service interfaces and support good practice in multidisciplinary and interagency working both in establishment of an NMCN and the service delivery associated with it;

Facilitate the various strands of user involvement in service delivery and future planning of services (including detailed public patient involvement framework) as indicated in HDL MCN guidelines and other associated MCN best practice documentation

Contribute to CQI systems, designed to facilitate organisational effectiveness.

The 2003 Review noted common causes of ABI as trauma, stroke, hypoxic and infective insults. However, head injury (or Traumatic Brain Injury) is often used as the paradigm of ABI. While all members of society are at risk of head injury, it occurs disproportionately in young men of low socio-economic and educational status from areas of multiple deprivation. Those affected show increased frequency of substance abuse, suicide, psychiatric disorders, physical disability, long-term unemployment and family breakdown. As a consequence, ABI reflects one of the key, yet often hidden, manifestations of health inequality. There is evidence that there is a higher incidence of ABI in Scotland per head of population than elsewhere in the UK; due, in part, to Scotland’s troubled relationship with alcohol.

In terms of duration of incapacity, SIGN 130 estimates that more than 100 out of every 100,000 people have a traumatic brain injury (TBI) that results in difficulties that persist beyond one year after injury. In terms of the population of Scotland, which the National Records of Scotland (NRS) estimated at 5.3 million in mid-2015, this would equate to over five thousand individuals.

In addition, mild brain injury is strongly associated with early mortality; 24.5 per 1,000 per year after mild traumatic brain injury (mTBI); a 4.2-fold greater risk of death in young adults compared to well matched controls. This is also reflected in the high rates of associated disability with only half of patients who have had a mTBI reporting good clinical outcome at one year. In mTBI these poor outcomes are unlikely to be the direct result of neuronal damage but rather a complex interplay of psychological behavioural and social/lifestyle factors.

SIGN 130 reiterates this, and, in a case control study which calculated mortality rates following brain injury in Glasgow over a 13 year period, the death rate was more than twice that for the general Scottish population (30.99 versus 13.85 per 1,000 per year). In addition, longitudinal research... has shown high rates of disability and elevated rates of death for up

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6 SABIN Proposal for SABIN Development and Support from National Services Division (2014)


In terms of the estimated number of patients that SABIN is concerned with; approximately 300 people are admitted to hospital per 100,000 of the population of Scotland each year with head injury alone. SIGN 110\(^9\) suggests ‘In the UK the annual incidence of attendance at the emergency department (ED) with a head injury is 6.6% and around 1% of all patients attending the ED are admitted with a head injury. In Scotland, this equates to 100,000 attendances at EDs each year, of which over 15% lead to admission.’

In simple terms, the Scottish population is more likely to sustain an ABI, and the outcomes of patients with ABI are poor. Even for patients who sustain a mild TBI, there is an associated risk of early mortality and severe disability.

### 2.2 Strategic policy context and service developments

The current SGHSCD policy focus is on integration of health and social care and on population based service planning and delivery that is unconstrained by existing geographical and organisational boundaries. A significant development is in relation to delivery of major trauma services; the Scottish Trauma Network will link four major trauma centres in Edinburgh, Glasgow, Aberdeen and Dundee with a remit to provide high quality, equitable care in a clinical pathway that spans pre hospital care through to rehabilitation. Given that patients with ABI are regularly treated in orthopaedic and other non specialist service areas there is an obvious interdependency with major trauma services and SABIN is a key stakeholder with a pivotal role to play in enabling the success of the STN model. SABIN has led the development of a model of ABI care that focuses on early identification and access to specialist ABI care and rehabilitation as a means to achieve optimal patient outcomes and cost effective service provision. It is designed to address known issues in relation to patient flows within orthopaedic and other services that are potentially detrimental to the success of the STN. The ABI model is currently being piloted in NHS Lothian and Tayside and findings will inform ABI and major trauma services in Scotland.

### 2.3 Network Structure and Function

SABIN is structured to align with current policy and guidance in relation to NMCNs; it operates under the direction of a Steering Group, with working groups convened as required, to reflect and address priorities within annual workplans.

Since inception, working groups have included;

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1. Data Working Group
2. Remote and Rural Working Group
3. Development of Standards Working Group
4. Development of Head Injury Advice Sheet Working Group
5. Patient Engagement Working Group
6. Mapping of Services Working Group
7. ABI Clinical Workbook Working Group
8. ABI Website Working Group* and Sub Group*
9. SABIN Website Working Group
10. Paediatric Working Group*

*denotes current group

The Steering Group meets four times per annum, with ad hoc meetings as required. It is multi-disciplinary in nature; further details of its makeup are noted in Section 3. The Steering Group reports to NSD through the governance cycle of annual and mid-year reviews.

Further to the successful launch of the ABI web resource on 30th March 2017, the ABI Website Working Group has moved to meet as and when required, but a monthly meeting has been retained for the editing sub-group as we work to evaluate the website and revise it accordingly.

The Paediatric Best Practice Statements Working Group has been re-convened to finalise the statements, with the assistance of Ruth Sumpter, Consultant Clinical Psychologist.

Many of the SABIN Steering Group members are actively involved in contributing to development of their local trauma network plans in support of strategic developments in major trauma care.

2.4 Network Support Model

In 2014, with the aim of better quality, increased resilience and economies of scale, support for national networks was consolidated into a single Network Management Service (NNMS). Through the NNMS all NMCNs are supported to fulfil their responsibilities within national commissioning policy and deliver against their work programmes.

A standard model is in place for SABIN, comprising dedicated support from one half time (0.5wte) Programme Manager, and 0.33wte Programme Support Officer. Strategic oversight is provided by a Senior Programme Manger and access to a wide range of support, including business and data analysis from the NNMS Information Management Service. In addition, through the NNMS, there is access to other expertise, including communications and web support.

The Lead Clinician is Dr Alan Carson, who took over responsibility for this role in 2009. Lead Clinician tenure is generally three years, with the option to renew for a further year, and work is scheduled to appoint a successor in 2017.
Section 3: Network Evaluation

3.1 Summary of performance against assessment criteria

The table below sets out the assessment criteria for SABIN. RAG status; Red - not met; Amber - partly met; Green - met in full, has been used to demonstrate ERG conclusions. The rationale for these conclusions is included below the table.

These findings have then informed an overall assessment by the ERG as to how well SABIN meets stakeholder needs and adds value to healthcare in Scotland.

<table>
<thead>
<tr>
<th>CORE PRINCIPLES (CP)</th>
<th>Criteria</th>
<th>R</th>
<th>A</th>
<th>G</th>
</tr>
</thead>
<tbody>
<tr>
<td>CP.1</td>
<td>Clear management arrangements and accountability, including the designation of a Lead Clinician and a publicly available annual report</td>
<td>Red</td>
<td></td>
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<tr>
<td>CP.2</td>
<td>Have a defined Managed Clinical Network structure setting out the points at which the service is to be delivered and the connections between them, (usually achieved by mapping the journey of care)</td>
<td></td>
<td></td>
<td>Red</td>
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<tr>
<td>CP.3</td>
<td>Use a Managed Clinical Network annual work plan setting out intended service improvements and where possible, quantifying benefits to service users and families</td>
<td></td>
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<tr>
<td>CP.4</td>
<td>Use a documented evidence base, such as SIGN Guidelines, and should draw on expansions of the evidence base arising through audit and relevant research and development</td>
<td></td>
<td>Red</td>
<td></td>
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<tr>
<td>CP.5</td>
<td>Have a multi disciplinary and multi professional constitution, with clarity about each professional's role</td>
<td></td>
<td></td>
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<tr>
<td>CP.6</td>
<td>Service user and voluntary sector representation</td>
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<tr>
<td>CP.7</td>
<td>Optimise the education and training potential and continuing professional development of network members</td>
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<td>CP.8</td>
<td>Generate better value for money</td>
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<tr>
<th>DESIGNATION OBJECTIVES (DO)</th>
<th>Criteria</th>
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<tbody>
<tr>
<td>DO.1</td>
<td>Ensure patients are managed according to evidence-based, nationally-agreed procedures and protocols;</td>
<td>Red</td>
<td></td>
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<tr>
<td>DO.2</td>
<td>Encourage multi-professional care;</td>
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<tr>
<td>DO.3</td>
<td>Enable provision of care for acquired brain injury in as cost effective manner as possible;</td>
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<tr>
<td>DO.4</td>
<td>Establish and maintain effective systems and processes to facilitate and provide evidence of continuous quality improvement (CQI) in the delivery of care;</td>
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<td></td>
<td>Promote equity of access and service delivery at the most appropriate point of contact (supported by agreed clinical standards and transparent service model);</td>
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<td>DO.6</td>
<td>Engage with NHS managers and planners to support service development, improvement and redesign;</td>
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<tr>
<td>DO.7</td>
<td>Facilitate effective service interfaces and support good practice in multidisciplinary and interagency working both in establishment of an NMCN and the service delivery associated with it;</td>
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<tr>
<td>DO.8</td>
<td>Contribute to CQI systems that are in place within Network Offices, designed to facilitate organisational effectiveness;</td>
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<tr>
<td>DO.9</td>
<td>Facilitate the various strands of user involvement in service delivery and future planning of services (including detailed public patient involvement framework) as indicated in HDL MCN guidelines and other associated MCN best practice documentation.</td>
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**STAKEHOLDER NEEDS (SN)**

|   | Drawing on the evidence presented for sections above, assess the extent to which the network is meeting the needs of its stakeholders |
3.2 Evidence

Core Principles of Networks

The focus here is on ensuring that the network is structured, organised and resourced to deliver its designation objectives.

Where appropriate, evidence has been collated to inform conclusions in relation to all related assessment criteria.

CP.1 Clear management arrangements and accountability, including the designation of a Lead Clinician and a publicly available annual report

The ERG found satisfactory evidence that SABIN has clear management arrangements and has fulfilled requirements within national commissioning policy in terms of producing annual and mid-year reports. These are available on the website and on request.

The ERG noted that the Lead Clinician had been in post for some seven years (beyond the usual maximum period of tenure) and a replacement will be sought during 2017/18. They also noted his valuable role in the Lothian pilot of a new model of care for patients with ABI which it is anticipated will inform service provision across Scotland in due course. They noted the potential benefit of engaging a Chair to enhance the SABIN Steering Group Structure and Leadership model.

ERG conclusion: Principle met.

Recommendation: SABIN should revise its leadership model to include a Network Chair.

CP.2 Have a defined Managed Clinical Network structure setting out the points at which the service is to be delivered and the connections between them (usually achieved by mapping the journey of care).

An immediate priority for SABIN was to undertake a national service mapping exercise. The findings (set out in detail in Section DO.5), were reported in 2009. They identified that ABI service provision remained patchy and poorly organised for this vulnerable and complex population of patients and their families in Scotland. SABIN used the findings to design a Network structure and membership that reflects the multi professional and multi disciplinary nature of ABI care as well as how services are distributed. The findings also informed SABIN workplan priorities, including the development of a set of service standards for adult service delivery in Scotland and proposals for a service delivery model.

The current Steering Group includes representation from eight territorial board areas, where specialist ABI care is provided. The range of healthcare professionals on the Steering Group reflects the patient pathway; from Emergency Medicine, neurosurgery, rehabilitation, specialist nursing and the Allied Health Professions, such as Speech and Language Therapy.
In terms of information flow between SABIN and ABI services, Steering Group members share information about local initiatives (e.g. the Forth Valley Care pathways work), or developments in major trauma, as well as reporting back to their Boards on SABIN work.

The structure ensures that the network is well linked into service delivery and SABIN works with territorial Boards to improve patient pathways.

However, the ERG highlighted the need to monitor service provision and patient pathways on an ongoing basis and concluded that this core principle had not been met in full.

ERG conclusion: Principle not fully met.

Recommendation: SABIN to repeat Service Mapping Exercise and update at regular intervals.

CP.3 Use a Managed Clinical Network annual work plan setting out intended service improvements and where possible, quantifying benefits to service users and families

The ERG were presented with evidence of consistent and effective use of annual workplans; they are available either on the website or on request.

The NNMS has identified a requirement to support all networks to plan strategically 3-5 years ahead. This is being done through staff training, use of standardised planning tools and ongoing peer support. Detailed annual workplans remain a fundamental requirement within the revised planning process.

ERG conclusion: Principle met.

CP.4 Use a documented evidence base, such as SIGN guidelines, and should draw on expansions of the evidence base arising through audit and relevant research and development

DO.1 To ensure patients are managed according to evidence-based, nationally-agreed procedures and protocols

Throughout its existence SABIN has undertaken a significant amount of work to develop and embed the evidence base for ABI care and audit service provision in Scotland.

Traumatic Brain Injury in Adults - Standards  
In 2008, further to a review of existing literature, SABIN undertook to develop national standards of care and used the annual SABIN conference in that year as an opportunity to engage stakeholders in shaping the future direction of the network and to canvas opinion on the draft standards.
The standards were published in 2009, and circulated widely to individuals with an interest in ABI, the NHS, local authority and voluntary sector organisations. They were published on the SABIN website. Meetings took place initially with A&A, GG&C, Forth Valley and Lothian and work continued with the other Boards to support implementation of the standards through 2010 and 2011.

An audit of implementation progress within NHS boards in 2012 highlighted poor uptake and in some areas there were conflicting reports of level of progress between those who responded and clinicians working in the Boards.

**Paediatric Standards / Best Practice Statements**

In 2012 work began to develop Paediatric TBI standards and continued through to 2015. In view of strategic changes within healthcare policy in relation to quality improvement (QI) approaches during that period, they were defined as statements of best practice. In 2016, a national review of paediatric ABI care was initiated with peer review by MDTs in Glasgow, Dundee, Lothian and Grampian. This work is nearing completion; review of the statements by the final team, in Inverness, took place on 1st December 2016, and a review of all sections of the document by patients and carers, in association with the Child Brain Injury Trust, is being scheduled prior to publication and dissemination at the end of the 16-17 financial year.

**SIGN Guidelines – production and implementation**


At least twelve SABIN Steering Group and Working Group Members (including Dr Alan Carson, Dr Douglas Gentleman, Dr Brian Pentland, Prof. Tom McMillan, and Dr Lance Sloan) were involved in either the Guideline Development Groups, or the Specialist Review Groups for the SIGN Guidelines.

Work was done by SABIN to ensure that SIGN 110 was adopted across the country; a pilot Head Injury Workshop was held at RAH in Oct 2009, linking SIGN 110 and the ABI standards produced. It was attended by Dr Ali El-Ghorr, Implementation Adviser from QIS and well received. This work was repeated in NHS Lanarkshire and NHS Lothian in 2010, with the offer of assistance from SABIN to run similar events in all Boards.

The development of SIGN 130 was informed by SABIN, with references to SABIN publications, service mapping and support for patients within the document. As with SIGN 110 many steering group and working group members contributed to the guideline development group or expert review group (including Claire O’Brien, Shiona Hogg, Avril Beattie and Angela Sprott.) and again, SABIN was instrumental in implementing the guideline across the Boards.

In an innovative project, SABIN produced a calendar to reinforce key messages from the
SIGN guideline regarding the importance of early access to specialist assessment and rehabilitation. Each month within the calendar focused on a key learning point. These were distributed to ABI services across Scotland as an education/information resource and also to direct healthcare professionals to online ABI resources, including the SIGN Guidelines.

Data
Robust data is the foundation for service planning and improvement. In 2009, SABIN established a data sub-group and work started on defining an ABI data set with NSS Information and Statistics Division. It became apparent, through the audits carried out, that fewer than 50% of ABIs were captured within existing national data systems; a result of poor case attainment at A&E and on admission to surgical units. A particular issue highlighted were the patients who had a head injury but who did not require neurosurgical intervention e.g. a scaphoid fracture, may leave hospital with only the scaphoid fracture recorded in SMR returns.

In 2011, planning started for a conference with the aim of securing a nationally agreed approach to ABI data collection. The Data Management Conference was held in Sept 2012, and a data management plan developed. Throughout 2013 work continued within SABIN to explore potential solutions to data collection issues, including an investigation of the use of TRAK and extensive consultation with stakeholders.

The ERG noted that at this time SABIN started work on a proposal to pilot a revised, evidence-based model of ABI care, and this proposal highlighted that data collection was key to benchmarking and improving the quality of care for patients. The Steering Group noted that, as Major Trauma Centres were a Scottish Government priority, (and the scope of the major trauma work included the development of a robust data set), this work required to be progressed in tandem, to maximise the likelihood of success. At present, neither STAG as a national system, nor any of the local systems in NHS Boards in Scotland capture the whole ABI pathway, and in the absence of a robust data set, it was impossible to provide evidence that ABI pathways are effective in improving patient outcomes. The ERG recognised that this was outwith the network’s control.

It was acknowledged that head injury data coding and management was problematic, not least due to the proliferation of different systems, codes and coding conventions across Scotland. In the short term, SABIN continues to engage with ISD to see what can be improved to make the SMR data more robust in relation to ABI. This work is ongoing.

It was clear, too, that SABIN has undertaken extensive work, including the production of standards and the input of many members to SIGN 110 and SIGN 130, the measurement of performance against guidelines was a fundamental component of audit and improvement systems, and at present – for reasons outlined above – this was not being done. It was agreed that the most appropriate mechanism for SABIN to define and secure a robust data set to enable high quality, equitable ABI care would be through its role in the ABI Care model pilot and the Scottish Trauma Network, as the planned developments in major trauma care present an appropriate opportunity for SABIN to influence the STN work to develop a national data set that incorporates ABI within major trauma requirements.
The ERG were concerned to hear of occasions when SABIN had sought information about brain injury services and had received replies from only a small minority of NHS Boards. Engagement with service providers is fundamental to the future success of SABIN, and the ERG recognised that this engagement required efforts on both sides. While the ERG recognised that Boards have a number of competing priorities, they were concerned that without greater engagement from Boards with SABIN work, the Network was unlikely to meet its objectives.

The ERG concluded that there is insufficient evidence that SABIN has been able to fulfil its remit in ensuring that care is evidence based.

ERG conclusion: Principle not met
Objective not met

Recommendations:

SABIN should focus on collaboration with current SG policy initiatives and strategic structures, including the Scottish Trauma Network, the Neurosurgery MSN and ABI model of care pilot, as a means to maximise its effectiveness in addressing barriers and achieving its objectives. To achieve optimal benefit of synergies between strategic aims and work programmes there should be reciprocal representation on respective Steering Groups.

SABIN should collaborate with the Neurosurgery MSN to develop a comprehensive national pathway that incorporates ABI and neurosurgery rehabilitative care, against which NHS Boards can be audited.

Access to robust and complete data is critical to SABIN success in enabling proposed improvements in ABI care; SABIN and NHS Boards should collaborate to explore options and ensure systems to collect, analyse and report ABI data meet requirements.
CP.5  Have a multi disciplinary and multi professional constitution, with clarity about each professional's role

DO.2  To encourage multi-professional care

SABIN’s Steering Group is multi professional and multi disciplinary, and reflects the variety of health service professionals involved in the care of patients with ABI and geographical distribution of services. Roles and responsibilities of Steering Group members are set out clearly in its Terms of Reference which were updated in 2017.

Current members include Consultants in Paediatric Neurodisability, Neuropsychiatrists and Consultants in Neurorehabilitation, local and national representatives from Headway (the UK-wide charity that works to improve life after brain injury), a Speech & Language Therapist, an AHP manager, a specialty doctor, patient representatives, a specialist head injury nurse, and an Acquired Brain Injury Service Coordinator. These professions are all key to the provision of care for patients with ABI.

There is a multi-disciplinary working group that was responsible for the development of a comprehensive on-line information and education ABI website, described more fully in the following section. Involving representatives from all aspects of patient care was key to defining the scope and ensuring that the information provided was relevant and what would be required by the target audience.

Given that currently patients with a brain injury are cared for in a wide range of non-specialist services, resources such as the ABI website are of key importance. Initial feedback on the ABI website from teams involved in the care of patients with ABI, has been almost wholly positive, with some suggestions for future improvements. This resource was launched at a Brain Injury meeting in Edinburgh City Chambers in March 2017, and its use and usefulness are being evaluated.

The network also promotes high quality multi-professional care through education events. Most recently the focus was on those working in emergency care. In September 2016 over 100 NHS staff attended the SABIN conference in person, (with web streaming available to those who could not attend on the day). Feedback from the 50% of attendees who submitted evaluation forms was very positive and included offers to support future events, including the provision of speakers and suggested topics for the 2017 event.

The ERG agreed that SABIN had a multidisciplinary constitution, and encouraged multi-professional care. It advised that SABIN should continue with its valuable educational role in the provision of MDT education and that this objective was met.

ERG conclusion:  Principle met  Objective met
CP.6  Service user and voluntary sector representation

DO.9  To facilitate the various strands of user involvement in service delivery and future planning of services (including detailed public patient involvement framework) as indicated in HDL MCN guidelines and other associated MCN best practice documentation.

SABIN’s approach to service user and voluntary sector involvement reflects the size and nature of the patient group. User involvement, both direct and via engagement with third sector, has been part of the network’s activities since its inception and is recorded consistently within annual reports and through specific working groups.

The SABIN Steering Group currently includes two patient representatives, and voluntary sector representation from Edinburgh Headway Group and Headway UK. Through these representatives, service users contribute to and help shape the future priorities of the network.

In 2008, a working group was set up to identify information requirements of patients with TBI / carers and to review existing resources. The findings informed the design of the SABIN website, which continued to be refined and improved each year. The website has an extensive ‘useful links’ page, with signposting to many other resources and organisations. There is an area for professionals, for parents and carers, a paediatric area, and links to the SABIN publications.

The network has supported a number of patient engagement events. One example of this was the Cafe Consultation project rolled out in 2011 and 2012, with feedback collected from carers & patients in GG&C, Grampian, Ayrshire, Dumfries (with Reach and Headway). Over the years, each annual report notes involvement in third sector initiatives. Outputs from these events have been used to inform SABIN priorities.

Third sector engagement is ongoing, with the network manager presenting at the Brain Injury Network Group, meeting with local Headway representatives, members of Headway UK, CBIT staff and making contact with other local support groups such as Vocal. Making connections with these groups ensures that the network is informed by the work of our third sector partners, has direct contact with the patients they support, and can in turn be involved in supporting their work. It also ensures SABIN has up to date information about other sources of assistance that can be passed on to patients and carers who contact us on a regular basis with queries.

In 2016, the network manager attended the Child Brain Injury Trust (CBIT) Family Day at the Climbing Centre in Ratho; CBIT are the leading voluntary sector organisation providing non-medical services to families affected by childhood acquired brain injury across the UK. The Head Injury Information days are an information and training event for staff, patients and carers, hosted by Digby Brown, solicitors.

These events provide the opportunity to meet service users and their carers and hear about their challenges and experience of care in a relaxed, non-clinical setting.
SABIN acts a source of information and signposting to a range of services for patients and carers; a dedicated email address NSS.SABIN@nhs.net receives a small but steady number of queries each week; generally from patients and carers, but also from health professionals.

As a means to explore new, innovative ways of seeking patient views the network tested the use of i-pads at a recent head injury information day in Glasgow. However, the numbers of patients providing feedback was small, and the medium did not suit all patients.

It is fair to say that patient engagement remains a challenge, not least because of the many physical and psychological difficulties this large and disparate group of patients face. SABIN is grateful to our third sector partners who work with us to facilitate patient engagement sessions.

Another example of a specific piece of work was the creation, review and dissemination of guidelines for parents or carers of children with an ABI, which were sent to every A&E department in Scotland. http://www.sabin-dev.scot.nhs.uk/wp-content/uploads/2017/02/paediatric-brain-injury-leaflet-2014.pdf Current work involves the review of the draft Paediatric Best Practice Statements with parents and carers prior to publication and dissemination. This is being facilitated by CBIT.

The network worked in partnership with Headway to support and deliver the Parliamentary reception; 'Brain Injury – a Scottish perspective on an ever increasing problem' in November 2014. Key Messages from this event were recorded and developed into an action plan.

The ERG found there was robust evidence of effective user involvement in the network, and members agreed this objective had been met.

ERG conclusion: Principle met
Objective met
CP.7 Optimise the education and training potential and continuing professional development of network members

In 2008 work was undertaken by SABIN to ascertain the extent ABI training was included in curricula for MDT members across the health service in Scotland. A report was produced, the results of which led to the development of competencies for staff aligned to the TBI Standards of Care that were published by SABIN in 2009. The competency document was piloted in Glasgow Royal Infirmary in 2010.

As a result of feedback, these evolved into a ‘Clinical Workbook’, which evolved yet further into an online resource designed particularly for staff working in non-specialist units (e.g. orthopaedic wards) in Scotland. This large piece of work was the primary focus of educational work for SABIN and developed by a multidisciplinary team. The competency document was piloted in Glasgow Royal Infirmary in 2010. The site was launched on 30 March 2017.

The rationale for transferring this information online was to reach a wider audience and to enable edits to be completed more quickly and in a cost effective manner.

This resource was designed to be accessible to Nursing staff, Allied Health Professionals, Medical staff, Social Workers/Mental Health Officers and support staff, and covers an extensive range of topics associated with brain injury. Throughout the site, there is an emphasis on the practicalities of how to help individuals with Acquired Brain Injury.

This website will continue to be improved and a future goal is to develop a training component aimed at supporting Continuing Professional Development. It is hoped that this website can be used to highlight relevant recent publications, guidelines and ongoing research in the field. The website will also provide signposts to local resources and sources of support.

Other Websites
The SABIN website http://www.sabin-dev.scot.nhs.uk/ is a source of information and signposting to relevant resources for health and other professionals, and for members of the public. It is currently being revised and the new site will be operational by the end of this financial year.

SABIN also supports a mild brain injury web information resource http://www.headinjurysymptoms.org/ Once the revised SABIN website moves to the new platform, it will link to the ABI learning site and the head injury symptoms site, signposting patients and staff to the most relevant information for them.

SABIN has been utilising the skills of the network members and colleagues, most recently in the development of the ABI educational website, and the website for mild TBI. It held a large and successful multidisciplinary conference in 2016, with topics including ‘alcohol-related emergency care’, ‘what actually happens in neurorehabilitation?’ and ‘the developing world of acute interventional neuroradiology’. The conference in 2017 is already in the final planning stages.
SABIN has carried out an extensive programme of education, and the sign-off and implementation of a revised educational strategy, is included in the workplan for SABIN for 2017-18.

The ERG commended SABIN on its important educational work.

ERG conclusion: Principle met.

Recommendation: SABIN to design and deliver an education strategy that meets stakeholder needs

CP.8 Generate better value for money

DO.3 To enable provision of care for acquired brain injury in as cost effective manner as possible

The ERG considered that SABIN’s role in enabling the provision of ABI care in as cost effective manner as possible was in designing a national model of care focused on better patient outcomes through early access to rehabilitation. There is evidence from Centres in England that this model is more cost effective than current models.

The Group noted that there were opportunities for societal gains in the cost effective management of TBI. It was noted that although it would be of benefit to measure cost effectiveness, it might be difficult to isolate all of the contributing factors, and an exhaustive enumeration of costs and benefits may prove impossible. However, while recognising the limitations of an imprecise analysis, it was felt that this could be an important component of the work of SABIN going forward.

It noted, in addition, that producing on-line learning materials and use of video and teleconferencing and webstreaming of events enables health and other professionals to access network events and train without the need to travel, and at a time that suits their schedule. This, too, has associated cost savings.

As part of the NNMS, SABIN operates in a structure that is designed to make the best use of limited financial, physical and human resources; such as use of shared templates and events. Transferring the SABIN website in-house from an external provider from 1 April 2017 will free up SABIN funds to support other priorities.

The ERG considered that SABIN itself was cost effective in terms of what it had provided year on year, with a nominal operational budget of £5k per annum and human resource of 0.5 WTE Programme Manager and 0.3 WTE Programme Support Officer.

It was agreed that that this objective was met, with the proviso that SABIN undertake work to explore and quantify potential cost savings.

ERG conclusion: Principle met. Objective met
Recommendation: SABIN to explore options to quantify potential cost savings associated with ABI care
Designation Objectives

DO.1  To ensure patients are managed according to evidence-based, nationally-agreed procedures and protocols

See evidence in CP.4

ERG conclusion:  Objective not met

DO.2  To encourage multi-professional care

See evidence in CP.5

ERG conclusion:  Objective met

DO.3  To enable provision of care for acquired brain injury in as cost effective manner as possible

See evidence in CP.8

ERG conclusion:  Objective met

DO.4  To establish and maintain effective systems and processes to facilitate and provide evidence of continuous quality improvement (CQI) in the delivery of care

In support of continuous quality improvement in ABI care across Scotland, SABIN has made significant progress in three of the four key areas through which national networks fulfil their remit of improving access to and quality of specialist care; mapping and planning services; education, stakeholder engagement.

Where it has been challenged is in ascertaining base line data, and measuring the impact as a means of providing tangible evidence of improvement. The situation is ongoing. Pending agreement on a national data set in support of developments in major trauma through which an ABI subset could be sought, SABIN is exploring other options. The Information Management Service of NNMS is supporting that work, as is ISD.

The ERG noted SABIN’s quality improvement initiatives, but advised that that an assessment of quality improvement was impossible without robust baseline data. (A consideration of data is included in more detail under designation objective 1 (Section DO.1).)  Use of the NHS NSS Information management (IMS) team to support SABIN data collection had been explored in the past, with the conclusion that the team would be unable to address the lack of standard coding across all health boards area (dealing with hundreds of thousands of patient records), within the relatively small IMS team.  It was agreed, however, that there would be a further meeting with IMS to again explore the potential IMS
role within SABIN, and that there could be merit in SABIN considering links between the MSN pathway and ABI patient pathways. (See DO.1 for the relevant recommendation.)

ERG conclusion: Objective partly met.

DO.5 To promote equity of access and service delivery at the most appropriate point of contact (supported by agreed clinical standards and transparent service model)

DO.7 To facilitate effective service interfaces and support good practice in multidisciplinary and interagency working, both in the establishment of an NMCN and the service delivery associated with it.

Service Mapping Exercise
In 2008, work started on mapping of services for Adults with TBI, with over 90 semi-structured interviews carried out in clinical services across Scotland. The interviews took place with NHS team members from all areas involved in the care of patients with ABI. Interviews also took place where there were other providers involved in the pathway of care, e.g. private and third sector partners.

The exercise identified that:

- It was apparent that no individual necessarily had an accurate overview of all services in their local area
- Even when services appear to be available people can “slip through the net”
- No NHS Board offered a fully comprehensive service. Provision remained patchy and poorly organised for this vulnerable and complex population of patients and their families in Scotland.

Recommendations arising from the exercise:

- There was a need to review which specialties should be responsible for the delivery of care to patients with head injury in the first 48 hours
- If general or orthopaedic surgeons in Scotland are to continue to provide care for head injured patients after admission and/or beyond 48 hours they and their staff should be provided with specific training
- Details of the number of people admitted to hospital after head injury and their subsequent journey should be kept by NHS Boards. This information should be used both locally and nationally to plan service provision
- Each NHS board should establish a policy for the provision of in-patient rehabilitation of head injured patients
- Discharges from NHS care should be planned taking account of any persisting difficulties. This should include provision of community based rehabilitation
- Each NHS board should have defined policies for the management of TBI patients with acute and persisting challenging behaviour
• Each NHS Board should establish a policy for the provision of continuing care of those with severe disabilities following head injury, including those in minimally conscious or persisting vegetative state
• Patients and their families/carers should have access to high quality information.

The findings of the mapping exercise identified where ABI care was delivered as well as gaps in provision. They were used to inform the Network structure, including Steering Group membership, as well as priorities for ABI service development within its initial workplan, including a set of standards for TBI in adults:

The Standards for Traumatic Brain Injury in Adults were designed as an evidence base to address the main issues identified in the mapping exercise. The report was completed and disseminated to NHS Boards in 2009. [http://www.sabin.scot.nhs.uk/files/service-mapping-report2.pdf](http://www.sabin.scot.nhs.uk/files/service-mapping-report2.pdf)

**Review of Services Against Standards**

This exercise highlighted very clearly ongoing inconsistency in how brain injury was managed across Scotland. From the Board responses, there appeared to be little appetite to adopt national standards. Where responses were positive, these sometimes conflicted with experiences reported by clinicians on the SABIN Steering Group who worked within these Boards.

These findings were a significant contributing factor which led to SABIN changing its strategic approach; concluding that a revised model of service delivery, based on Royal College of Surgeons[10] and NICE (‘Head Injury Assessment and Early Management’ [https://www.nice.org.uk/guidance/cg176](https://www.nice.org.uk/guidance/cg176)) recommendations, would be the best way to effect a significant improvement in the care of brain injured patients across Scotland.

**ABI Pilot, and Interdependencies with Major Trauma Centre work**
In December 2013, the main output of a SABIN strategic planning workshop with key stakeholders was a logic modelling exercise and agreement that the 2014/15 priority should be to garner support at a national level for a redesigned and improved model of service delivery. Key to this was the early identification of brain injury and early access to rehabilitation, a description of national care pathways, the provision of rehabilitation, and systematic data collection. The 2014-15 annual report noted that ‘significant and demonstrable improvement in clinical and other outcomes for patients with traumatic brain injury (TBI) would only be achieved with support at national level for a revised model of service delivery’.

[10] Royal College of Surgeons (England) *The Provision of Surgical Services to Patients with Head Injury*, 1986
The current SGHSCD policy focus is on integration of health and social care, and on population based service planning and delivery that is unconstrained by existing geographical and organisational boundaries. A significant development is in relation to delivery of major trauma services; the Scottish Trauma Network (STN) will link four major trauma centres in Edinburgh, Glasgow, Aberdeen and Dundee with a remit to provide high quality, equitable care in a clinical pathway that spans pre hospital care through to rehabilitation. Given that patients with ABI are regularly treated in orthopaedic and other non-ABI specialist service areas there is an obvious interdependency with major trauma services and SABIN is a key stakeholder with a pivotal role to play in enabling the success of the STN model.

SABIN has led the development of a pilot model of ABI care that focuses on early identification and access to specialist ABI care and rehabilitation as a means to achieve optimal patient outcomes and cost effective service provision. It is designed to address known issues in relation to patient flows within orthopaedic and other services that are potentially detrimental to the success of the STN. The ABI model is likely to be piloted in NHS Lothian and Tayside, and findings will inform ABI and major trauma services in Scotland.

With support for the Network now provided within the NNMS, through NSD the network submitted a proposal to the NHS Directors of Planning in Feb. 2015, requesting funding to support a pilot. Following confirmation of Scottish Government funding in August 2015 to appoint a Project Manager, NHS Lothian was identified as the host board for the pilot to develop a new model of care for patients with brain injury. There was continuing support for this project throughout 2016 from SABIN Steering Group members and Lead Clinician.

The interdependencies with the national major trauma work meant that there was a hiatus in the work of the pilot, pending a decision by Scottish Government on the number of trauma centres. Work continues at a strategic level at present, with members of the network engaging with the CMO, Dr Calderwood, and Chief Adviser to the CMO, Dr Caesar, to highlight the need for collaborative working across existing networks, and the need for greater investment in the care of brain injured patients. Many of the members of the network attend the territorial Board trauma planning groups, with Douglas Gentleman, as Adviser to the CMO, attending the Major Trauma Subgroup. Most recently, the Chair has written to Dr Caesar to highlight the role of the network, and the value in having it input to the Major Trauma Centre Network. It was noted that three national networks now exist that are concerned with the care of brain injured patients across Scotland, and there is a need for clarity around how they work together to influence strategy within the territorial boards.

NHS Lothian have recently appointed a new Lead for the MTC work, with whom dialogue continues.

It is clear that influencing policy on head injury care is neither a quick or simple process and it is critical that SABIN’s role and function as expert clinical and other stakeholder group is recognised and utilised appropriately to inform and support service developments at national, regional and local levels. An example highlighted was SGHSCD guidance on concussion issued without reference to SABIN.
Remote and Rural Services
From 2010, SABIN put in place a Remote and Rural Working Group, to consider how best to tackle equity of access to services. Scoping work was carried out and a remote and rural commissioning report produced in 2012. The findings were in line with those of the Service Mapping and illustrated the great degree of service variation in all areas, particularly outpatient and community follow up.

Brain Injury and Offending
A great deal of work has been carried out by Professor McMillan, a SABIN Steering Group member, including with the National Prison Healthcare Network, on the interaction of people with brain injury and the criminal justice system. Most recently, a report has been produced http://www.nphn.scot.nhs.uk/wp-content/uploads/sites/9/2016/07/Brain-Injury-OffendingFinal-Report-21March2016.pdf which has led to calls from MSPs for Scotland to open its first secure brain injury unit amid growing evidence linking head knocks and offending. This report and its implications were presented at the Network Steering Group in November 2016, and were considered at a Parliamentary Reception in December 2016; with members of the network Steering Group attending.

The ERG noted that SABIN's efforts to work collaboratively with health boards to encourage joint and interagency working, had met with a disappointing response. It was therefore agreed that SABIN should seek further support, possibly in the way of a stronger representation from health board planners on the Steering Group to help influence communications, otherwise, this priority would not be achievable. The Steering Group strongly supported this approach.

It was noted that, from 2000 Stroke had been a priority for investment and had had a very good joint working relationship with health boards, compared to the lower profile which traumatic brain injury (TBI) has across health board areas. It was noted that stroke targets were highly advanced for scans, and the perception was that scans in the acute stage were busier, therefore, the Scottish Government had attention to reduce waiting times. However, it was noted that TBI does not have the same Government attention. It was suggested that SABIN ensure it continued to engage at a variety of levels with the work on Trauma Centres, to raise the profile of care of patients with brain injury.

The Service mapping exercise from 2007/09 was discussed, and it was noted that the pilot in NHS Lothian is in progress. Members agreed with SABIN's direction of travel and on the piloting of one board initially. It was agreed that equity of access was an issue and something that SABIN was right in addressing via the pilot. It was agreed that objective DO.5 was met.

Members agreed that SABIN supported good practice in multidisciplinary and interagency working, albeit the limited interaction it has received from some territorial health boards. It was agreed that objective DO.7 was met.

ERG conclusion: Objectives met
DO.6 To engage with NHS managers and planners to support service development, improvement and redesign

See evidence in SN.1

ERG conclusion: Objective met.

DO.7 To facilitate effective service interfaces and support good practice in multidisciplinary and interagency working both in establishment of an NMCN and the service delivery associated with it

See evidence in CP.2, CP.5.

ERG conclusion: Objective met

DO.8 To contribute to CQI systems, designed to facilitate organisational effectiveness within Networks.

National Network Management Service (NNMS)
The Networks were aligned under NSS’ National Network Management Service in April 2014, and it was noted that, as such, ‘Network Offices’ no longer exist. The SABIN network continues to input to the National Network Management Service, most recently with the Lead Clinician providing a lively and informative webinar session to other Lead Clinicians in September 2016. A planning day was held in December 2013 with NSD to develop a ‘logic model’, and learning is shared regularly at NNMS Lead Clinicians’ and team meetings. In 2009 the network bid for NHS QIS MCN Accreditation for the Clinical Standards for Adults with TBI, and followed QIS methodology in the structuring of its ‘Standards’ documents.

The SABIN support staff; the Programme Manager and Programme Support Officer are employed, managed and supported as part of the wider network team within NSS. While the staff resources dedicated to the network has fluctuated over the years, there appears to have been no detriment to the network in terms of outputs.

There is a great deal of additional benefit and support through the NNMS in terms of shared team learning, access to data management expertise, and access to other networks and other parts of NSS such as ISD. There are also frequent CPD opportunities regarding quality improvement, and standardised approaches to governance and risk management. Costs to the wider NHS are also, arguably reduced, in sharing learning and not ‘reinventing the wheel’.

The SABIN network assisted with the successful ISO 9110 quality audit carried out in 2016, relating to information storage and handling.

As with all networks supported by NNMS, SABIN benefits from the improvement projects and shared learning within the NNMS team. The quality improvement initiative to improve
admin standards, as ensuring efficient administration helps the network perform more effectively and enhancing stakeholder engagement.

This was discussed with objective DO.4, and was awarded the status of ‘amber’; partially met.

ERG conclusion: Objective partly met.

DO.9 To facilitate the various strands of user involvement in service delivery and future planning of services

See evidence in CP.6

ERG conclusion: Objective met.

SN.1 Stakeholder Needs

The following stakeholder groups have been identified:

Patients, Carers and Families

SABIN ran a series of consultation events across Scotland in 2011 - 2013, facilitated by partner organisations such as Headway, Momentum and the Brain Injury Experience Network (BIEN). The purpose was to understand the perspective of service users. It should be noted that these service users are likely to be the individuals who have suffered the most debilitating of traumatic brain injuries.

Feedback was grouped across a number of common areas, and while there were some areas of excellent care highlighted, there were many other instances where it is clear that a national approach could be helpful. The action plans from these Service User events were shared with the ERG. Common themes from the cafe consultations were, (not in order of importance);

- Experience of Acute care generally positive
- Need for better communication throughout NHS care; what is happening and why
- Dedicated units would be beneficial – stroke or orthopaedic wards were not appropriate
- Outreach support teams very good (where they exist)
- More staff training in understanding ABI is required, both in hospital and primary care
- Dedicated brain injury nurses / one point of contact would be helpful
- Need for aftercare post-discharge and links to third sector and social work
- More advice for patients and carers
More education for the general public
More support for families and carers.

While some of these requirements will be addressed by the pilot of the new model of care within NHS Lothian, and the network is at present addressing staff training, other items will be taken forward as part of SABIN's ongoing workplan; encouraging the provision of outreach support, the need for one point of contact (preferably a dedicated brain injury nurse), better communication, and working with clinicians and third sector for the provision of better advice about ABI.

An in-depth interview with one service user was carried out, which echoed the themes from the Cafe Consultation responses. This interview highlighted the lack of follow-up, feelings of isolation by the patient and carer, noted that links to community rehabilitation didn’t exist (in their experience), and suggested that there needs to be more local services and better coordination of existing provision. The service user suggested SABIN needs to work to improve links to ensure acute and community provision are joined up to deliver seamless care, and needs to work to help Boards provide better information and support to patients, carers and their families.

SABIN sought Headway’s help in gaining responses to a questionnaire about patient experience. They kindly interviewed patients for us, recording feedback in an electronic survey. The feedback was generally positive, with 100% of respondents assessing their care as adequate or better. When asked what they would change, 40% said they wouldn’t change anything about their care or felt it had been good, 20% wanted more communication / family involvement in decisions, 20% noted that more access to physiotherapy during hospital or on discharge or both would have been helpful, and 20% didn’t answer the question directly. While it is possible that patients would not be able to imagine all of the characteristics of a gold-standard service, it is likely that they were able to identify major gaps in service provision, or where they feel the services they received were not adequate.

**Primary Care**

From a Primary Care perspective, SABIN sent a survey to all GPs in Scotland in October 2016, eliciting 207 fully completed responses (~6%). 97% of respondents noted they had seen a patient with a head injury, (full results were circulated to the ERG). It should be noted that the response rate reflects a small number of the overall population of GPs in Scotland, and should be treated with caution. The Steering Group suggested that not all GPs would be likely to have an informed view of what a good service for patients with head injury would look like.

When asked *What do you think of the current NHS provision for patients with head injury - is it adequate?* 38% of the GP responses received considered it was adequate, particularly in the Acute setting, but even within this group of responses there were a number
of additional comments noting that while Acute care was acceptable, aftercare and rehabilitation was less satisfactory. A further 25% made the point explicitly that they thought that care was mixed; very many mentioning that Acute care was acceptable, but other aspects of care were not acceptable. 30% provided comments noting that they thought care was inadequate. A further 7% did not answer the question directly, or noted that it was difficult to generalise, due to the care varying according to age of patient, level of severity of injury or geographical location.

GPs in Tayside and Fife were the most positive about services, and those in Shetland and Highland were the most negative.

GPs were then asked ‘If you could change one thing about the care of patients with a head injury, what would it be?’

Grouping the responses very broadly, of the 183 responses to this question; 52% considered that their priority would be better access to services or improved services throughout the care pathways, especially for rehab. 15% felt that better information for patients and the wider community should be available, and 10% identified additional training, tools and information for staff as their first priority. 4% identified additional support for patients, particularly 3rd sector and social care as key, and 2% wanted clearer care pathways set out. 4% wanted access to scanning to be improved. 6% felt that nothing needed to change, and 5% weren’t sure.

**Recommendation: Ensure the key themes from the patient consultation and GP feedback are considered as part of future workplans**

**NHS Staff in Non-Specialist Units**

Currently, statistics as provided by the Lead Clinician from local audits suggest that 95% of patients are cared for in non-specialist units.

The main area in which SABIN is supporting these staff is through the development of an on an online resource aimed particularly at staff working in non-specialist units (e.g. orthopaedic wards) in Scotland. This resource is designed to be accessible to Nursing staff, Allied Health Professionals, Medical staff, Social Workers/Mental Health Officers and Support staff, and covers an extensive range of topics which may arise following brain injury. Throughout the site, there is an emphasis on the practicalities of ‘how to help’ individuals with Acquired Brain Injury. The site was launched at the end of the 16-17 financial year. We will be reviewing page usage, and ‘bounce rate’ as the site is further refined, and an evaluation tool is being built into the site.
Third sector
SABIN retains strong links with Headway and the Child Brain Injury Trust, with representation from Headway Lothian (local office) and Headway UK on the Steering Group. More details of SABIN’s work with the third sector is noted in section DO.9 and CP.6.

Scottish Government
SABIN has strong links to Scottish Government. Douglas Gentleman, who sits on the Steering Group and who has been active in SABIN since its inception, has fulfilled the role of CMO Adviser in rehabilitation medicine for six years; linking between the consultants in the specialty throughout Scotland and the various parts of Scottish Government that have an interest in specialist rehabilitation services. Information is gathered each year via a structured questionnaire to the rehabilitation consultants working within specialist rehabilitation services across Scotland, with responses collated by the Adviser and fed back to the Government, covering issues such as workforce, training, and service redesign. These speciality advisers also fulfil other roles, such as working to introduce the major trauma network throughout Scotland.

Other work with the Government has included SABIN representation on the Scottish Neurosciences Council, which entailed liaising with SG at CMO/senior civil servant level to discuss matters of common interest such as education, training, workforce and service redesign. Links also continue with Dr Caesar, National Clinical Advisor to CMO (Secondary Care), regarding the Major Trauma work. Dr Caesar also spoke at the large SABIN Educational conference held in 2016.

Work has also taken place with MSPs, with a Parliamentary reception raising awareness around Brain Injury in 2014, and in 2016 a further event at the Parliament discussing the work done on brain injury within the prison population.

The National Clinical Strategy, with its emphasis on new ways of delivering trauma care, has important implications for SABIN. As noted elsewhere in this report, for several years SABIN has been working closely with colleagues at Scottish Government and the territorial boards to ensure that the pilot model of a new more integrated brain injury care ties in with the Major Trauma Centre work, and that the SABIN network is closely involved in the implementation of the new MTC structure. It is not clear, as yet, how successful these efforts have been, but the commitment from SABIN is not in doubt.

NHS Planners
In October 2016, all territorial Health Boards were asked, via the Directors of Planning circulation list and with the agreement of the Chair of the Group;

1) Whether they had a strategy which details how patients with an Acquired Brain injury are managed within their Board/Area?
2) If the answer to the above was 'yes', to provide a copy.

The request was made on 19th October then followed up with a reminder on 10th November.
Ten of 14 boards provided a response. Three (Lothian, Grampian and Lanarkshire) had a strategy of some description that they could share, and the planner in Lanarkshire noted they were keen to learn from other Boards.

Of the Boards that responded that they had no written strategy, Western Isles noted that they manage patients on a case by case basis, as numbers are low. Borders provided a post-concussion information sheet they use, and many provided a little information about their patient pathways. Forth Valley provided information about the ABI pathway redesign work that is taking place, and with which SABIN is involved. No response was received from NHS GG&C, Tayside, Highland or Orkney. The review group was concerned that the territorial board with perhaps the largest burden of head injury was not able to respond to the request for information.

**Recommendations:**

- **Ensure the SABIN network forges stronger links with NHS planners**
- **SABIN should work with NHS Boards to establish more effective two way communication between the Network and local planning and management systems**

It is difficult to generalise and make a simple judgement as to whether SABIN is meeting all the needs of all of its stakeholders. However, given the work that it has carried out over the years, with the various stakeholder groups as noted above, it could be suggested that it meets some of the stakeholder needs, some of the time. It has therefore been suggested that this objective has been partially met, and is awarded ‘amber’ status.

**ERG conclusion:** Objective partly met
Section 4: Resources

The SABIN network is allocated the same nominal, non-staff budget as all other networks supported by NNMS, namely £5,000. This is managed by the Programme Manager in accordance with NSS’ Standing Financial Instructions. There is no spend on backfill for the Lead Clinician at present because the host board is unable to support this. Scottish Government policy is that backfill is paid on the basis of arrangements put in place and so varies across networks.

For the purposes of the Review, a more comprehensive assessment of the costs of SABIN was undertaken and submitted to the ERG. This suggested a total cost to the NHS per annum, on average, for SABIN’s manager, support staff and clinical lead time of £45k, over the lifetime of the network.

Current annual cost of SABIN Network is £31k

The Review Group agreed that there were societal gains in the cost effective management of TBI. It was noted that although it would be of benefit to measure cost effectiveness, it would be very difficult to isolate all the contributing factors and this may prove an impossible task.
Section 5: Options Appraisal

At the strategic planning day and throughout the review, the network Steering Group and representative stakeholders considered carefully the options available for the future of SABIN, and recommended continued designation of the SABIN Network. The ERG did, however, wish to highlight the difficult job SABIN had to try to effect change for a large patient group with long-term, complex care requirements, within the existing NMCN model that is mandated by Board Chief Executives to influence without authority.

They thought there would be no benefit in moving to a Regional network model.

The Review Group looked in some detail at other styles of national commissioned networks. The Neurosurgical network, and the Forensics network were both considered. Both had a different commissioning model, and a larger staff wte, and both appeared to have levels of funding in the region of £300k per annum. The Review Group concluded that SABIN had been very cost effective to date.

It was noted that the direct commissioning of the Forensic Network by Scottish Government, and the high-level stakeholder input to the Neurosurgical MSN, (representation from Scottish Government on the Neurosurgery Network, and input from Sir David Carter), with accordant resourcing approximately six times that of SABIN, had helped those national networks effect real change. In such a setting the importance of pilot activities such as testing the utility and costs of different methods of ascertainment for patients with ABI, might be very helpful. This work could involve comparing data entry as part of routine care with the use of audit facilitators; the use of machine learning approaches to extract relevant information from existing free text sources; and support for work with ISD to use CHI linkage to identify future trajectories of patients admitted with ABI.

The option to move to a Managed Care Network was discussed by SABIN Steering Group members at their meeting on 19th January 2017, and it was agreed that the network could support the integration agenda by supporting the articulation of a national standard relating to discharge of patients back into the community, e.g. to have a complex discharge plan in place within 4-6 weeks was recommended as a potential action for the future.

It was suggested that the Network could review as a first stage the option to evolve into a managed care network, taking into consideration how health and social care integration might assist planning for complex discharge, pathways and agreed decision making tools. It was agreed that NSS could scope a commissioning model for this, taking into consideration possible benefits of having social care money included to enable commitment from the health and social care area.

The Steering Group also highlighted the value in identifying social care expenditure and that of independent rehabilitation and suggested looking at a framework to consider these issues, with the aim of creating better outreach services and rehabilitation. Members agreed that working with Headway to help achieve this was an option for the future.
Section 6: Conclusions

Following analysis of the evidence presented, the ERG concluded that the network had added value to NHS Scotland through the following key achievements:

- Patient engagement
- Standards documentation
- Service Mapping
- Contribution to Guidelines such as SIGN 110 and 130
- SABIN’s cost effectiveness
- Piloting a new model of care in Lothian
- MDT Education

The ERG recommended that the network should retain its designation status.

During the course of the review, the Review Group considered what the implication would be if SABIN were to cease to exist, and agreed it was important for SABIN to remain, in order to continue to improve the standards of care for patients with ABI.

SABIN needs to increase its partnership working in order to maximise its effectiveness; there should be reciprocal representation between SABIN Steering Group and other stakeholders working towards similar ends, such as the Neurosurgical Network Board, the Major Trauma Centre Network Board and SABIN Steering Group.

With regard to the links which SABIN has forged in taking forward the new more integrated models of care, ERG Members agreed with SABIN’s work to pilot a new model of service delivery within Lothian, in tandem with the changes around Major Trauma Centres. It was agreed that equity of access to care was an issue and something that SABIN was right in addressing via the pilot, and that this work should continue.

SABIN requires stronger representation from health board planners on the Steering Group to help influence communications, otherwise, the priority objective around engagement with NHS managers and planners to support service development, improvement and redesign will not be achievable.

Data needs to be used to gather information to support Acquired Brain Injury care, (whether this be via NSD, in house audit facilitators, or in other ways). Without robust baseline data, it was impossible to ascertain if quality was improving. SABIN should work with other stakeholders to ensure a robust dataset for ABI, using the opportunities that the current focus on trauma care created.

SABIN should continue its valuable work in MDT education.

Continued designation of SABIN as a national managed clinical network was recommended.
Section 7: Recommendations

On the basis of evidence of progress to date and of SABIN’s ongoing role in delivering key strategic policy aims, the ERG recommended continued designation of the network.

The ERG made a number of additional recommendations to enhance SABIN’s effectiveness and impact:

1. SABIN should revise its leadership model to include a Network Chair.

2. SABIN should repeat and update the service mapping exercise at regular intervals.

3. SABIN should focus on collaboration with current SG policy initiatives and strategic structures, including the Scottish Trauma Network, the Neurosurgery MSN and ABI model of care pilot, as a means to maximise its effectiveness in addressing barriers and achieving its objectives. To achieve optimal benefit of synergies between strategic aims and work programmes there should be reciprocal representation on respective Steering Groups.

4. SABIN should collaborate with the Neurosurgery MSN to develop a comprehensive national pathway that incorporates ABI and neurosurgery rehabilitative care, against which NHS Boards can be audited.

5. Access to robust and complete data is critical to SABIN success in enabling proposed improvements in ABI care; SABIN and NHS Boards should collaborate to explore options and ensure systems to collect, analyse and report ABI data meet requirements.

6. SABIN should design and deliver an education strategy that is based on current stakeholder needs.

7. SABIN should explore options to quantify potential cost savings associated with ABI care.

8. SABIN should ensure the key themes from the patient consultation and GP feedback inform future workplans.

9. SABIN should foster stronger relationships with NHS planners, including revision of its Steering Group membership to include representation from local/regional planning.

10. SABIN should work with NHS Boards to establish more effective two way communication between the Network and local planning and management systems

The ERG also recommended that NHS Boards and other service providers be encouraged by Scottish Government to interact constructively and effectively with SABIN.
Annex A – Membership

The Expert Review Group includes representation from the following groups and organisations:

<table>
<thead>
<tr>
<th>Role</th>
<th>Name and Details</th>
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<tbody>
<tr>
<td>Chair and Clinical expert</td>
<td>Prof. Malcom MacLeod, Consultant Neurologist, NHS Forth Valley</td>
</tr>
<tr>
<td>Regional Planning</td>
<td>Mr David Munro, Senior Planner, NHS Forth Valley</td>
</tr>
<tr>
<td>Clinical reference group (Attendees dependent on availability)</td>
<td>Dr Imran Liaquat, Consultant Neurosurgeon, NHS Lothian</td>
</tr>
<tr>
<td></td>
<td>Dr Neil Mukerjee, Consultant in Emergency Medicine / Honorary Clinical Senior Lecturer, Clyde Emergency Departments</td>
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<tr>
<td></td>
<td>Dr Andreas Demetriades, Consultant Neurosurgeon and Spinal Surgeon Honorary Clinical Senior Lecturer, University of Edinburgh</td>
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<tr>
<td>Nursing Representation</td>
<td>Ben Sutherland, Nurse Consultant, Rehabilitation Nursing, NHS Fife</td>
</tr>
<tr>
<td>Public / Patient</td>
<td>Simon Glen, Project Co-ordinator, Headway Glasgow / Michelle Keenan, Chief Executive, Edinburgh Headway Group</td>
</tr>
<tr>
<td>Social care</td>
<td>Wendy Jack, Planning and Improvement Manager, West Dunbartonshire Health and Social Care Partnership</td>
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<tr>
<td>Managed Services Network for Neurosurgery</td>
<td>Eric Ballantyne, Consultant Neurosurgeon</td>
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<tr>
<td>National Network Management Service</td>
<td>Liz Blackman, Senior Programme Manager</td>
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Annex B – Current network staffing

Lead Clinician: Dr Alan Carson
Programme Manager: Aileen Ferguson
Programme Support Officer: Mary Adams