











# Optimal clinical pathway for adults: Traumatic Brain Injury

**National Neurosciences Advisory Group (NNAG)**

Published: May 2023

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# Overview: About the optimal pathway

This pathway is part of a suite of optimal neuroscience clinical pathways that have been developed by the neurological community, with the support of NHS England and the National Neurosciences Advisory Group (NNAG).

The development of this pathway was overseen by NNAG, with input from professional bodies and patient organisations. A 6 week public consultation was held to gather input, views and experience from people affected by neurological conditions and wider stakeholders.

The pathways set out what good treatment, care and support looks like. This includes treatment and support for people who may be experiencing the first symptoms of a neurological condition, right through to people who have lived with a condition for a long time. They set out the aspirations for good care, support improvement of services and enable commissioning of quality services, locally and nationally.

## Optimal Clinical Neuroscience Pathways



### NEUROSCIENCE

SUBARACHNOID/INTRACRANIAL HAEMMORHAGE

MULTIPLE SCLEROSIS (MS)

EPILEPSY

AUTOIMMUNE

HEADACHE & FACIAL PAIN

NEUROMUSCULAR CONDITIONS

MOVEMENT DISORDERS

MOTOR NEURONE DISEASE (MND)

FUNCTIONAL NEUROLOGICAL DISORDER (FND)

TRAUMATIC BRAIN INJURY (TBI)



### CROSS-CUTTING

TRANSITION FROM CHILDREN TO ADULT SERVICES

NEUROGENETICS

MENTAL HEALTH

REHABILITATION

## FIND OUT MORE

Optimal clinical pathways and resources (NHS England and NHS Improvement. NHS log in required): [www.future.nhs.uk/about](http://www.future.nhs.uk/about)

Optimal clinical pathways and resources (NNAG): [www.nnag.org.uk/optimum-clinical-pathways](http://www.nnag.org.uk/optimum-clinical-pathways)

Neurological patient organisation websites & resources (Neurological Alliance): [www.neural.org.uk/membership/our-members](http://www.neural.org.uk/membership/our-members)



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## Executive summary

This optimum clinical pathway for adults with traumatic brain injury (TBI) was designed by a working group of TBI specialist healthcare professionals in consultation with relevant stakeholders (see Appendix for group membership).

The group agreed that following the hyper-acute management of TBI, except for a few isolated examples of good practice, the current pathway for patients is poorly defined with a lack of specialist healthcare teams capable of managing the sub-acute and chronic needs of these patients. Often patients are stepped-down to teams not used to managing this patient cohort and who do not have easy access to the specialist services needed to optimise care. This leads to misdiagnoses, suboptimal rehabilitation outcomes, worse long-term disability and increased costs to the individual and society.

The group acknowledged that the symptoms, disability and co-morbidities of people with TBI are highly heterogeneous. The group agreed that an integrated care pathway, tailored to current

local and regional staffing and infrastructure, is needed to deliver accurate and timely diagnosis and treatment at all stages during a TBI patient's care at the level of pathology, impairment and function. This will require the co-ordinated involvement of numerous healthcare specialists including neurosurgeons, neurologists, rehabilitation medicine physicians, neuropsychiatrists, neuropsychologists, specialist nurses and specialist TBI allied health professionals including physiotherapists, occupational therapists, dieticians and speech & language therapists.

To do this we propose the standardised introduction of a specialist interdisciplinary TBI Team, led by a brain injury consultant, as already exists in a few networks, trained in the restorative and rehabilitation neurosciences. This team would work within the major trauma network, be based in major trauma centres, outreach to trauma units and the community, and engage acutely and longer term after TBI to provide accurate diagnoses, so that correct management is prescribed, and more efficient collaboration between researchers and clinicians encouraged.

Traumatic Brain Injury (TBI) is a huge and growing health problem for the UK. In England, TBI is responsible for around 900,000 A&E attendances and over 200,000 hospital admissions annually<sup>1</sup>. 10-20% of head injuries are rated 'severe'. The rest are classified as being 'mild' and are either discharged directly from A&E or have no need for surgical or critical intervention<sup>2</sup>. Nevertheless, TBI is the single biggest cause of death and disability in those aged <40 and clusters in populations who are socio-economically deprived, have pre-existing health problems, fall, or take risks<sup>3,4</sup>.

Survivors of TBI in England, particularly after more severe injury, are increasing in number as a result of the introduction from 2010 of a major trauma network (MTN), a network of 27 major trauma centres (MTCs) and their associated trauma units (TUs)<sup>5</sup>. They usually then face multiple physical, cognitive, emotional and neuro-behavioural problems, which can have long-term and far-reaching consequences.

Neurobehavioural problems, in particular, contribute to poor functional outcomes, high burden on carers and families, and predict ongoing long-term healthcare utilization<sup>4,6,7</sup>. Within the 'mild' TBI population, contrary to popular belief, up to a third (resulting in around 300,000 patients annually in England) can be left with a range of persistent symptoms that prevent them from working and living normally<sup>8,9,10</sup>. It is thus estimated that TBI costs the UK around £15 billion per year in direct and indirect costs<sup>3</sup>.

Currently, the majority of patients presenting with TBI are initially seen by clinicians who have little training in the diagnosis and management of the consequences of TBI at the level of pathology and neurological impairment. Inevitably, their knowledge of prognosis and long-term outcomes is poor, so subsequent rehabilitation and care is delayed and disorganized, management breaks down over time, and inappropriate or no treatment options are prescribed. Thus, the use of precious specialist resources is inefficient and fails to contribute to the development of a generic pathway that optimises post-acute management of single incident brain injury, including new pathologies resulting from Covid-19 and infective, inflammatory and antibody mediated encephalitides.

This document is the output of the TBI Clinical Working Group's efforts to define the optimal pathway for patients with TBI. It outlines:

- The "optimal" pathway for patients with TBI from first presentation to ongoing management.
- The definition of "specialised" TBI care.
- A workforce model to support implementation.
- Possible efficiency savings to come out of the optimum pathway.
- Barriers to implementation, and recommendations about patient flow, information sharing, and research and clinical trials.



## Pathway: First presentation to diagnosis and initial care plan

### Good practice

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TBI is, to a large extent, preventable. Policies designed at increasing awareness and preventing TBI can have dramatic effects on reducing the burden of TBI. Collaboration between research and policy-makers is crucial to maximise the public health benefits.

Individuals suffering an acute TBI can present to A&E, primary care or directly through the major trauma services. Patients do not always seek medical attention at the time of injury but may instead present after a delay to A&E or primary care. All patients admitted to a major trauma centre due to a traumatic brain injury should be referred to and managed by a specialist interdisciplinary TBI team once stabilised. Patients presenting acutely or subacutely after TBI to A&E or primary care should be assessed and given appropriate advice about post-traumatic brain injury problems. If there are no concerns, these patients can be managed in primary care. If there is an isolated problem (e.g. headache) this can be referred appropriately if required (e.g. local neurology service). If there are multiple or complex issues then referral into a regional specialist TBI clinic should be made to allow specialist assessment and access to specialist

services including neurology, neurosurgery, neuropsychiatry, neuropsychology, rehabilitation medicine, specialist nurses and specialist therapies. Given the potential complexities of care after a TBI, effective case management is important to facilitate access to relevant services for all individuals, especially those less able to advocate for themselves.

### Specialist TBI service

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A specialist TBI service (outpatient and inpatient) should be led by a doctor with expertise in TBI. The service should comprise a specialist interdisciplinary team able to access neurosurgery, neurology, neuropsychiatry, rehabilitation medicine, neuropsychology and specialist therapy input e.g. speech and language therapy, occupational therapy, physiotherapy, dietetics. Expertise in TBI may be demonstrated by the following:

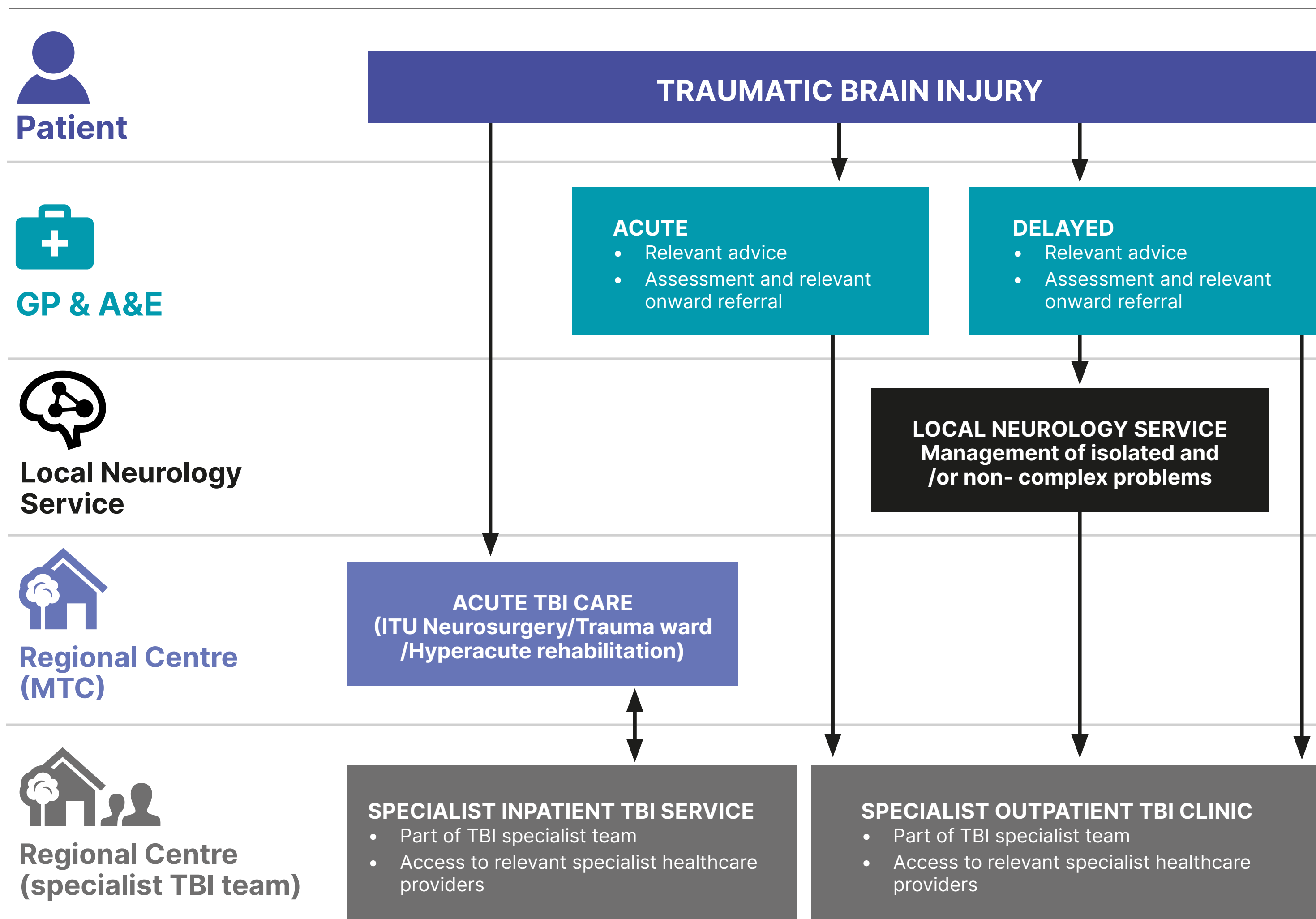
- Training and continuing education in TBI
- Peer review of practice and patient feedback
- TBI must be a significant part of their clinical workload (equivalent to at least one session/week).

# Pathway: First presentation to diagnosis and initial care plan

At diagnosis, the diagnosing physician should agree a care plan with the patient that includes the following:

- Diagnosis, cause of symptoms (including if TBI related) and identification of relevant comorbidities;
- Treatment plan with regard to presenting symptoms (e.g headache, vertigo);
- Referral onwards for cognitive assessment as required;
- Referral onwards for neuropsychiatric assessment as required;
- Referral onwards for cognitive and/or communication assessment
- Patients with complex rehabilitation needs, including extracranial injuries, need a rehabilitation prescription with ongoing care overseen by a rehabilitation medicine specialist.
- Recommendations and signposting for independent support services; and
- Practical and/or psycho-social self-management actions agreed with patient, with a progress review plan that allows for additional support to be provided as needed.

## TBI PREVENTION PROGRAMMES AND STRATEGIES



ITU Intensive care unit, MTC Major trauma centre, TBI Traumatic brain injury,



# Pathway: Treatment and ongoing management

## Good practice

- 1. Patients with TBI are highly heterogeneous in symptoms, severity and the underlying pathophysiology. Therefore, the care pathway should prioritise effective triage.** There is no “one size fits all” treatment for TBI. Many different services may be of help to individual patients with TBI, and clinicians have a responsibility to ensure that patients are referred to the most appropriate service(s) depending on need. Effective case management is a vital part of this care coordination.
- 2. As much care as possible should be kept local.** Given that TBI is common and a significant proportion of people have persistent disabling symptoms, local care is essential to maintain the viability of specialist assessment and treatment services and to provide efficient local support for patients with long-term symptoms.
- 3. A First Point of Contact (FPOC)/Case Manager for people with TBI will facilitate management of new symptoms/relapse.** A patient’s FPOC/case manager will be named in their care plan. The FPOC/case manager should have clinical expertise in TBI. Many

people with TBI with chronic symptoms need assistance in navigating the social care system. An FPOC/case manager can ensure appropriate assessment and support. A range of professionals can adopt the role of an FPOC/case manager including, but not limited to, specialist nurses, doctors, and allied healthcare professionals.

- 4. Intensive specialist treatments for TBI are necessary for a proportion of patients.** Specialist assessment and treatments are necessary for a proportion of patients and should be accessible with minimal delay to ensure best outcomes. This includes readily available access to mental health and psychology support.
- 5. Managing the whole person.** TBI is often associated with non-neurological injuries (e.g. fractures and soft tissue injuries), medical and mental health co-morbidities. Therefore, the specialist team requires access to expertise in rehabilitation of patients with polytrauma and non-neurological conditions.

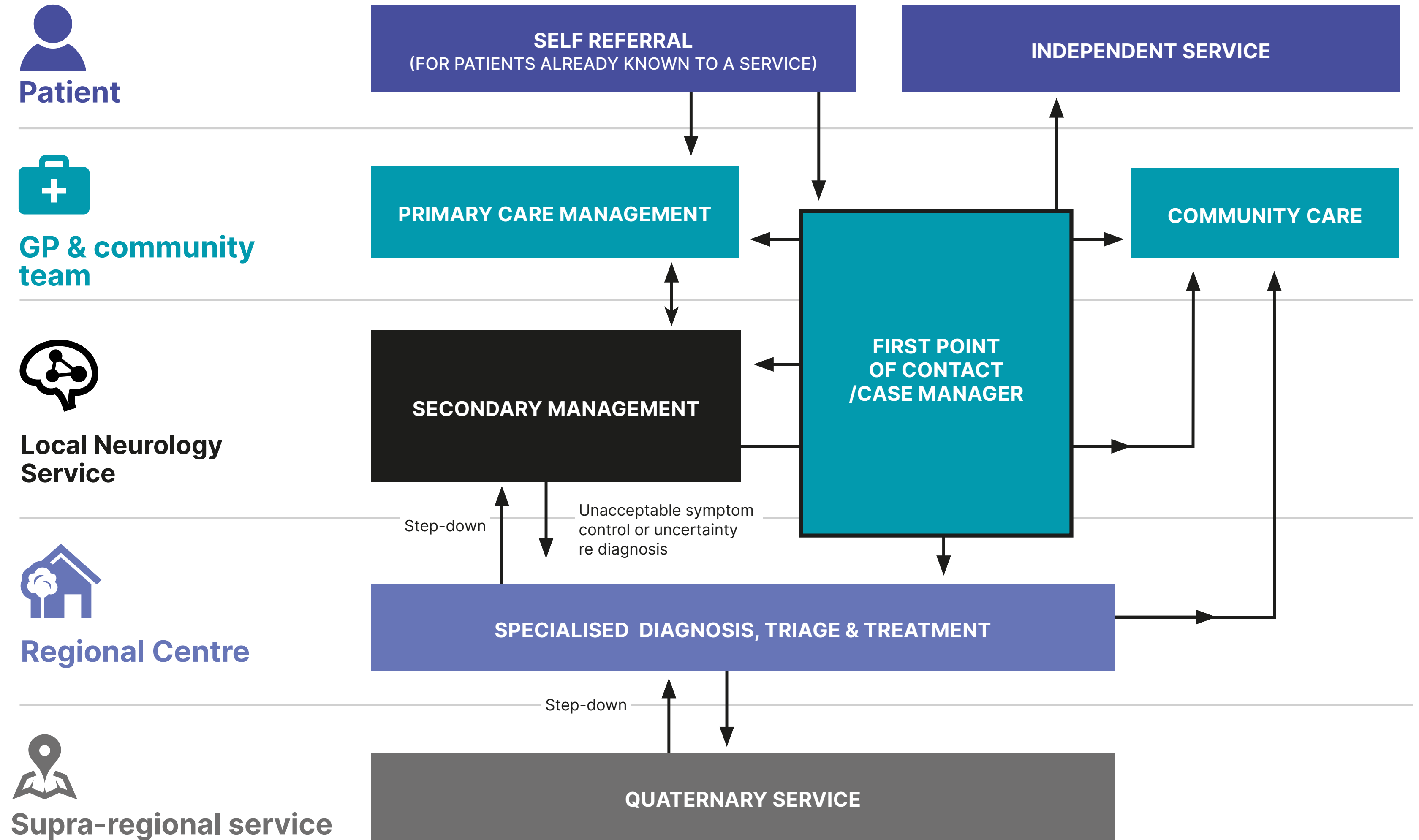


# Pathway: Treatment and ongoing management

## Secondary care functions include the following:

- Organising appropriate investigations, diagnosis and diagnostic explanation, managing medications.
- Providing self-management advice and signposting to sources of information and support (e.g. charity).
- Follow up in selected patients, including assessment of new symptoms
- Acting as a FPOC and patient advocate.
- Triaging the patients directly into appropriate secondary care and primary care treatment services (e.g. community neurotherapy, NHS Talking Therapies).

FPOC first point of contact,



# Pathway: Defining a specialised TBI service

All TBI patients requiring inpatient care will be admitted via pre-hospital triage either to a regional MTC under the initial care of neurosurgical and critical care teams, or, if neurosurgical or critical care is not required or deemed unlikely, to a local TU for initial management by the Emergency Department (ED) team, after consultation with the MTC.

After initial critical care and neurosurgical input in the MTC, acute patient management and care will become the responsibility of a specialist interdisciplinary TBI team, led by a traumatic brain injury consultant, trained in the restorative and rehabilitation neurosciences, based in the MTC, and working in the MTC, and face to face or remotely in the TUs and other arenas. Patients with complex rehabilitation needs, including extracranial injuries, require a rehabilitation prescription overseen by a rehabilitation medicine specialist.

For those people with a TBI not requiring inpatient care, many could be effectively cared for at primary and secondary care levels. However, a proportion of these will need the input of a specialist service for TBI located within Regional Neuroscience Centres, for example via a TBI clinic.

## Referral Criteria for Access to a Specialised TBI Service:

- Symptom severity and/or complexity is high.
- Patient has failed to improve with primary/secondary management.
- Requires complex interdisciplinary assessment and treatment

### Elements of specialised care: Tertiary

Tertiary services are provided by all specialised centres and are not available at district general hospitals.

- Specialist assessment, investigation and diagnosis
- Neuropsychiatry and neuropsychology services
- Research and clinical trials
- Specialist multidisciplinary day-patient treatment
- Specialist multidisciplinary inpatient treatment (level 2)

### Elements of specialised care: Quaternary

Quaternary services are considered ‘super specialised’ and are only provided at some specialised centres.

- Highly Specialised inpatient multidisciplinary rehabilitation (Level 1).
- Quaternary specialised neuropsychiatric (e.g. for PTSD, FND) and neuropsychological (e.g. for day-patient cognitive rehabilitation) services.

## Pathway: Efficiency savings

### Improved patient care and pathway efficiency

This proposed pathway will improve patient care and pathway efficiency, and is likely to produce substantial cost savings. A retrospective study of 9,000 neurosurgical bed occupancy days found that the lack of an organised acute TBI service with rehabilitation capability led to 72% of TBI patients remaining in neurosurgical beds when they no longer required neurosurgical management<sup>11</sup>. A Norwegian cohort study compared outcomes in 2 groups of patients who had received acute rehabilitation and were transferred either directly to sub-acute rehabilitation or, as a result of bed availability, via alternative routes. This study found shorter hospital stays and better functional outcomes in those who had direct transfer to sub-acute rehabilitation<sup>12</sup>. The experience of St George's Hospital acute TBI pathway, which is a neuroscience-led service, has been that inpatient stay and costs for TBI patients are reduced (by 37% and £30,000 respectively) by timely rather than delayed transfer to an acute brain injury unit (ABIU) (Griffin C, Dilley M. 2018, Personal Communication). In addition, a prospective randomized study of a specialist multidisciplinary domiciliary outreach team late after TBI showed increased independence and lessened care needs compared with usual care<sup>13</sup>, suggesting significant cost savings result long-term.



### Access to appropriate treatment improves outcomes and reduces long-term costs

Studies consistently demonstrate that any upfront investments made in acute, early and late specialist rehabilitation services are rapidly offset by the cost savings made through increased and faster functional improvements. Data from the UK Rehabilitation Outcome Collaborative shows that inpatient rehabilitation early after TBI saved about £34,000 per annum per patient and paid for itself over 18 months after discharge,<sup>14</sup> with net total lifetime savings of £1.1m per patient<sup>14</sup>, while rehabilitation of medically unstable (“hyperacute”) patients saved about £24,000 per annum per patient<sup>15</sup>.

In addition, late residential rehabilitation for patients with neurobehavioural disorders after TBI has been shown to improve functional outcomes and is estimated to result in lifetime savings of up to £1.13 million<sup>16</sup>.



## Barriers & enablers : Patient flow

With current models of care, there is a very large gap in provision of services for people who have suffered a TBI. Some services do exist, but these are largely fragmented and offer a specific intervention (e.g. inpatient multidisciplinary rehabilitation) without being part of a specific care pathway. Community and secondary care services that could help some people with TBI often report lack of expertise or support as barriers to them providing care for people with TBI. Access to specialist assessment and treatment is patchy across England.

### Cross-cutting recommendation: Support for self management

Access to online self management programmes and support groups will help patients navigate the service.

- Apps to help patients navigate the service.
- Advice to help self-manage symptoms in between appointments (e.g. charity websites, peer-to-peer support groups, apps and web-based applications that help manage common symptoms such as sleep or mood disturbance).

TBI traumatic brain injury,

Barrier	Potential solution(s)
Lack of recognition by acute trauma teams of post-traumatic brain injury sequelae and their management	<ul style="list-style-type: none"> <li>■ Integration of TBI specialist teams into the current major trauma networks</li> <li>■ Mandated use of the Rehabilitation Prescription to identify rehabilitation needs and central collation of data.</li> <li>■ Implementation of NICE guidance, including on early diagnosis and treatment of hypopituitarism</li> </ul>
Lack of recognition by A&E and primary care physicians of treatments available for post-traumatic brain injury sequelae, and access to specialist TBI services	<ul style="list-style-type: none"> <li>■ Clear referral framework and education of primary care to allow recognition and timely referral of patients</li> <li>■ Implementation of NICE guidance, including on early diagnosis and treatment of hypopituitarism</li> </ul>
Community and secondary care generic rehabilitation services often report lack of expertise and support for managing patients with TBI	<ul style="list-style-type: none"> <li>■ Education program for NHS Talking Therapies, community neurotherapy and secondary care neurotherapy teams in TBI.</li> <li>■ Establishing direct links between specialist TBI services and community services for support and to facilitate patient flow.</li> </ul>
Lack of specialist TBI services and TBI specific beds	<ul style="list-style-type: none"> <li>■ Support development of specialist TBI interdisciplinary services within each regional neuroscience centre underpinned by rigorous data collection on outcomes</li> <li>■ Use of technology including remote assessment and treatment to provide access to specialist treatments not local to the patient</li> </ul>
Uncertainty about which patients should be referred to which treatment service	<ul style="list-style-type: none"> <li>■ Clear referral guidelines agreed within each region</li> </ul>

## Barriers & enablers : Access to research and clinical trials

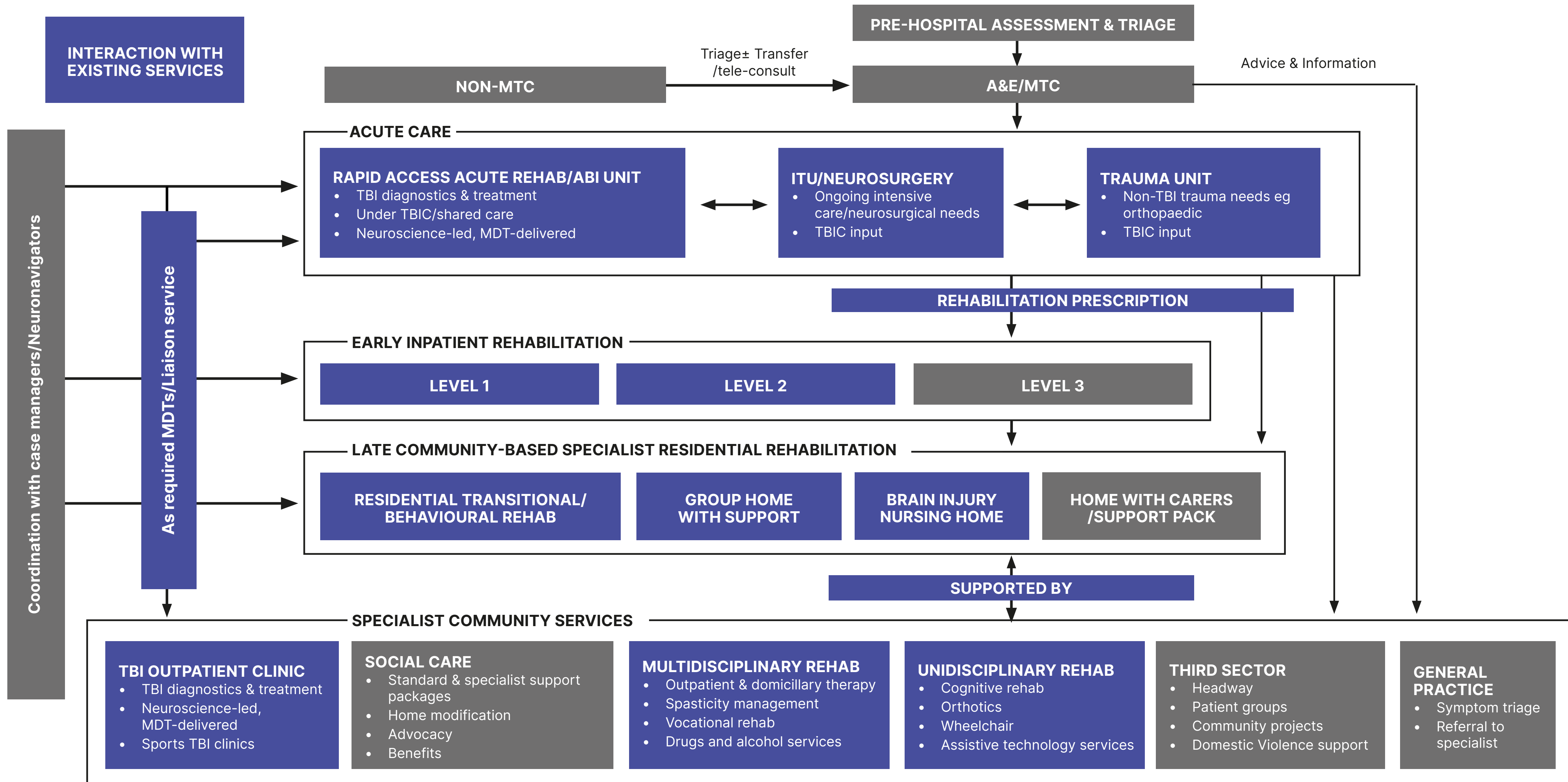
Investment in research and clinical trials is necessary to continue to improve outcomes after a traumatic brain injury. A recent international commission of traumatic brain injury experts highlighted that the “evidence underpinning guidelines for medical, surgical, and rehabilitation interventions for TBI is weak” and recommended the need for greater research at all points along the care pathway to improve clinical outcomes (Maas et al. 2017). The specification of an optimum clinical pathway for TBI is an opportunity to embed research at every stage of the patient pathway in order to monitor and improve practice and outcomes. It will also facilitate the rapid translation of advances identified through research to clinical care.

The traumatic brain injury clinical working group recommends the following to address barriers to research and clinical trials of any intervention used at any point in the care pathway after TBI, whether pharmacological, surgical, technological or service, training or talking based:

Barrier	Potential solution(s)
Lack of capacity and incentives for Trusts to enable clinicians to participate in research. The main barrier is lack of time given heavy clinical workload in job plans.	<ul style="list-style-type: none"> <li>■ Identify and free up capacity.</li> <li>■ Joined up TBI registry/database that is linked to routine clinical care.</li> <li>■ Clinician and patient partnerships with TBI organisations to improve access to funding and PPI support for projects.</li> </ul>
Inadequate networks.	<ul style="list-style-type: none"> <li>■ Establish networks to build and deliver research programmes.</li> <li>■ Horizon scanning to identify research opportunities.</li> <li>■ Aim to create National database and information repository accessible to all TBI team</li> </ul>
Lack of consensus on research priorities	<ul style="list-style-type: none"> <li>■ Develop a formal process for all stakeholders to establish clinical research priorities in TBI, including patient and public involvement initiatives.</li> </ul>



# Map of the optimum clinical pathway for TBI: Flow







## Clinical guidance:

To be considered alongside the pathway

### Traumatic brain injury: integrated approaches to improve prevention, clinical care and research

A recent commission comprised of experts and clinicians involved in the care of patients with TBI reviewed the priorities and provided expert recommendations on how to improve TBI care.

A key recognition by this commission was that:

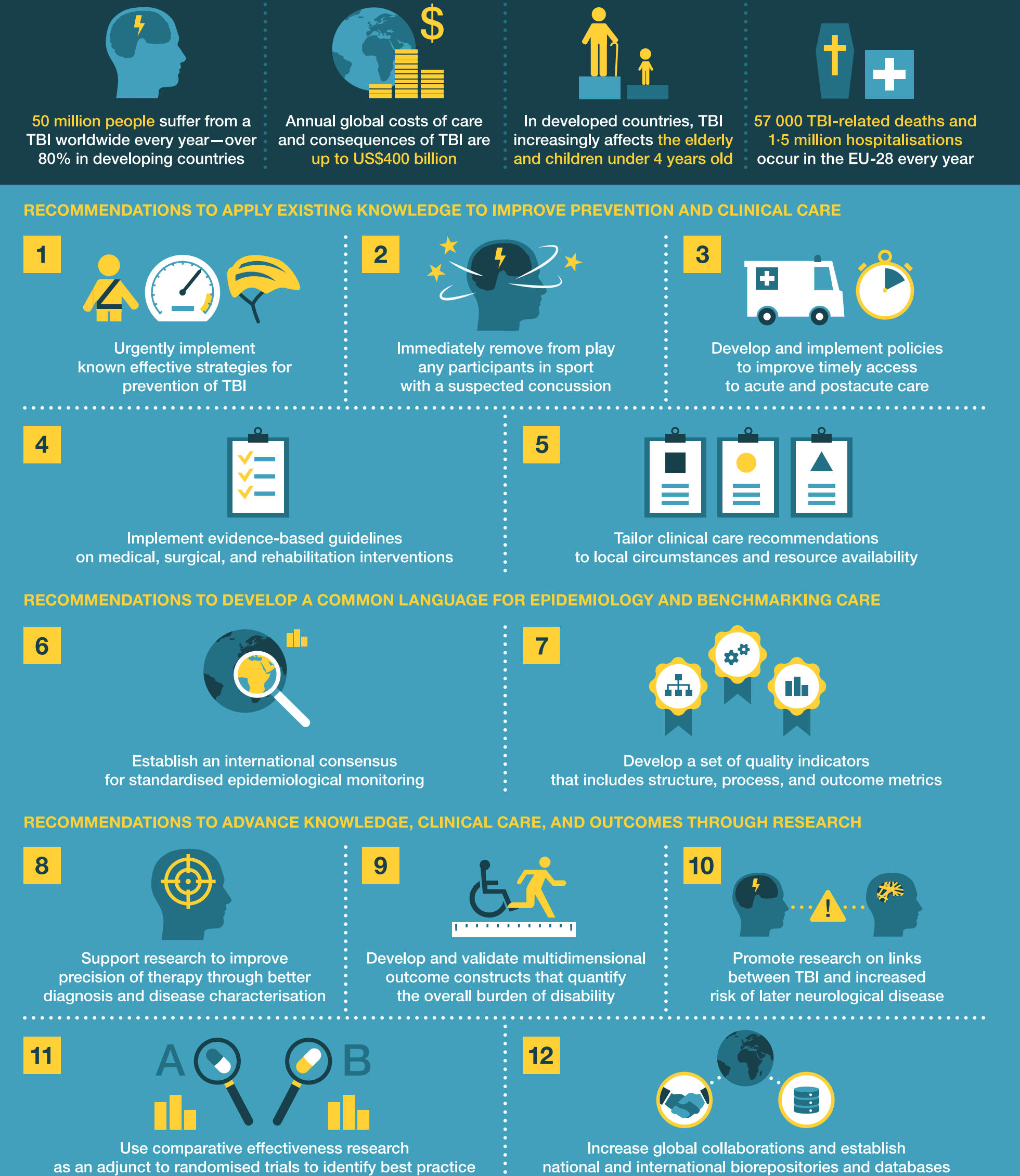
“Access to health care is often inconsistent between centres, regions, and countries, especially for acute and post-acute care”  
And their recommendation was that:

“Health-care policies should aim to improve access to acute and post-acute care to reduce the effects of TBI on patients, families, and society”

This pathway aims to standardise the care received by individuals suffering a TBI based on best practise and to improve efficiencies.

Maas, A.I., Menon, D.K., Adelson, P.D., et al., 2017. Traumatic brain injury: integrated approaches to improve prevention, clinical care, and research. *The Lancet Neurology*, 16(12), pp.987-1048.

## Traumatic brain injury: integrated approaches to improve prevention, clinical care, and research



## Clinical working group membership

Name	Profession	Organisation
<b>Antonio Belli</b>	■ Professor of Neurosurgery	■ Birmingham University Hospital NHS FT
<b>Shai Betteridge</b>	■ Consultant Neuropsychologist	■ St George's University Hospital, NHS FT
<b>Alan Carson</b>	■ Consultant Neuropsychiatrist and Honorary Professor	■ University of Edinburgh
<b>Paul Cooper</b>	■ Consultant Neurologist and ABN TBI Advisory Group Chair	■ Salford Royal NHS Foundation
<b>Mike Dilley</b>	■ Consultant Neuropsychiatrist	■ St George's University Hospital NHS FT
<b>Miranda Gardner</b>	■ Head Injury Nurse Specialist	■ University Hospital Southampton NHS FT
<b>Richard Greenwood</b>	■ ABN representative, Consultant Neurologist	■ National Hospital for Neurology
<b>Colette Griffin</b>	■ Consultant Neurologist	■ St George's University Hospital, NHS FT
<b>Peter Hutchinson</b>	■ Professor of Neurosurgery	■ Cambridge University Hospital NHS FT
<b>Peter Jenkins</b>	■ Workstream clinical lead, Consultant Neurologist	■ St George's University Hospital, NHS FT
<b>Lucia Li</b>	■ NIHR Clinical Lecturer in Neurology	■ Imperial College, London
<b>Clarence Liu</b>	■ Consultant Neurologist	■ Homerton University Hospital, NHS FT
<b>David Sharp</b>	■ Professor of Neurology	■ Imperial College, London
<b>Richard Sylvester</b>	■ Consultant Neurologist	■ National Hospital for Neurology
<b>Jacqueline Twelftree</b>	■ AHP Clinical Lead, Neuro Rehab	■ Homerton University Hospital, NHS FT
<b>Martha Turner</b>	■ Clinical Psychologist & Neuropsychologist	■ Homerton University Hospital, NHS FT
<b>Mark Wilson</b>	■ Professor of Neurosurgery	■ Imperial College Healthcare NHS Trust, London
<b>Sancho Wong</b>	■ Consultant Physician in Rehabilitation Medicine	■ St George's University Hospital, NHS FT
<b>Georgina Carr</b>	■ Chief Executive	■ The Neurological Alliance



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**National Neurosciences Advisory Group c/o The Neurological Alliance (England)**  
**[www.nnag.org.uk](http://www.nnag.org.uk)**

The Neurological Alliance is a coalition working together to improve treatment, care and support for people affected by neurological conditions. Together we campaign to ensure people affected by neurological conditions can access high quality, joined up care and support to meet their individual needs, at every stage of their life.

**[www.neural.org.uk](http://www.neural.org.uk)**

**Email: [info@neural.org.uk](mailto:info@neural.org.uk)**

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