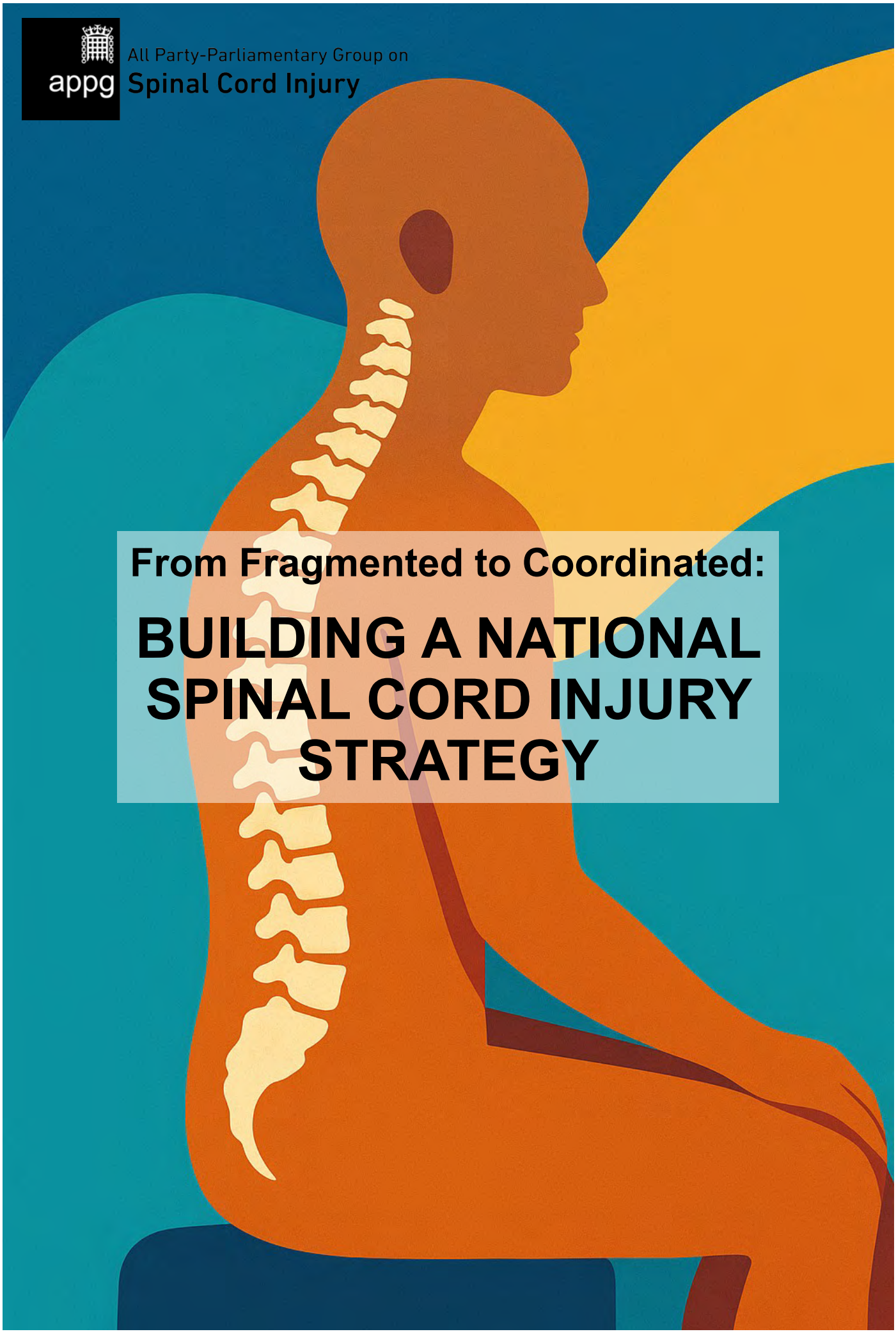
All Party-Parliamentary Group on
Spinal Cord Injury



From Fragmented to Coordinated:

BUILDING A NATIONAL SPINAL CORD INJURY STRATEGY

About the Authors

Dharshana Sridhar
A medical doctor and geneticist, Dharshana has over 22 years as a senior civil servant, especially as part of the Prime Minister's Council for Science and Technology and later as policy advisor to subsequent Prime Ministers.

Glyn Hayes
A former borough councillor and army veteran, Glyn sustained a spinal cord injury in 2017 following a motorbike accident. He joined Spinal Injuries Association in August 2023 as the Parliamentary and Public Affairs Coordinator.

George Atwell
A history and politics graduate, George joined Spinal Injuries Association this year as Policy Coordinator.

Secretariat to the All-Party Parliamentary Group (APPG) on Spinal Cord Injury

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Any errors remain the authors' responsibility.

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(Hudgell Solicitors do not have control over the content of this report).

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"Conditions are chronic,
they are long-term, they need to be managed.
And that means we need to reform [the NHS] to make it fit for the future….so your care is done with you, not to you".

Rt Hon Sir Keir Starmer MP, Prime Minister, announcing the NHS 10-Year Plan, July 2025

About the APPG for Spinal Cord Injury

Andy McDonald

Chair of the APPG for Spinal Cord Injury

Andy McDonald is the Labour MP for Middlesbrough and Thornaby East, and has been an MP continually since 29 November 2012.

Gill Furniss

Vice Chair of the APPG for Spinal Cord Injury

Gill Furniss is the Labour MP for Sheffield Brightside and Hillsborough, and has been an MP continually since 5 May 2016.

John Glen

Vice Chair of the APPG for Spinal Cord Injury

The Rt Hon John Glen is the Conservative MP for Salisbury, and has been an MP continually since 6 May 2010.

Helen Morgan

Vice Chair of the APPG for Spinal Cord Injury

Helen Morgan is the Liberal Democrat MP for North Shropshire, and has been an MP continually since 16 December 2021. She currently undertakes the role of Liberal Democrat Spokesperson (Health and Social Care).

The UK has a proud legacy in spinal cord injury care, pioneered by Professor Sir Ludwig Guttmann, whose visionary work at Stoke Mandeville laid the foundations for modern SCI rehabilitation. What began as a radical transformation in the treatment of war veterans became a model for holistic, person-centred care around the world. It is with that spirit that we now revisit our national commitment to people with spinal cord injury.

As Chair of the All-Party Parliamentary Group on Spinal Cord Injury, I have had the privilege of hearing directly from experts, patients, clinicians, and charities who live and work with the consequences of spinal cord injury every day.

This inquiry was launched with one simple but urgent aim: to understand why the UK must adopt a National Strategy for Spinal Cord Injury, and to develop clear, achievable recommendations to make that strategy a reality. Despite significant advances in acute trauma care, what follows spinal cord injury is too often a postcode lottery, marked by delayed admissions, fragmented discharge planning, inadequate housing, and a troubling absence of community-based care.

Throughout this process, we have been struck by the resilience of those living with SCI, and equally, by the avoidable failures they face. A national strategy is no longer optional; it is essential. This report is not an endpoint, but a starting point. It is a call to action for government, health and care systems, and wider society to ensure that no one with a spinal cord injury falls through the cracks.

We are grateful to everyone who contributed their time, evidence, and lived experience to this inquiry. Your voices will shape what comes next.

Andy McDonald MP
Chair
All-Party Parliamentary Group on Spinal Cord Injury

Immediate Priorities (1–2 years):

Stabilise the System

Embed national standards and accountability
Fix the data deficit
Secure specialist capacity and safety
Strengthen patient voice and early support
Tackle preventable delays in discharge

Medium-Term Reforms (3–5 years):

Build Resilient Infrastructure

Expand specialist rehabilitation capacity
Establish integrated regional SCI networks
Develop a national workforce strategy
Embed psychological and vocational support
Integrate third-sector partners

Long-Term Transformation (5–10 years):

Deliver a National SCI Strategy

Research and innovation leadership
Digital and data integration
Whole-life care model
Prevention and population health

Executive Summary

This report from the All-Party Parliamentary Group on Spinal Cord Injury brings together powerful evidence from people with lived experience, healthcare professionals, and other professionals working within the spinal cord injury community to create a clear and achievable blueprint for a National Strategy on Spinal Cord Injury.

Once a world leader in spinal cord injury (SCI) care and rehabilitation, the United Kingdom has regrettably vacated this position. Instead, a fragmented, inequitable, and uncoordinated system now operates in the UK. Healthcare professionals' hard work and unwavering commitment is being undermined by a system that perpetuates avoidable suffering and drives higher long-term costs. Patients are left navigating a system defined by complexity, inconsistency, and delay, often without adequate support or accountability. As this report sets out, the need for a National Strategy on Spinal Cord Injury is not theoretical. It is urgent, evidence based, and morally unavoidable.

The key recommendations set out a 10-year blueprint to stabilise the system, build resilient infrastructure, and bring about long-term transformation through the delivery of a National Strategy on Spinal Cord Injury. While past reviews and reports have repeatedly identified the same solutions, there has been an abject failure to act. These missed opportunities have now accumulated into a national crisis of capacity, coordination, and leadership that demands immediate and sustained reform.

Evidence heard by the Inquiry demonstrated that from the moment someone sustains their injury, their future is determined by chance rather than national standards. They may, or may not, be referred to a specialist spinal cord injury centre – or they may be "lost" in the system. If referred, they have a 1 in 5 chance that they will receive inpatient rehabilitation in a spinal cord injury centre. Upon discharge, they may be the 11% that are discharged into permanent, specialist housing. But they may be part of the 20% that are placed in care homes, not because their health requires them to be there, but because they are effectively homeless. When living in the community, they may develop secondary conditions. Upon admittance to non-specialist healthcare settings, there is very little chance that the healthcare professionals managing them have any experience with SCI. The likelihood of life-threatening conditions being mismanaged, or preventable complications arising, is unacceptably high, in these settings. A system that leaves care to chance cannot claim to uphold respect or dignity.

New data shows that, in the UK, someone will sustain an SCI every two hours. Whether caused by an accident or an illness, they will be thrust into this system. The UK has the expertise, the will, and the economic rationale to lead the world in SCI care. Across rehabilitation, standards and training, reintegration into the community, patient voice and representation, and research and innovation, the UK has the opportunity to ensure that every person with an SCI can live an independent and fulfilling life. One that is defined by dignity, consistent care, and hope.

The recommendations set out in this report provide the blueprint to remove duplication, reduce waste, and prevent harm from a system that results in preventable complications, prolonged hospital stays, readmissions, and reduced opportunities for people to live independently. They represent a call to action for Government, NHS England, and wider society to restore coordination, leadership, and ambition in spinal cord injury. The recommendations ensure that resources are effectively and efficiently directed to long-term, cross-cutting priorities, so that both economic and human costs are reduced and outcomes transformed.

The inquiry has heard clear, consistent evidence that spinal cord injury (SCI) care is fragmented, under-resourced, and inequitable. Addressing these systemic failings requires both immediate corrective action and sustained long-term reform. The APPG therefore sets out the following overarching recommendations, encompassing the individual recommendations under each emerging themes, structured into three phases aligned with the NHS 10-Year Plan.

Immediate Priorities (1-2 years): Stabilise the System

Embed National Standards and Accountability

Mandate the 2022 SCI Rehabilitation Standards and updated service specifications, with outcome-based quality metrics.

Ring-fence budgets for SCI services within NHS trusts to prevent diversion and ensure transparency.

Fix the Data Deficit

Establish a modern, national SCI registry capturing all patients (traumatic and non-traumatic), including those outside SCI centres.

Publish annual reports on SCI outcomes, modelled on cancer and stroke registries.

Strengthen Patient Voice and Early Support

Embed automatic referral to trusted SCI charities from the point of diagnosis via the Government's *Diagnosis Connect* programme.

Ensure every SCI patient receives a personalised care plan at discharge, co-produced with lived experience input, with help from the charities that are currently filling this gap.

Secure Specialist Capacity and Safety

End unsafe variation by guaranteeing access to SCI centre outpatient services, specialist nursing (neurogenic bladder/bowel, tissue viability), and psychology.

Require face-to-face SCI expertise in all Continuing Healthcare assessments, with interim funding during appeals.

Tackle Preventable Delays in Discharge

Expand timely access to appropriate housing adaptations and specialist equipment, including and especially wheelchairs.

End misuse of the "discharge to assess" policy where it undermines housing responsibilities.

Key Recommendations

Medium-Term Reforms (3–5 years): Build Resilient Infrastructure

Expand Specialist Rehabilitation Capacity

Deliver additional bed capacity and staffing across the 8 SCI centres to eliminate current waiting lists and harmful delays.

Ensure equitable paediatric provision, with expansion of children's SCI beds and consistent transition pathways into adult care.

Establish Integrated Regional SCI Networks

Scale up best-practice models such as the London SCI Network to provide consistent outreach, in-reach, and community follow-up across the UK.

Require every region to designate at least one SCI centre of excellence with full multidisciplinary teams.

Integrate Third-Sector Partners

Formalise and fund the role of charities in delivering peer support, mentoring, family services, and housing advice.

Create a commissioning framework that recognises proven third-sector outcomes and ensures sustainable contracts.

Embed Psychological and Vocational Support

Make psychological care a universal and lifelong component of SCI services, with minimum staffing ratios.

Expand vocational rehabilitation, employer engagement, and access to work programmes that work, to increase SCI employment rates.

Develop a National Workforce Strategy

Create accredited SCI training pathways for nurses, therapists, and doctors, including specialist rotations and fellowships.

Formalise rehabilitation nursing as a specialist field, with nurse leads at Integrated Care Board or regional level to coordinate complex discharges.

Expand employment opportunities across the NHS for people living with SCI.

Long-Term Transformation (5-10 years): Deliver a National SCI Strategy

Research and Innovation Leadership

Substantially increase government funding for SCI research, bringing parity with comparable neurological conditions.

Establish a UK-wide clinical trial infrastructure by upgrading at least half of SCI centres to international trial-readiness standards (diagnostics, tissue banking, research beds). Launch a time-limited, high-impact “moonshot” initiative into function-restoring therapies, leveraging UKRI, NIHR, and ARIA-UK.

Whole-Life Care Model

Guarantee lifelong specialist pathways spanning acute, rehabilitation, and community services, integrated with housing, employment, and social care.

Ensure every child and young person with SCI has access to specialist services, peer mentoring, and education/transition planning, preventing “cliff-edge” losses at adulthood.

Digital and Data Integration

Build a fully interoperable SCI registry that links trauma, rehabilitation, social care, and long-term outcomes (housing, employment, psychological wellbeing).

Align with international registries to enable UK participation in global research and benchmarking.

Prevention and Population Health

Embed SCI within wider prevention priorities of the NHS 10-Year Plan, including falls prevention, healthy ageing, and secondary complication reduction (e.g., pressure ulcers, UTIs).

Invest in community fitness and rehabilitation to maintain readiness for future therapies and reduce long-term costs.

Taken together, these recommendations constitute a blueprint for a National Strategy on Spinal Cord Injury. The immediate priorities stabilise safety and equity; the medium-term reforms build sustainable infrastructure; and the long-term transformation restores the UK’s international leadership in rehabilitation, research, and innovation.

Above all, they ensure that every person with a spinal cord injury can live an independent and fulfilling life, with dignity, consistent care, and hope.

Spinal cord injury (SCI) is a life-altering condition caused by damage to the spinal cord, disrupting communication between the brain and the rest of the body, leading to paralysis. It broadly falls into:

- **Traumatic SCI** – resulting from external events such as falls, road traffic collisions or violence.
- **Non-traumatic SCI** – arising from internal pathology like tumours, vascular incidents, infections, or degenerative disease.

While both types have immediate and devastating physical impacts, the long-term challenges, span physical health, psychological wellbeing, independence, and participation in society.

Epidemiology

Although SCI is relatively uncommon, its impact is profound and lifelong.

- UK charities’ 2024–25 analysis of NHS datasets indicates around 4,700 new SCI cases annually (2025). The total UK population living with SCI is now estimated at over 105,000, significantly higher than the older 2,500/50,000 figures often cited.
- NHS England also reports a steady rise in age related injury, with associated increases in comorbidities and rehabilitation duration. The modal age range shifted from 30–40 years (2009) to 65–69 years (2017/18); ~5% of patients are 80+. In the same period, non-traumatic SCI more than doubled from 21% (2008) to 51% (2017/18).

A UK economic analysis estimated mean lifetime costs of ~£1.12 million per case (2016 prices), ranging from ~£0.47 m (AIS D) to ~£1.87 m for tetraplegia (AIS A–C); around 71% of lifetime costs fall on the public purse (McDaid et al., *Health Economics* (2019)).

Pressure ulcers remain a major, preventable cost driver in UK services, with estimates of £1.4 –£2.1 billion annually (Guest et al., BMJ Open (2017)).

As the SCI population ages and comorbidities accumulate (cardiovascular disease, diabetes, osteoporosis, frailty), demand for specialist care, equipment and home adaptations grows, escalating lifetime costs (NHS England Service Specification (2019)).

Social and economic participation:

- Due to housing shortages and delayed adaptations, most people with SCI are unlikely to be discharged into a suitable home. Many are discharged into unsuitable nursing homes for the elderly, causing significant further impact on mental health, whilst many others are not discharged at all. This inevitably leads to bed blocking, re-admissions and longer waiting lists for treatment and rehabilitation.
- Employment rates for people with SCI remain challenging, despite many expressing the ability and desire to work.
- Inaccessible transport, slow provision of essential equipment including basic wheelchair provision, and limited community services restrict independence and increase reliance on carers.

Mental health:

- Elevated rates of depression and anxiety, compounded by loss of independence, social isolation and service access barriers. (Spinal Injuries Association's annual 'What Matters' surveys)

Family and carers:

- Families often take on long-term unpaid care, with significant impacts on physical and mental health, finances and general wellbeing.
- The unrelenting inefficiency of the Continuing Healthcare system, further exacerbated by the pandemic related changes including online assessments, has led to frustrated families, and tragic deaths of patients over the years.

Long-term Impact on Physical, Mental, and Social Wellbeing

Why age matters:

- Older people are both sustaining new SCIs and living longer with existing SCIs. Recent trends from NHS England show a clear ageing shift, with more non-traumatic cases and higher comorbidity loads, which prolong rehabilitation and complicate discharge (NHS England Service Specification (2019)). Greater need for housing adaptations and supported living; stronger focus on falls prevention and lifelong care within specialist pathways are needed to mitigate this.
- On the opposite end of the spectrum, children and adolescents with SCI face lifelong challenges including disrupted growth and development, difficulty in accessing inclusive education, psychosocial adjustment and identity formation, and ongoing needs for evolving assistive technologies and transition planning.

Physical health:

- Loss of mobility and sensation; bladder and bowel dysfunction; respiratory complications. (Spinal Injuries Association's annual 'What Matters' surveys)
- Ageing with SCI leads to increased comorbidities, longer rehabilitation durations, and greater need for managing complications (NHS England Service Specification (2019))
- Secondary complications such as pressure ulcers, urinary tract infections and other recurrent infections remain common and costly, leading to readmissions (Guest et al., *BMJ Open* (2017)).
- Autonomic Dysreflexia (AD) remains a life-threatening condition that many of the above can lead to, and we have heard from many in the SCI community that many medical professionals outside of specialist spinal cord injury centres have not even heard of the condition.

"Rehab is key.
Not just to good recovery, but prevention of future demand on the NHS. So whether it's in the NHS or in social care, we definitely need to do more on rehabilitation. Because rehabilitation is often secondary prevention."
Rt Hon Wes Streeting
Secretary of State, Department for Health and Social Care

Long-term Impact on Physical, Mental, and Social Wellbeing

Over the long term, spinal cord injury (SCI) imposes pervasive and compounding burdens across physical, mental, social, economic and familial domains. Physically, loss of function, autonomic dysfunction, ageing-related comorbidities and recurrent complications impose continuous demands on health and social care systems. Mentally, high rates of depression, anxiety and social isolation are intertwined with the daily struggle for independence and the barriers to meaningful connection. Socially and economically, obstacles to appropriate housing, employment, transport and assistive provision curtail participation and trap many in dependency. Carers and families shoulder the weight of long-term support with heavy costs to their health, finances and quality of life. Meanwhile, the shifting demographic of the SCI population; more older people acquiring SCI, more people ageing with SCI, and children living long into adulthood with evolving needs, intensifies the complexity of lifelong care.

The totality of this evidence underscores that SCI is not a one-off event with a fixed recovery period but is a lifelong condition requiring coordinated, anticipatory, and adaptive systems of support. Current service fragmentation, regional inequities, lack of consistent follow-up, and low awareness of critical risks (e.g. autonomic dysreflexia) mean many people fall through the cracks over time. It makes the case for a National Strategy clear: to establish a unified, equitable, forward-looking framework ensuring that everyone living with SCI in the UK, whatever their age, background or stage, can access proactive, integrated care, support and opportunity over the full life course, to live independent, fulfilled lives.

Why a National Strategy is Needed

Across all the evidence sessions and submissions, one message has been clear: spinal cord injury (SCI) care in the UK is fragmented, inequitable, and under-coordinated. While centres of excellence exist, access to them is inconsistent, and the pathway beyond specialist care is often disjointed and opaque. The absence of a national framework has left patients, families, clinicians, and local systems navigating complexity without adequate support.

This inquiry heard from clinicians, charities, and patients that the current system results in preventable complications, prolonged hospital stays, readmissions, and reduced opportunities for people to live independently. These failings are not just clinical, they are systemic. The lack of a national strategy perpetuates avoidable suffering and drives higher long-term costs.

Fragmentation and inequality

SCI care is deeply affected by regional variation. Whether a patient receives timely rehabilitation, access to pressure sore treatment, or community support depends largely on their postcode. Only 2 out of 42 Integrated Care Boards have any SCI-specific policy. Discharge planning is often delayed by housing shortages or unclear commissioning responsibilities, creating dangerous gaps in care. The evidence received during this inquiry demonstrated that fragmentation begins from the moment of injury, with delays in referrals, unequal access to spinal centres, and confusion among healthcare providers in emergency settings. For many patients, the journey through the system is defined by duplication, conflicting advice, or total absence of coordinated care. Stakeholders told us that in some regions, clinicians are forced to create informal workarounds simply to ensure that SCI patients receive even basic continuity of care. In rural or under-resourced areas, these challenges are exacerbated by travel distances and a shortage of trained professionals. Without a unified national pathway, health inequality becomes the rule rather than the exception.

Absence of data and national oversight

The UK has no national SCI patient registry. As a result, we lack even the most basic data on prevalence, outcomes, and long-term needs. Without this data, workforce planning, service design, and funding decisions are made in the dark. Evidence from our inquiry highlighted that this absence of central coordination also hampers clinical research, innovation, and international benchmarking. A functioning registry would not only enable strategic planning, but also

support research, quality improvement, and public accountability. Several clinicians highlighted the inability to track long-term outcomes or understand how many people with SCI are being re-admitted for avoidable complications. Without baseline data, we cannot benchmark services or identify best practices. A national registry would empower commissioners, support innovation, and allow patients to be more engaged in managing their condition across their lifetime.

Gaps in lifelong and community-based care

While acute trauma care has advanced significantly, lifelong care for SCI remains underdeveloped. Patients face delays in admission, insufficient psychology provision, inadequate access to outpatient services like neuro-urology or respiratory care, and no clear pathway into community rehabilitation or employment support. Where outreach exists, it is usually charity-funded, patchy, or under-resourced. The lack of a clear national service specification means there is no guarantee of access to services such as wheelchair provision, mental health support, or vocational rehabilitation. Several charities and clinicians described the strain placed on families who are left to coordinate care, often without clinical knowledge or support. The transition between paediatric and adult care is especially problematic, as young people with SCI are often excluded from adult services entirely or fall through eligibility gaps. The case for a nationally commissioned, lifelong pathway has been made repeatedly in both clinical and patient testimony.

Preventable complications and disjointed transitions

Patients frequently fall through the cracks during transition from hospital to community. Our inquiry heard testimony about the “cliff edge” patients experience at discharge, with core needs such as bowel care, skin care, and housing going unmet. In some cases, young people are placed in care homes for older adults due to lack of appropriate housing, a systemic failure repeated over decades. During the inquiry, multiple examples were shared of patients developing pressure ulcers, urinary tract infections, and mental health crises shortly after discharge, all of which were preventable with better planning and support. This breakdown often occurs at the interface between hospital and community, where no single organisation takes full responsibility. The absence of mandated multidisciplinary discharge planning was cited as a key factor in poor outcomes. Witnesses also stressed the need for a formalised role for case managers or specialist coordinators to ensure continuity and accountability during these transitions.

Why a National Strategy is Needed

The role of charities and third sector organisations

In the absence of a national framework, charities such as the Spinal Injuries Association, Aspire and Back Up have stepped in to fill gaps in patient education, housing, and support. However, these organisations operate with limited resources and without formal roles in the statutory system. A national strategy would formalise and fund these contributions as essential components of a sustainable SCI care pathway. The Government’s recently announced ‘Diagnosis Connect’ initiative, intended to ensure that newly diagnosed patients are automatically linked to trusted support organisations, would be particularly impactful for a severe condition such as spinal cord injury. Early access to information, peer support, and community resources are critical following a life-changing diagnosis. For SCI, where timely intervention can prevent complications and set the foundation for independence, this type of connection must become a standard part of care. Implementing Diagnosis Connect for SCI would formalise what charities have long provided and ensure that no newly injured person navigates the system alone.

Conclusion

The need for a national strategy is not theoretical; it is a practical imperative. It is about removing duplication, reducing waste, and preventing harm. Above all, it is about dignity, equity, and ambition. The UK has the expertise, the will, and the economic rationale to lead the world in SCI care, as it once did.

We must honour our legacy as a global leader in spinal cord injury rehabilitation, born from Professor Sir Ludwig Guttmann’s pioneering work. Now, we must show that same leadership once again, not only by diagnosing the failures of the current system, but by committing to tangible, meaningful and lasting progress. Every person with a spinal cord injury deserves the chance to live an independent and fulfilling life. What’s missing is the national vision to connect the parts. That is the gap, a national strategy must fill.

Professor Sir Ludwig Guttman

Rehabilitation
The inquiry heard that across the UK, the system is under-resourced, fragmented, and deeply inequitable.

Standards and Training
The inquiry heard powerful evidence that too often, patients are put at risk in non-specialist settings because NHS staff lack the training, awareness, and support to meet SCI-specific needs.

Reintegration into the Community
For people with spinal cord injuries (SCI), the transition from hospital to community life is often the most challenging part of their journey.

Patient Voice and Representation
The inquiry heard that the lived experience of people with spinal cord injury (SCI) is not consistently embedded within NHS decision-making, research, or care delivery.

Research and Innovation
Witnesses made clear that without a coherent national research and innovation strategy, the UK risks falling behind international peers and failing to deliver hope of functional restoration to people with SCI.

Data and the Case for a National SCI Registry
The inquiry heard compelling evidence that without a modern, centralised SCI registry, the UK cannot plan services, reduce inefficiencies, or improve patient outcomes.

Children and Young People: Supporting Early Adjustment and Transition
Too often, young people are discharged without the skills, confidence, or support to live independently, while families struggle without adequate guidance.

"If you've got the wrong wheelchair, you're not going to be up to getting out and about. It's like giving you the wrong pair of legs, or making you go around in a pair of wellies. Actually it can lead to you putting more strain on the system, if you've not got the right posture or the right cushion, all of that can lead to pressure sores or worse."

Andy Masters, Head of Engagement, Back Up

Rehabilitation is a defining stage in the journey of every person with a spinal cord injury. It is where individuals begin to regain independence, adapt to new circumstances, and maximise functional outcomes. The inquiry heard compelling evidence that access to specialist rehabilitation is the single most important determinant of long-term health, wellbeing, and cost-efficiency. Yet, across the UK, the system is under-resourced, fragmented, and deeply inequitable.

Current barriers

The inquiry heard from senior rehabilitation professionals including the current Chair of the Multidisciplinary Association of Spinal Cord Injury Professionals. They identified several significant systemic barriers:

Severe Capacity Shortfall

Only 1 in 5 patients referred to a spinal cord injury centre are admitted for rehabilitation. Demand has doubled with the inclusion of non-traumatic SCI, but no new beds or staff have been added.

Trauma Networks

While they improved access to surgical care, they inadvertently delay transfer to rehabilitation by keeping patients in major trauma centres for too long.

Outreach Limitations

Outreach teams provide valuable early input but cannot substitute for specialist beds, equipment, or the intensive therapies delivered in specialist centres.

Inappropriate Settings

Many patients are managed in general or orthopaedic wards without the specialist expertise, staff ratios, or equipment needed for spinal rehabilitation.

Regional Inequity

Access depends on where a patient lives, with stark differences in bed-to-population ratios across England and the devolved nations.

Rehabilitation

The inquiry also heard from the current Chair of the NHS England Clinical Reference Group for Rehabilitation and Complex Disability and Spinal Cord Injury, who provided additional national-level evidence highlighting further systemic barriers:

- **Failures of early recognition and referral**

  Despite national trauma rehabilitation pathways (established in 2012), SCI patients are still not consistently referred to specialist centres. Peer review has ceased, and referral protocols are often not followed.

- **Lost patients**

  In 2024/25, 76 patients were lost to the SCI referral system, 60 in London alone, due to being repatriated locally without notifying spinal centres. In 2023/24, the figure was even higher at 107.

- **Centre capability gaps**

  SCI centres are historically located, not strategically planned, and many lack essential co-located specialties (renal, gastroenterology, plastics, mental health). As a result, patients are left in acute hospitals instead of entering rehabilitation.

- **Exclusion of complex and non-traumatic patients**

  Those with cancer, degenerative disease, learning disabilities, or severe mental health needs are often turned away, undermining the principle that specialist services should serve the most complex.

- **Paediatric failings**

  Only 12 specialist beds for children exist in England (3 at Stanmore, 9 at Stoke Mandeville), leaving young people travelling hundreds of miles or being managed inappropriately in general paediatric wards. Transition into adult care is inconsistent and poorly tracked.

It was noted that these systemic failures are not just operational gaps but reflect a fundamental absence of strategic planning and accountability. It was strongly argued that SCI rehabilitation must be embedded within the National Rehabilitation Strategy, given the parallels with acquired brain injury, neuropathies, and complex trauma.

I really recognise the very important role that rehabilitation medicine plays. There are multiple reasons why that's the case. The ability to transform lives, including in working age, so people can get back to the workforce and at various other stages in life.
Professor Sir Chris Whitty
Chief Medical Officer for England
2019-present

The value of national standards

National standards for SCI rehabilitation exist, but they are advisory rather than mandatory. NHS England has yet to formally sign them off, leaving them without funding or enforcement mechanisms. As a result:

- Some centres, such as Stanmore, can meet or exceed standards by reinvesting funds directly into rehabilitation services.
- Others fall short due to underinvestment by local trusts, leaving patients subject to a postcode lottery in both waiting times and quality of care.

The inquiry heard that without enforceable standards, even the best evidence-based guidelines remain aspirational rather than operational.

Best Practice: The Stanmore Model

The Royal National Orthopaedic Hospital in Stanmore provides an instructive example of what high-quality rehabilitation looks like, even within resource constraints:

- Highest therapist-to-patient ratio in the UK.
- 15 hours of therapy per week per patient, in line with national standards (a target most other centres cannot meet).
- Rigorous discharge planning to maintain efficient bed turnover.
- Outcomes equal to or better than other centres despite the lowest bed-to-population ratio nationally.

This model demonstrates that high-quality, cost-effective rehabilitation is possible when funding is protected and reinvested, and when services are designed around efficiency and patient outcomes.

Rehabilitation

Risks of delayed access

Delays to rehabilitation were described as “morally indefensible and financially wasteful”. They lead to:

- Preventable medical complications such as pressure ulcers, contractures, and bowel dysfunction, in some cases irreversible.
- Prolonged hospital stays and delayed return to the community.
- Increased long-term dependency and costs to both NHS and social care.
- Emotional harm to patients and families, particularly where delays force discharges into care homes rather than adapted housing.

COVID-19 demonstrated that with urgency, delayed discharge can be resolved. The inquiry concluded that systemic barriers, and not inevitability, drive the current inefficiencies.

Wheelchair services

The inquiry also heard that wheelchair services, essential to independence and rehabilitation, are chronically underfunded and inconsistent.

- Current funding averages £230 per patient, while an appropriate SCI wheelchair costs between £2,300 and £5,000.
- Commissioning by Integrated Care Boards has led to wide regional variation, long waits, and inadequate provision.
- No national accountability framework exists.

This failure undermines rehabilitation outcomes and quality of life and represents poor value for money.

Key findings

From this session, the APPG identified:

- A national capacity crisis in SCI rehabilitation, driven by historical underinvestment.
- Outreach as valuable but insufficient, as it cannot replace specialist beds and expertise.
- Proof that best practice models exist and can deliver excellent outcomes at reasonable cost
- The need for mandatory national standards with funding and accountability.
- The urgency of addressing delayed discharges and housing barriers.
- A major gap in wheelchair provision, requiring systemic reform.

Recommendations

1. Create a National Strategy with a focused SCI Rehabilitation, with capital investment to increase specialist bed capacity.
2. Mandate and fund national standards through NHS England, ensuring consistent access and quality across the UK.
3. Protect and ring-fence SCI funding to prevent diversion by local trusts, with transparency through reporting mechanisms.
4. Tackle delayed discharges via integrated NHS social care budgets and investment in accessible housing.
5. Standardise and properly fund wheelchair services, with a centralised model aligned to actual patient needs.
6. Expand outreach only as a complementary measure, not a substitute for inpatient rehabilitation.
7. Build national data and accountability systems to track referrals, admissions, discharges, and outcomes.

Specialist knowledge and skills are the foundation of safe and effective spinal cord injury (SCI) care. The inquiry heard powerful evidence that too often, patients are put at risk in non-specialist settings because NHS staff lack the training, awareness, and support to meet SCI-specific needs. Despite the existence of standards and guidelines, their application across the NHS is inconsistent, underfunded, and largely unenforced.

The evidence from clinicians, nurses, and international experts underlined the urgent need for a nationally consistent approach to SCI standards and training, embedded across all levels of the health system.

Gaps in training and knowledge

Witnesses described systemic failings in SCI training:

Lack of Awareness in General Hospitals
Patients admitted outside spinal centres are frequently managed by staff without training in SCI care. This leads to mismanagement of life-threatening conditions such as autonomic dysreflexia, poor bladder and bowel management, and preventable complications including pressure ulcers and infections.

Reactive Training
Many hospitals only train staff after a crisis occurs, and knowledge is often lost when staff rotate.

Community and Social Care Gaps
Care home staff and community nurses are rarely trained in SCI, leaving patients vulnerable after discharge.

Reduced Exposure for Clinicians
Junior doctors and nurses no longer rotate through spinal centres, reducing opportunities for hands-on learning and continuity of specialised trained staff.

These gaps create a postcode lottery again in safety and outcomes. Families often resort to charities like Spinal Injuries Association for help because hospitals refuse to consult specialist centres or follow expert advice.

Standards and Training

The case for national standards

Specialist standards for SCI care already exist but are not mandated by NHS England, once again, leaving them aspirational rather than operational. This lack of enforcement results in:

- Wide variation in practice between hospitals and regions.
- Spinal centre budgets being raided by trusts to cover deficits, further undermining service delivery.
- Centres struggling to maintain training programmes due to lack of protected funding.

Witnesses stressed that standards without funding and accountability are meaningless. A national framework is needed to ensure minimum expectations across the NHS, from community services to specialist centres.

Best practice and tiered training models

The inquiry heard that standards and training work best when they are structured, tiered, and nationally consistent.

- **Tier 1 – Basic awareness for all NHS staff**: Training in red-flag conditions (autonomic dysreflexia), pressure area care, and bowel/bladder regimes. This could be delivered as e-learning, embedded in mandatory training, with clear escalation protocols and SCI centre contact points.
- **Tier 2 – Enhanced training for general wards and community teams**: Especially for hospitals with major trauma centres that are likely to admit SCI patients, ensuring competence in day-to-day care and safe management until transfer.
- **Tier 3 – Specialist training for SCI clinicians**: Structured, accredited programmes for doctors, nurses, and therapists. Witnesses highlighted the need to restore longer specialist rotations and fellowships, bringing the UK in line with international practice.

Best practice examples show that when training is embedded, outcomes improve, costs fall, and patients' safety is maintained.

Patient safety and the human cost

The inquiry heard the story of Steve, a ventilator-dependent patient who died weeks after discharge due to unsafe care in a district hospital. He endured delays in A&E, was left without carers or a call bell, and developed pressure sores. He never saw an SCI specialist during multiple admissions. Steve's case illustrates the life-threatening risks of inadequate training and the absence of clear referral pathways.

As one of the specialist senior nurses from the Spinal Injuries Association told the inquiry: *"Steve's story is sadly not an isolated case".* This is unacceptable and untenable, especially when patient safety and people's lives are compromised.

International learning

Other countries offer useful insights, though no system has solved these issues completely:

- Sweden uses a hub-and-spoke model with centralised expertise and a national registry.
- Canada has national standards, education modules, and a unified approach to training.
- North America often requires post-graduate training specifically in SCI, helping to define clinicians as true specialists.

Witnesses stressed that the UK should not attempt to make every hospital a centre of excellence but instead centralise expertise while embedding national minimum training across the system.

Standards and Training

Systemic challenges

Beyond training, the session highlighted wider systemic issues undermining standards:

Fragmented Geography of SCI Centres	Lack of a National Spinal Register	Funding Pressures	Cultural Barriers
Some centres are clustered closely, while large regions have little provision, reflecting historical decisions rather than clinical logic	A recurring theme that shows that without robust data, planning and accountability remain weak	Spinal budgets are often diverted within trusts, training budgets are first to be cut when resources are tight	Some hospitals refuse to seek external advice, insisting they "know best" even when patient safety is at risk

Key findings

- Training in SCI is inconsistent, underfunded, and reactive, leaving patients unsafe.
- National standards exist but lack enforceability and funding.
- A tiered national training model would raise baseline competence across the NHS.
- Patient safety failures, such as Steve's case, are not isolated but systemic.
- International models demonstrate the value of centralisation, national registries, as well as the need for structured, mandated, and curriculum directed training for doctors and nurses.
- Funding raids and lack of accountability undermine SCI centres and training delivery.

Recommendations

1. Establish a National SCI Strategy anchored in mandatory standards and consistent training, using the ISCoS Toolkit as a framework.
2. Create a national SCI register, with mandatory case reporting across NHS trusts to support planning and evaluation.
3. Develop and fund a tiered training model for all levels of staff: awareness for all clinicians, enhanced training for general wards and community teams, and accredited specialist training programmes.
4. Restore spinal rotations and specialist fellowships for junior doctors and nurses, ensuring future expertise.
5. Ring-fence spinal budgets and training funds, to prevent diversion to other services.
6. Ensure referral pathways between general hospitals and SCI centres are mandatory, automatic, and enforced.
7. Adopt the ISCoS Toolkit to embed a cycle of continuous quality improvement, co-designed with people with lived experience.
8. Undertake a strategic review of SCI centre locations to align provision with population needs, trauma networks, and evidence-based access standards.

"In all my years since 2004 I have not been able to find any carers apart from those 'live in' with specific training for bowel care. If it wasn't for my wife, I don't know what I would do when it comes to bowel care. If she wasn't there, I would literally be in a mess, and I wouldn't know where to turn."

Spinal Injuries Association member

Reintegration into the community is the stage where rehabilitation outcomes are either consolidated or lost. For people with spinal cord injuries (SCI), the transition from hospital to community life is often the most challenging part of their journey. The inquiry heard that without adequate housing, psychological support, continuing healthcare, and vocational pathways, individuals risk losing the gains made in rehabilitation and face long-term dependency, isolation, and poorer health outcomes.

Housing and independent living

Housing was consistently identified as the most urgent barrier to successful reintegration:

- Only 11% of patients are discharged into permanent, specialist housing; around 20% are placed in care homes, not because they require them, but because they are effectively homeless.
- The majority return to inaccessible homes, often confined to a single room without proper kitchen or bathroom access, eroding rehabilitation progress and independence as well as causing additional mental health issues.
- Evidence showed a two-year window post-discharge in which securing appropriate housing is critical. Failure to do so leads to long-term institutionalisation or decline.
- Case studies revealed unsafe and unacceptable outcomes, such as discharges to caravans or prolonged temporary housing.

The charity Aspire's housing advisors, reported spending much of their time chasing local authorities, with systemic failures, delays, and lost paperwork leaving patients stranded in unsuitable accommodation.

"We commissioned independent research to identify what happened to patients being discharged. We identified that one in 5 would be discharged into care homes. Only 10% involved in our research went to suitable accessible accommodation. The vast majority, because there is no other solution, are discharged into their own home. If they're lucky, they'll have a wheelchair, and they become a prisoner in their own front room."

Brian Carlin, Chief Executive, Aspire

Psychological support

Adjustment to spinal cord injury is not purely physical. Expert witnesses emphasised that 80% of recovery is psychological, covering not only mental health but also identity, intimacy, confidence, and coping with chronic pain and fatigue.

- Around 55% of patients show symptoms of depression at admission; 40% experience anxiety, and 30% report adjustment difficulties.
- Psychological adjustment can take up to five years, yet most support ends on discharge.
- Specialist services are underfunded and inconsistent, with psychologist-to-bed ratios ranging from 1:15 to 1:100.
- The absence of universal psychological screening means many patients “fall off a cliff” after leaving rehabilitation, with long-term deterioration.

The inquiry concluded that psychological care must be embedded as a universal, lifelong component of SCI services, comparable to the stroke model under NICE guidelines.

Continuing healthcare (CHC) and care packages

The inquiry heard serious concerns about the NHS Continuing Healthcare (CHC) process:

- Eligibility is a postcode lottery, with approval rates varying from 5% to 58% across Integrated Care Boards.
- Assessments are often subjective and confrontational, with inappropriate care packages commissioned from providers lacking SCI expertise.
- Reviews and appeals are lengthy and distressing, leaving families carrying heavy financial and emotional burdens.
- Virtual assessments, widely used since COVID-19, were described as ineffective and unjust, obscuring physical needs.

The inquiry concluded that CHC reform is essential: assessments must involve SCI specialists, be face-to-face by default, and guarantee funding during appeals.

Reintegration into the Community

Vocational support and community participation

Reintegration must go beyond housing and care to support education, employment, and community life. Witnesses emphasised that:

- Many people with SCI want to return to work, but vocational support is minimal, leaving talent and ambition wasted.
- Wheelchair provision remains a critical barrier: inappropriate chairs lead to pressure sores, reduced independence, and higher NHS costs.
- Peer mentoring and voluntary sector programmes play a vital role in smoothing transition, yet they remain underfunded and poorly integrated into NHS pathways.

Charities such as Spinal Injuries Association, Aspire, and Back Up, fill systemic gaps, but their contribution is precarious without sustainable funding and formal partnership.

Key findings

- Housing inadequacy and delays undermine rehabilitation and trap patients in unsuitable care.
- Psychological needs are universal and long-term, yet services are underfunded and inconsistent.
- The CHC process is inequitable, subjective, and often hostile to SCI patients and families.
- Vocational support and wheelchair provision are insufficient, limiting independence and participation.
- Charities play an essential role but need formal integration into statutory care.
- Data gaps and poor coordination prevent efficient service delivery and planning.

Systemic failures and data gaps

The inquiry identified recurring systemic issues undermining reintegration:

- Poor discharge planning, worsened by misuse of the “discharge to assess” policy to bypass housing responsibilities.
- Lack of a functional national SCI registry (database), leaving services unable to plan or evaluate provision.
- Fragmented accountability between health, housing, and social care, with patients often left to navigate complex bureaucracies unaided.

RECOMMENDATIONS

1. Expand accessible and wheelchair accessible housing stock and ensure patients are discharged into appropriate accommodation within two years.
2. Mandate psychological support as a universal, lifelong element of SCI care, with national standards and adequate staffing ratios.
3. Reform CHC assessments to standardise eligibility, require SCI specialist input, default to face-to-face, and provide interim funding during appeals.
4. Improve vocational support, including workplace adaptations, training, and employer engagement.
5. Guarantee timely wheelchair provision with specialist oversight to prevent complications and support independence.
6. Integrate peer mentoring, family support, and voluntary sector programmes into NHS spinal services with sustainable funding.
7. Establish a comprehensive national SCI registry, including psychological health metrics, to inform planning and crisis response.
8. End misuse of “discharge to assess” by ensuring housing responsibilities are met before discharge.
9. Strengthen integration between NHS, social care, and local authorities, supported by shared digital systems and accountability mechanisms.

The inquiry heard that the lived experience of people with spinal cord injury (SCI) is not consistently embedded within NHS decision-making, research, or care delivery. Unlike other long-term neurological conditions, SCI lacks a formalised patient voice infrastructure. This absence leaves many people unsupported post-discharge and results in services that fail to reflect what matters most to those living with SCI.

Current gaps in representation

Limited Access to Specialist Centres Of the estimated 4,700 new cases each year, only around 793 patients access a specialist centre, leaving thousands without comprehensive rehabilitation.	**Variable Support Across Trauma Centres** Some provide strong voluntary sector links, while others provide none, creating a postcode lottery.
Lack of Holistic Planning Patients are often left to navigate housing, mental health, employment, and continence issues alone, despite their interconnected impact.	**Inconsistent Care Planning** Unlike in stroke or MS, SCI patients are rarely given a personalised care plan at the point of injury, leading to fragmented support.

Why patient voice matters

- Evidence from the Spinal Injuries Association (SIA) highlighted that patient-led organisations support 1,500–2,000 new individuals each year after failures in general healthcare.
- Lived experience is a critical resource: patients identify priorities that professionals may overlook, such as bowel care, pain, sexual health, and employment.
- Peer support and patient advocacy help resolve issues quickly, often preventing deterioration, hospital admissions, or long-term dependency.

Government's Diagnosis Connect initiative

In July 2025, the UK Government announced **Diagnosis Connect**, a new service set to launch in 2026 that will automatically refer people diagnosed with long-term conditions to trusted charities from the point of diagnosis. This service aims to complement NHS care by providing immediate access to emotional, informational, and community support, helping patients feel more connected and in control from day one.

The Spinal Injuries Association welcomed the initiative, noting that:

> *Individuals with long-term conditions like a spinal cord injury … have felt isolated and overwhelmed in the early moments of a life-changing diagnosis. Diagnosis Connect means connection to third sector support from the outset … information, support, and community connections at the most critical time in their lives*.

This approach presents a prime opportunity for the SCI field to replicate what certain other conditions are already receiving through other pathways, which is immediate, structured linkage to specialist support from diagnosis onward.

Key findings

- SCI patients often feel unsafe accessing general health services due to lack of staff knowledge.
- Patient voice is fragmented and underutilised in shaping care pathways, standards, and training.
- There is no permanent infrastructure to embed patient voice into policy, research, or NHS planning.
- The recently announced Diagnosis Connect model demonstrates that early referral to charity support is both feasible and welcomed by patient organisations.

Patient Voice and Representation

"Clearly there is much to be learned within general hospitals in regard to medical understanding of those people with a spinal cord injury. I found the experience of staying on the ward extremely distressing: virtually every aspect of my health deteriorated except for the cyst for which I was admitted. This was particularly distressing as the methods of avoiding or treating these other problems have been well established by specialist medical practice and have been part of my daily life for many years."

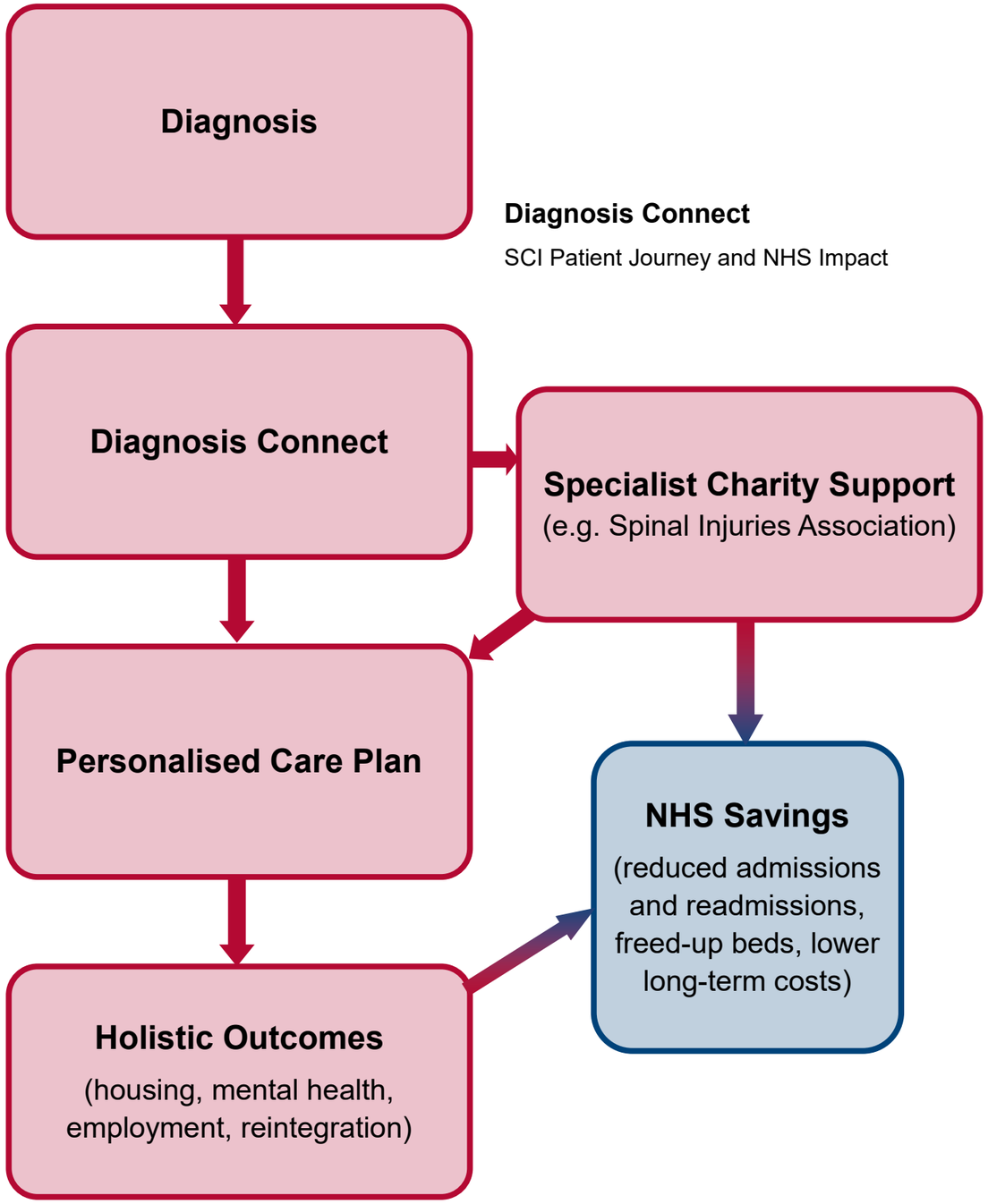
Tim Clare, Spinal Injuries Association member

Recommendations

1. Embed patient representation from the point of injury: Every new patient should be automatically connected with patient-led organisations and peer support networks.
2. Ensure personalised care plans: All SCI patients should receive a tailored care plan at diagnosis, aligned with NHS commitments under the NHS 10-Year Plan.
3. Link patient voice to standards and training: What matters most to people living with SCI must drive expectations of care.
4. Actively include SCI in Diagnosis Connect: The model should be extended to spinal cord injury, ensuring that newly diagnosed individuals receive early referral to trusted organisations like the Spinal Injuries Association.
5. Fund and formalise partnerships with voluntary organisations: Recognise their key role as trusted, cost-effective providers of patient-led services.
6. Ensure representation in NHS England and Department of Health and Social Care policymaking structures, with direct input into Diagnosis Connect implementation.

"General health and care services are struggling to meet the specialist needs of people with spinal cord injury, so they come to us, at the Spinal Injuries Association, to find the answers. For years now, we've been filling the gaps in essential services. The positive thing is that we can quickly identify what's gone wrong, and once we help put people back on track, everything else starts to fall into place. However, the fact remains that access to essential specialist care remains fragmented and disjointed within the healthcare service, negatively impacting many people with spinal cord injury."

Nik Hartley OBE, Chief Executive, Spinal Injuries Association



Diagnosis Connect

SCI Patient Journey and NHS Impact

Research and innovation are central to transforming outcomes for people with spinal cord injury (SCI). While the UK has a proud heritage in medical research, evidence presented to the inquiry highlighted a stark mismatch between the cost of SCI to the NHS and society, and the level of investment in research to reduce this burden. Current public funding is inadequate, infrastructure for clinical trials is fragmented, and opportunities to translate discoveries into practice are being lost. Witnesses made clear that without a coherent national research and innovation strategy, the UK risks falling behind international peers and failing to deliver hope of functional restoration to people with SCI.

Current challenges

The inquiry heard from the Spinal Research charity and other experts that SCI research in the UK faces systemic barriers:

Underinvestment

Government spending is estimated at around £3 million annually, against £3.5 billion in annual SCI care costs, equivalent to just £1 of research for every £875 spent on care. This contrasts sharply with investment in conditions such as MS or MND.

Weak Translational Funding

Promising areas such as neurotechnology, regenerative medicine, and rehabilitation science struggle to bridge the gap from discovery to clinical use.

Workforce Gaps

There is no structured pipeline of clinical researchers in SCI, leaving NHS services without the expertise needed to translate therapies into practice.

Data Limitations

Fragmented outcome data and the absence of a national registry make it difficult to recruit participants, track long-term outcomes, or assess cost-effectiveness.

Fragile Academic Base

Several UK neurosciences and neurotechnology labs have closed in recent years due to financial pressures, visa restrictions, and loss of EU research funding.

Lack of Clinical Trial Readiness

The UK has no coordinated national clinical trial infrastructure for SCI. Many spinal centres lack the facilities, research beds, and outcome data systems needed to participate in global trials.

Research and Innovation

International comparisons

The UK lags behind countries such as the United States, Switzerland, and Germany, which invest between £7 million and £75 million annually in SCI research and maintain trial-ready infrastructures. International collaboration is further limited by the UK's underdeveloped registry and trial systems, reducing the ability of UK patients to benefit from cutting-edge global trials.

Opportunities for transformation

Despite these challenges, evidence presented to the inquiry identified clear opportunities:

- **Strategic investment in trial infrastructure:** Upgrading at least half of the UK's specialist spinal centres to international clinical trial standards with MRI, tissue banking, diagnostics, and outcome tracking would allow UK patients to access emerging therapies and attract investment from industry.
- **Building a national SCI research workforce:** Establishing fellowships and specialist training pathways across the care continuum (from trauma to rehabilitation) would embed translational expertise in the NHS.
- **Focused "moonshot" initiatives:** Targeted, time-limited funding to accelerate function-restoring research, drawing inspiration from models such as ARIA-UK and international "Focused Research Organisations" could deliver breakthroughs in drugs, biologics, or neurotechnologies.
- **Integrating rehabilitation and research:** Ensuring equitable access to long-term rehabilitation and fitness services would prepare the SCI population for participation in clinical trials and maximise the benefits of future treatments.
- **Leveraging national platforms:** Existing UK infrastructure such as the UK Biobank, Catapults, and Biomedical Research Centres could be harnessed to accelerate SCI discovery and translation.

"We need people that are experts in adoption implementation, scientists. We need clinical researchers on hand. To soak up that bandwidth and deliver on effectively innovation in our centres from the major trauma centres, all the way through to community hubs that are operating and delivering community care. So that's an important partnership that we would like to see. I think it's a straightforward investment and was mentioned in the life sciences 2030 document about embedding clinical research income into care."

Harvey Sihota, Chief Vision Officer, Spinal Research

Key findings

- SCI research in the UK is underfunded and structurally disadvantaged compared with similar long term, severe conditions.
- The absence of a coordinated national infrastructure prevents participation in international trials and limits patient access to emerging therapies.
- Workforce gaps and fragile academic capacity threaten long-term research sustainability.
- International comparators demonstrate that higher levels of investment and coordination deliver measurable advances in treatment.
- A national strategy could integrate research, data, and rehabilitation to create a world-leading ecosystem for SCI innovation.

Recommendations

1. Substantially increase government investment in SCI research, bringing funding levels closer to parity with other long-term neurological conditions.
2. Establish a UK-wide clinical trial infrastructure for SCI, upgrading spinal centres to international readiness standards.
3. Create a national clinical research workforce programme, including fellowships and specialist training across NHS pathways.
4. Develop a modern national SCI registry with integrated outcome measures to underpin research, trial recruitment, and service planning.
5. Launch a time-limited, high-impact initiative focused on function-restoring research, leveraging ARIA-UK, UKRI, and NIHR funding models.
6. Protect and expand UK academic SCI labs, addressing barriers such as funding instability and international collaboration.
7. Embed research and innovation in a National SCI Strategy, ensuring sustainable governance, funding, and cross-sector collaboration.

Reliable data is the foundation of effective health planning. For spinal cord injury (SCI), data collection is fragmented, underfunded, and at risk of collapse. The current national SCI database was built in 2012 for local use, yet it remains the only national system. It is outdated, managed by a single individual, and excludes large cohorts of patients.

The inquiry heard compelling evidence that without a modern, centralised SCI registry, the UK cannot plan services, reduce inefficiencies, or improve patient outcomes.

Current limitations

Single Point of Failure
The database is run by one project manager without a team or funding increase since 2012. The host organisation is considering withdrawing support as a result of non-payment for years of work, making this need an urgent requirement.

Data Blind Spots
No tracking of deterioration while waiting; limited capture of long-term outcomes such as employment, housing, and psychological wellbeing.

Patchwork Fixes
Regional pilots and enhanced referral tools have been introduced, but without national funding, risks of fragmentation and data loss remain.

Lost Patients
In 2024/25, 76 patients were “lost” from the referral system and their outcomes unknown.

Outdated Assumptions
The system still assumes admission within 28 days, which no longer reflects patient journeys.

Narrow Scope
Only patients referred to SCI centres are captured. Those rejected, deemed inappropriate, or never referred remain invisible.

“So in 2024/25, spinal centres said there were 76 lost referrals, and in noting where the patients had gone, 60 were in London. And that's because patients are repatriated to local hospitals and the spinal cord injury centre isn’t always notified as to where that patient went. That's better than the year before, when 107 patients were lost.”

Krystyna Walton,
Rehabilitation and Complex Disability and Spinal Cord Injury CRG, Chair

Why a national registry matters

A national SCI registry would:

- Provide real-time data on referrals, admissions, discharges, and outcomes.
- Identify inequities in access to specialist care and track where patients are lost.
- Support service planning by regions, Integrated Care Boards (ICBs) and national commissioners.
- Enable benchmarking across centres on outcomes such as readmission rates, pressure sores, and community reintegration.
- Support research and innovation, providing the data backbone for clinical trials and translational studies.
- Empower patients and families with transparent information on what to expect from the care pathway.

Learning from other registries

Other conditions already demonstrate the value of national registries:

- **Cancer Registry**: Provides comprehensive data on incidence, treatment, and survival, informing NICE guidance and workforce planning.
- **National Stroke Register (SSNAP)**: Real-time stroke care data has transformed services, driving measurable improvements in outcomes.
- **Trauma Audit and Research Network (TARN)**: Tracks outcomes across trauma centres, influencing investment in major trauma services.
- **Acquired Brain Injury (ABI) datasets**: Pilots have shown the value of tracking rehabilitation and community outcomes, though provision is uneven.

SCI, with its small population but high cost and complexity, stands out as a condition urgently needing similar infrastructure.

Data and the Case for a National SCI Registry

Key findings

- The national SCI database is outdated, fragile, and excludes large patient groups.
- Data gaps undermine planning, funding allocation, and patient safety.
- Without reform, regional workarounds will fragment the national picture.
- Other registries (cancer, stroke, trauma) demonstrate the transformative value of real-time, comprehensive data.

Recommendations

1. Establish a National SCI Registry, with sustainable funding and governance, covering all SCI patients, both traumatic and non-traumatic, as well as admitted and non-admitted.
2. Integrate registry data with wider neurorehabilitation datasets (e.g. ABI), creating a comprehensive system for complex neurological conditions.
3. Capture broader outcomes beyond the acute phase including employment, housing, psychological health, and community reintegration.
4. Mandate standardised referral reporting, ensuring no patient is “lost” from the system.
5. Invest in modern digital infrastructure with live dashboards, outcome tracking, and interoperability with NHS records.
6. Align with international best practice, ensuring UK data supports global SCI research and innovation.
7. Secure national leadership for SCI data within the framework of the National Rehabilitation Strategy.

Children and Young People …

Spinal cord injury (SCI) in childhood and young adulthood presents unique challenges that extend beyond immediate medical needs. It disrupts education, family life, psychological development, and long-term vocational prospects. The inquiry heard from Back Up, the UK's only charity with dedicated services for children and young people with SCI, that current provision is patchy and under-resourced. Too often, young people are discharged without the skills, confidence, or support to live independently, while families struggle without adequate guidance.

Systemic gaps in care

Witnesses and written submissions highlighted that almost 80% of people sustaining SCI in England do not reach a specialist spinal centre. For children and young people, this frequently means:

- Limited or no exposure to peers with SCI, leading to isolation and low expectations about what is possible.
- Discharge before mastering essential independence skills such as transfers, self-catheterisation, or managing daily
- Rare opportunities to stay in purpose-built flats with families to practise independent living before returning home.
- Reduced access to outpatient and psychological services, despite evidence that recovery and adjustment in younger people are heavily dependent on psychological resilience.
- Significant regional variation, with families often travelling long distances to visit their child in hospital or to access specialist support.

The importance of peer support and role models

Evidence received by the inquiry stressed that positive disabled role models are essential in the early days following injury. Without them, many young people and families believe that life opportunities are permanently closed off. Programmes such as wheelchair skills training, mentoring, and youth activity courses provide both practical skills and hope for the future. However, these services are limited in availability, and in many regions, they do not exist at all.

Education and transition to adulthood

The inquiry heard that children and young people with SCI face major barriers to reintegration into education and to the transition into adult services. Families often feel unsupported when navigating local authorities for accessible schooling or adaptations. At transition points, young people risk "falling off a cliff" as paediatric provision ends and adult services are not adequately prepared to meet their needs. This mirrors wider failures in continuity of care identified throughout the inquiry.

Key findings

- Children and young people with SCI are frequently discharged without the independence skills that were historically expected as standard.
- Lack of access to peers and role models undermines confidence and limits aspirations.
- Families carry disproportionate responsibility, often without adequate psychological or practical support.
- Regional inequity means that children in some parts of the UK have little or no access to specialist SCI services.
- Transition into adulthood remains poorly managed, leading to loss of continuity and missed opportunities in education, employment, and independent living.

Recommendations

1. Ensure specialist access – All children and young people with SCI should have access to specialist spinal centres, including outpatient and psychological services.
2. Invest in paediatric provision – Expand paediatric SCI bed capacity and ensure opportunities for independence training (e.g. stays in self-contained flats with families).
3. Embed peer mentoring – Formalise peer support and role model programmes within NHS pathways, recognising their value for confidence, adjustment, and long-term outcomes.
4. Guarantee educational support – Strengthen statutory duties on local authorities to provide adapted housing, accessible schooling, and transition planning for young people with SCI.
5. Smooth transition to adulthood – Establish dedicated pathways for transition from paediatric to adult services, including vocational and psychological support.
6. Regional centres of excellence – Commit to at least one spinal cord injury centre of excellence in every region, ensuring equitable provision for children and young people as well as adults.

Timeline of Relevant Policy Moments … … England 2012-2025

2012	**Major Trauma Networks established (England):** trauma care reorganised around regional networks and Major Trauma Centres, associated with substantial survival gains; the spine pathway increasingly interfaces with these networks.
2013-14	**D13 Spinal Cord Injury (SCI) National Contract Materials & Quality Dashboard:** early national definition/specification work and metrics for SCICs (referral-to-admission times, LOS by level of injury).
2016	**NHS England Commissioning Guidance for Rehabilitation:** set expectations for consistent, outcomes-based commissioning across the rehab pathway (relevant to SCI).
2016-17	**NHS England Peer Review of SCI Services (the "2016 Service Review"):** a national peer-review exercise of SCI services established quality indicators for delivery (D13–D16) and triggered improvement projects locally (e.g., at the NSIC).
2016-17	**Prescribed Specialised Services CQUIN (TR2):** incentivised Acute SCI Centre outreach to newly injured patients; a time-limited lever to strengthen early specialist input.
2019	**Updated NHS England SCI Service Specification (all ages):** codified expectations for comprehensive, lifelong specialist SCI care delivered by the eight SCICs, including outreach and data participation.
2019	**Internal Review Highlights Capacity Gaps and Delays:** reporting identified "unacceptable" waits and the need for additional specialist bed**s** to reduce harm.
2019	**National Clinical Audit of Specialist Rehabilitation following Major Injury (NCASRI):** reinforced the value of specialist rehabilitation and the role of national audit in improving outcomes.
2019	**GIRFT Spinal Services Report:** broader spinal services review (surgical and network-wide) with recommendations to reduce unwarranted variation; important context for SCI interfaces.
2023	**NHS England Spinal Services Clinical Network Specification:** establishes expectations for spinal clinical networks to standardise pathways and reduce variation; an opportunity to embed SCI pathways and data.
2023	**Psychological & Mental Health Standards for Adults with SCI (professional consensus):** highlights national gaps in provision and proposes matched-care models within SCICs.
2025	**Government's 10-Year Health Plan for England ("Fit for the Future"):** commits to three system shifts (hospital → community; analogue→digital; sickness→prevention), a policy vehicle to align SCI rehabilitation, data and community support.
2025	**"Diagnosis Connect" Announcement:** automatic signposting from diagnosis to trusted charities from 2026 onwards; a model the inquiry recommends should include SCI from the outset.

Promised vs Delivered and Missed Opportunities

Time-limited outreach incentive (2016/17 CQUIN) was not mainstreamed. The TR2 CQUIN recognised the value of specialist outreach to newly injured patients, but it was time-limited, and there is no subsequent national, permanent mechanism requiring or resourcing universal SCI outreach to acute hospitals, a missed opportunity given ongoing delays to specialist admission.

The 2023 Spinal Services Clinical Network specification provides a platform for standardising spinal care. Harnessing it to deliver SCI-specific standards, capacity planning and data nationally is an opportunity the system has not yet fully seized due to lack of centralised accountability.

2019 SCI Service Specification is comprehensive but not fully implemented. The specification sets out lifelong, specialist, coordinated care by SCICs, including outreach and participation in national data. Yet persistent capacity shortfalls, delayed transfers, and variable access for non-traumatic/complex patients demonstrate gaps between policy and practice. The 2019 reporting on “unacceptable delays” and the need for additional beds underscores the implementation deficit.

Promised vs Delivered and Missed Opportunities

Data infrastructure is a strategic blind spot. Unlike cancer, stroke and trauma, SCI still lacks a modern, comprehensive national registry that captures the whole pathway (including patients not admitted to SCICs). This undermines planning, benchmarking and research, once again a missed opportunity that contrasts with other national registries driving improvement.

Prevention and early support policies need explicit SCI adoption. The 10-Year Health Plan and Diagnosis Connect can reduce downstream costs and improve outcomes if applied to SCI (e.g., early referral to specialist charities; community rehab capacity). That explicit inclusion has yet to be secured but is a near-term opportunity that must be enabled.

The 2016/17 peer review created clear quality indicators and catalysed local improvement projects (e.g., regular audit cycles). However, in the absence of a mandated national compliance regime and sustained peer-review infrastructure, delivery has varied; a key driver of the current postcode lottery evidenced across this inquiry.

Rehabilitation commissioning guidance (2016) hasn’t prevented wide variation. Despite national guidance on outcomes-based commissioning, rehabilitation access and intensity remain highly inconsistent, with consequences for length of stay, complications and community reintegration documented across this inquiry and national audits.

2016 NHS SCI service review (peer review) set quality indicators (D13–D16), but national follow-through has been inconsistent.

Mandate and resource the 2016/17 SCI quality indicators (updated where needed) within a national assurance framework — with transparent reporting.

Mainstream SCI outreach (not just incentivise episodically), building on the 2016/17 CQUIN learning.

Deliver capacity (beds and workforce) in line with 2019 findings to end harmful delays.

Stand up a national SCI registry to the standard of cancer, stroke and trauma audits, covering all SCI patients and outcomes.

Exploit current policy windows, and specifically use the 10-Year Health Plan to embed many of the individual and themed recommendations that have come from this inquiry, to create a national strategy for those with spinal cord injury (SCI).

What Should Happen Next

“What would a national strategy do?

It would present a coherent vision to government, media and the general public. Both the opportunities and the challenges.

It would allow a health and care system to plan services nationally, regionally and locally, and justify the need of the allocation of resource through health economics and be evidence-based.

I think that there's all sorts of things that would come out of a national strategy. Improve patient outcomes and safety, address health inequalities, enhance research and innovation, and the list goes on.”

Mark Ridler, Director of Programmes and Services, Spinal Injuries Association

Acknowledgements

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Oral Evidence:

Carol Adcock – Spinal Injuries Association, SCI Specialist Nurse Lead for North Regions
Carol Barraclough – Spinal Injuries Association, Support and Advocacy Manager
Brian Carlin – Aspire, Chief Executive Officer
Andrew Coxon – NHS England, National Spinal Cord Injury Database Manager
Jane Duff – National Spinal Injuries Centre, Head of Clinical Psychology Team
Nik Hartley – Spinal Injuries Association, Chief Executive Officer
Benita Hexter – London Spinal Cord Injury Centre, Rehabilitation Nurse and Chair, Multidisciplinary Association of Spinal Cord Injury Professionals
Faisal Hussain – Chair of Spinal Injuries Association
Mandy Jameson – Spinal Injuries Association, Continuing Healthcare Caseworker
Andy Masters – Back Up Trust, Head of Services Strategic Partnerships
Alex Rankin – Aspire, Director of Services
Mark Ridler – Spinal Injuries Association, Director of Programmes
Alexander Rouse – London Spinal Cord Injury Network, Children and Young People Clinical Lead
Simon Shaw – National Spinal Injuries Centre, Clinical Lead
Harvey Sihota – Spinal Research, Chief Vision Officer
Richard Tolkein – Stoke Mandeville Spinal Research, Chair of Trustees
Krystyna Walton – Rehabilitation and Disability and Spinal Cord Injury Clinical Reference Group, Chair

Written Evidence from Organisations:

NHS England
Spinal Cord Injury Centres:

- Duke of Cornwall Spinal Treatment Centre, Salisbury
- Golden Jubilee North East Regional Spinal Injuries Centre, Middlesborough
- London Spinal Cord Injury Centre, Stanmore
- Midland Centre for Spinal Injuries, Oswestry
- National Spinal Injuries Centre, Stoke Mandeville
- North West Regional Spinal Injuries Centre, Southport
- Princess Royal Spinal Injuries Centre, Sheffield
- Yorkshire Regional Spinal Injuries Centre, Pinderfields

Other NHS Commissioned Healthcare Services:

Acute Neuroscience Therapy Team, Alder Hey Children's NHS Foundation Trust
Acute Spinal Cord Injury Team, John Radcliffe Hospital, Oxford University Hospitals NHS Foundation Trust
Bladder and Bowel Care Service, Cornwall Partnership NHS Foundation Trust
Bristol and South West Regional Paediatric Neurorehabilitation Team, University Hospitals Bristol and Weston NHS Foundation Trust
Community Neurology Service, Dorset HealthCare University NHS Foundation Trust
Community Integrated Stroke and Neurology Service, Leicestershire Partnership NHS Trust
Department of Clinical Neuropsychology, King's College Hospital NHS Foundation Trust
Department of Clinical Neuropsychology, Manchester Centre for Clinical Neurosciences, Northern Care Alliance NHS Foundation Trust
London Spinal Cord Injury Network
Neuro Rehabilitation Services, Royal Manchester Hospital
Trauma & Orthopaedics, Hampshire Hospitals NHS Foundation Trust

Other Organisations:

Aspire Law
Back Up Trust
Bolt Burdon Kemp LLP
Calidus Care Consultancy
Eximius Live-In Support
Fletchers Solicitors
Hobbs Rehabilitation
Horwich Cohen Coghlan Solicitors
Society of Clinical Injury Lawyers
Spinal Research
Spirit
Stewarts Law
Stoke Mandeville Spinal Research

"Poor practice is expensive. Good care saves money and, more importantly, lives. The need for a National Spinal Cord Injury Strategy is now undeniable".

Andy McDonald MP, Chair, All-Party Parliamentary Group on Spinal Cord Injury

And all personal contributors of written evidence from their lived experience, their family or friend's lived experience, or their professional experience.
In total the inquiry received 88 contributions. Their support in developing the evidence base for this report is gratefully acknowledged by the officers and secretariat of the All Party Parliamentary Group on Spinal Cord Injury.