Spinal Cord Injury Strategy Consultation

The Open University

Contents

Thanks

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Introduction

The Spinal Cord Injury Strategy Consultation aims to shine a light on the case for developing a Spinal Cord Injury (SCI) Strategy to improve the care, support, and quality of life for people living with SCI in the UK. It does not aim to provide a systematic or comprehensive evidence base for the development of a strategy, and it purports to be a call to action and useful first step in a much wider process of consultation to include the voices of those living with spinal cord injuries in the UK and the professional expertise by those working in the field.

By inviting a wide range of voices, including patients, families, healthcare professionals, researchers, and third-sector organisations to contribute, the consultation seeks to assess whether a SCI strategy is necessary and, if so, what its focus should be. It was supported by a coalition of SCI Charities; Aspire, Back Up, Cauda Equina Spinal Cord Injury, Horatio's Garden, Inspire Foundation, Regain, Spinal Injuries Association, Spinal Research, Stoke Mandeville Spinal Research, and WheelPower.

The consultation acknowledges the significant physical, mental, and social challenges currently faced by people with SCI, and crucially is cognizant of the inconsistencies in current healthcare provision, including long wait times, limited support, and barriers to critical services such as housing, employment, and mental health care. **It also acknowledges the decades of exceptional work in this area being carried out by professionals and volunteers across the sector in the UK.**

Central to this initiative is the pursuit of equitable, high-quality, and consistent care for every person living with SCI, regardless of geographical location or personal circumstance. The consultation explores several key questions, including the potential benefits of a SCI Strategy, the areas of care that should be prioritised (e.g. rehabilitation, staff training, social reintegration, and research), and how the lived experiences of those affected by SCI can influence both the strategy's design and delivery.

This consultation represents a hopeful first step in building a unified and responsive framework that ensures all individuals in the UK with SCI receive the comprehensive care and support they need.

Spinal Cord Injury in the UK

Spinal Cord Injury Incidence in the UK

Spinal cord injury (SCI) represents a significant public health concern in the United Kingdom. Based on global estimates, the prevalence of SCI varies from 236.0 to 1,298.0 per million inhabitants, with increasing prevalence rates in recent years and highest burden found in middle-income countries but still significant in the UK [1,2].

In the UK, an estimated 4,700 people sustain a spinal cord injury each year, with the total size of the UK SCI population now believed to be over 105,000. These figures have recently been made available and are double those indicated by previous records, which estimated 2,500 people diagnosed with a SCI yearly [3]. There were approximately 871 annual admissions to specialist SCI rehabilitation units in England[4].

Spinal Cord Injury Experience in the UK

A long-term analysis of life expectancy in SCI patients reveals that despite improvements in acute care, the average life expectancy of individuals with a SCI remains reduced compared to the general population [5,6]. Traumatic SCI remains one of the costliest and most life-altering injuries around the world, with UK data aligning with this trend. SCI research remains underfunded relative to its impact. The Lancet Neurology identified SCI as one of the areas with the greatest mismatch between disease burden and research funding [7].

The impact of SCI is multifaceted and lifelong. People living with spinal cord injuries endure a wide array of secondary physical complications, especially bladder and bowel dysfunction, sexual impairment, chronic pain, spasms, pressure injuries and autonomic issues. They also experience markedly higher rates of depression, anxiety, PTSD and suicidal thoughts, all of which together severely diminish quality of life and necessitate comprehensive, multidisciplinary care (Appendix 1).

The impact of SCI is not limited to physical and psychological complications. People with spinal cord injury face major social challenges, including low employment rates, social isolation, and widespread accessibility barriers to housing, transport, healthcare, and equipment. These are compounded by stigma, complex bureaucratic systems, and often-inadequate support services, all of which significantly hinder their autonomy, inclusion, and quality of life (Appendix 2).

Spinal Cord Injury Care in the UK

The effects of SCI extend well beyond the individual, affecting healthcare systems and public services. Acute care, long-term rehabilitation, assistive technologies, and community support come with considerable costs. A 2019 study estimated the total cost of caring for people with SCI in the UK to be £1.46 billion in 2016 prices [8]. Accounting for inflation, this would translate to approximately £1.96 billion in 2025 prices[9]. However, the estimated number of people living with SCI was 50,000 at the time of the 2019 study, and has recently been revised upward to over 105,000, which suggests £1.96 billion is a significant underestimation.

It is estimated that approximately 70% of these costs are paid for by the public purse, with the remaining 30% due to reduced employment both of people with SCI and their caregivers [8]. NHS England's spinal cord injury (SCI) service includes a comprehensive, lifelong care pathway for people with SCI. NHS England mandates timely access to specialized, multidisciplinary care, from acute management after injury to rehabilitation and ultimately long-term follow-up. The SCI service within NHS England emphasizes patient-centred outcomes and integrated support including psychological, urological, and respiratory care. Key performance metrics for the service include referral times, length of stay in care, and complication rates [10]. Early and sustained involvement of specialist spinal services is a key part of NICE guidance for spinal injury assessment and initial management aimed at reducing long-term disability [11].

Specialist rehabilitation

Specialist rehabilitation and clinical management have shown huge potential in improving function and decreasing morbidity in some groups of people living with SCI [12]. For instance, electrical stimulation has been shown to improve bladder, bowel and sexual

function in people living with chronic SCI[13].

Standards published by the British Society of Physical and Rehabilitation Medicine (BSPRM) emphasize timely access to specialist SCI centres, multidisciplinary rehabilitation, patient-centred goal setting, and continuity of care[14]. Specialist SCI rehabilitation is available at a number of centres throughout the UK.

A multi-center UK study demonstrated that specialist rehabilitation not only improves function but also reduces long-term care costs by an average of £25,500 per person annually [15]. Extrapolated to UK figures, this represents savings of over £10 million per year. Specialist rehabilitation was shown to be highly cost-efficient for all neurological conditions, resulting in long-term savings [16].

Despite the robust case for the effectiveness and value-for-money of specialist rehabilitation, a significant number of individuals in the UK do not have access to it, with access to specialist centers being a grave concern for 42% of people with SCI in the UK[17].

Psychological rehabilitation

Psychological factors can play an important role in recovery, including rehabilitation [19] and long-term quality of life and morbidity [20]. BSPRM guidelines stress the importance of psychological support, vocational rehabilitation, and community reintegration for people living with SCI to optimize recovery, independence, and quality of life [14].

However, psychological health screening and standards for people with SCI have been delayed compared with many other physical health conditions, including severe burns, cancer, and stroke [21]. Recent research indicates that nearly half of SCI patients are dismissed from hospital while still experiencing sustained psychological need [22]. Importantly, a recent survey conducted by the Spinal Injuries Association indicated that 68% of people with SCI who had access to standard mental health services withdrew themselves from treatment early, with some finding these services worsened their issues [23]. Specifically, in 2024 74% of surveyed people living with SCI mentioned a lack of access to mental health professionals who understand spinal injury[17].

Methodology

In preparation for this consultation, the Spinal Injuries Association (SIA) sought advice from government officials on how to ensure its impact. Three clear criteria emerged: the consultation should be delivered in partnership with other charities; it should centre lived experience, securing input from at least 80 individuals; and it should run for a minimum of three months.

SIA subsequently convened eight national charities to assess appetite and capacity for collaboration. All but one engaged: Spinal Injuries Scotland opted out due to the devolved nature of healthcare in Scotland and the timing of a forthcoming national consultation. REGAIN joined the process shortly after initial discussions.

A four-month development period followed, culminating in the launch of the consultation in January. The process was deliberately consensus-led. It was agreed the consultation would be unbranded, with each charity responsible for dissemination via their own networks. Two tailored questionnaires were created: one for professionals and one for people with lived experience. The latter was written in plain, accessible language, aligned with NHS guidance on patient communications. The consultation was open for a total of 91 days (7th January to 7th April 2025).

Data analysis and report write-up was carried out by the Open University.

Professional Stakeholders Consultation

The professional stakeholder consultation was composed of 55 questions, including a mix of multiple choice, scoring, and open-ended questions. The consultation gathered 92 responses, predominantly from the health and social care (79%), third sector (9%), and research and academia (4%) fields. Responses were predominantly from England (75%) but also included representation from Wales (8%) and Scotland (4%).

Lived Experience Consultation

The lived experience consultation was composed of 43 questions, including a mix of multiple choice, scoring, and open-ended questions. The consultation

gathered 321 responses, predominantly from people living with SCI (81%), but also including family, friends, and carers. The most represented age groups among respondents were 56-65 (32%) and over 65 (29%), with only 16% responses coming from those aged 45 and under. Responses were predominantly from England (89%) but also included representation from Wales (4%) and Scotland (2%), and Northern Ireland (0.6%).

Data and Stakeholder Analysis

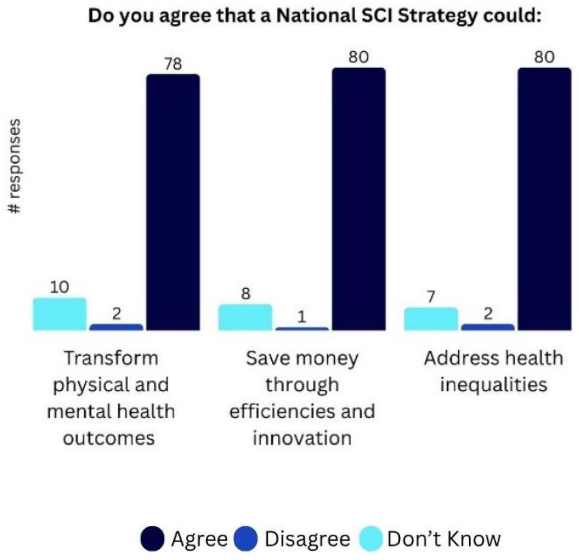
Open-ended questions were analyzed to identify key themes throughout the responses. Stakeholder perspectives were further developed through one evidence cafe session hosted by the Open University, including professional stakeholders.

Results

Professional stakeholder consultation

Broad Support for Strategic Transformation

The majority of respondents support the creation of a Spinal Cord Injury (SCI) Strategy and recognise its transformative potential. Specifically, 86% believe it could significantly improve physical and mental health outcomes for people living with SCI, and 89% see potential for a strategy to bring about cost savings by driving efficiency and innovation. Furthermore, 89% assert a SCI strategy could reduce health inequalities.



Priorities for Impact

Respondents identified the top three outcomes that could most be improved by a SCI strategy as standardisation of care, improved patient outcomes and safety, and addressing inequalities. On a 10-point scale, these areas scored highest among other potential benefits such as enhanced research, integrated care, resource optimization, and international collaboration.

Strategy Design

A majority of respondents stressed the importance for a SCI strategy to balance national consistency with localized flexibility. System-level barriers, equitable care access, and data-driven decision-making were cited by over half the respondents as critical to developing a strategy approach. While 33% clearly endorsed adopting international models, most respondents favoured adapting lessons to the UK context, citing differences in healthcare funding, infrastructure, and cultural norms.

Defining Rehabilitation Expectations

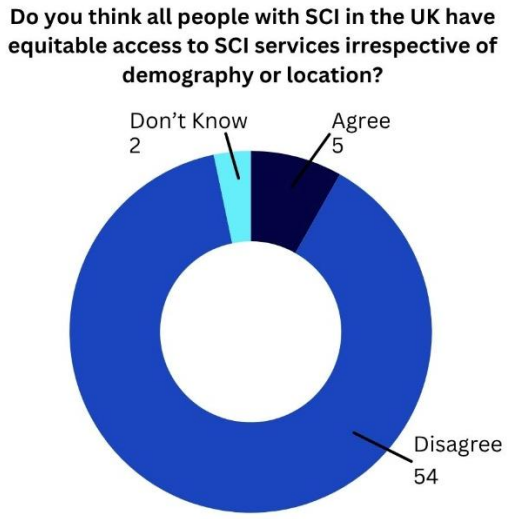
A compelling 98% agreed on the need for nationally defined rehabilitation pathways. Agreement was similarly high on specifics: 93% endorsed clarity on admissions criteria, 91% on minimum rehabilitation standards, 90% on wait time expectations, and 84% on staffing minimums. Key priorities identified in this area were consistency of care, professional standards, and clear expectations.

Public communication, realistic recovery goals, and involvement of patients and families were identified as crucial for setting public-facing expectations. Additionally, a national notification system was viewed positively for data collection, coordination, and resource allocation, despite some implementation concerns.

Access, Equity, and Systemic Barriers

Only 54% of respondents believe SCI services are equitably accessible. Key recommended steps to drive equitable access include standardised protocols, telehealth, and integration with social care. The biggest barriers to equitable access to SCI services identified by respondents were funding (72%), staffing (42%), resistance to change (36%), and infrastructure gaps (24%).

85% of respondents agreed on the requirement of competency requirements in SCI care across all NHS settings, 93% endorsed universal care standards, and 88% favoured standard training course content. Key topics to be covered in standardised training included autonomic dysreflexia, respiratory issues, and mobility care.

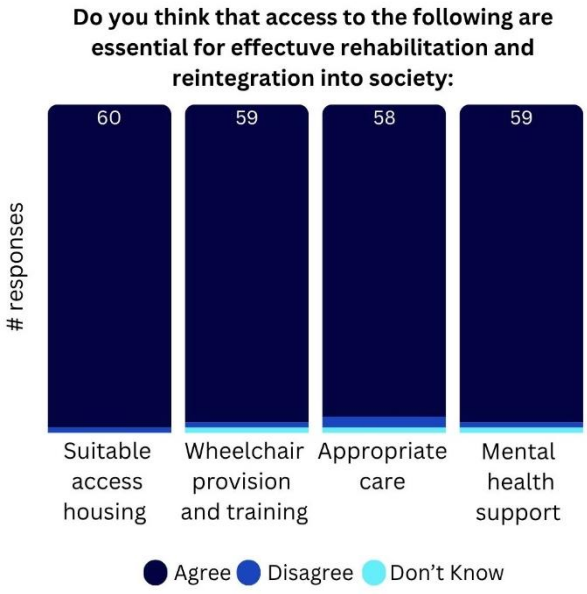


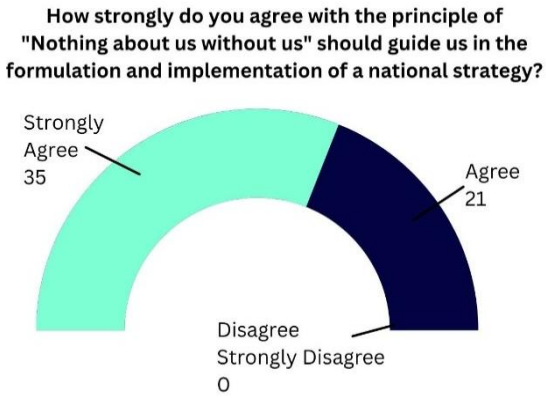
"It must be so degrading for an individual with a spinal cord injury to not be able have those very basic human needs met and it is very frustrating from a nursing staff point of view to not be in a position to help somebody because our greatest driver is to be able to make things right for people."

Emma McClean, Stroke Team Leader Advanced Practitioner

Housing, Equipment, and Mental Health Gaps

A majority of respondents highlighted essential needs such as accessible housing (98%), wheelchair access (96%), and mental health support (96%). However, 78% reported current housing access as being inadequate, leading to discharge delays and worsened health outcomes. Similar gaps were reported in wheelchair access, with 67% reporting it as inadequate, and mental health provision, which 75% of respondents reported as inadequate.





"Knowledge is power and we support many to become an expert in their own condition. Simple specialist knowledge can save lives and mental trauma."

SIA specialist nurse

Research, Innovation, and Accountability

An overwhelming 91% of respondents agreed a coordinated research programme would improve care and 77% believed it would save costs. Respondents emphasized the need for local-to-national innovation scaling, stakeholder integration, and a robust database to track outcomes. A key theme was balancing enforceable standards with best practice (50%), backed by equitable UK policies.

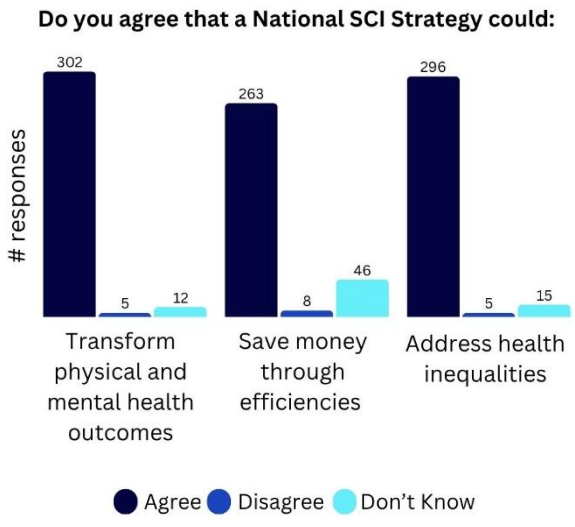
Centring the Patient Voice

Respondents strongly endorsed patient representation: 99% agreed with the principle "Nothing about us without us." While 63% supported involvement of a patient representative network from diagnosis, concerns about timing and emotional readiness were raised. Integration into care pathways, strategic roles, and structured support for representation were recommended to elevate patient voices systemically.

Lived Experience Consultation

Strong Support for a SCI Strategy

Respondents overwhelmingly endorsed the need for a Spinal Cord Injury (SCI) Strategy. Nearly all agreed it could transform physical and mental health outcomes (94%), address health inequalities (93%), and improve financial efficiency (82%). On a 10-point scale, the strategy was rated particularly high for its potential in enhancing healthcare integration (71%), standardising care (71%), and increasing access to specialist services and prevention (67%). Most (79%) preferred a unified UK-wide strategy, and 88% supported learning from international SCI models, with the necessary adaptations for the UK context.



Respondents emphasised unresolved gaps in service continuity, disparities caused by the "postcode lottery," a lack of non-specialist SCI knowledge in general care, and insufficient mental health and bladder, bowel, and pressure care provision. Improved post-discharge support and systemic consistency were seen as essential.

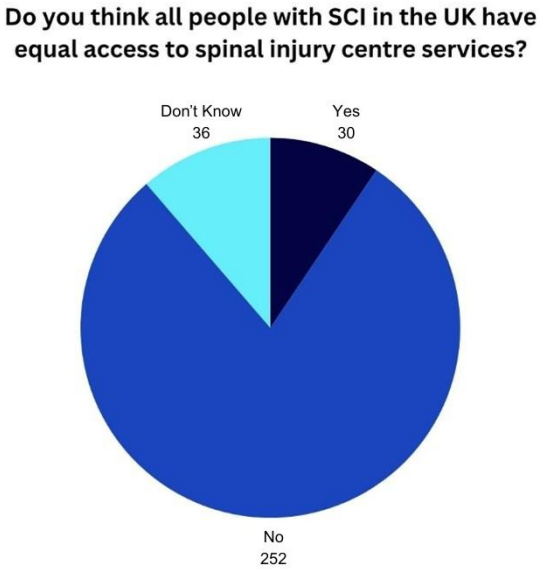
Rehabilitation: access, equity, and continuity

There was overwhelming support (>88%) for defined expectations in rehabilitation pathways, which included clear admission criteria, maximum waiting times, and minimum staffing levels. Respondents believed an SCI health alert being included in medical records would improve care experiences (85%) and reduce overlooked symptoms (89%).

79% said equitable access to spinal injury centres is currently lacking. To address this, respondents called for more specialist capacity, an increased focus on geographical equity, improved communication, better-trained staff, and fair resource allocation across traumatic and non-traumatic injuries. Respondents, however, identified major implementation barriers: insufficient funding, staffing shortages, systemic bureaucracy, poor coordination, and inequities based on location or injury type were among the most highly rated.

"How am I supposed to live this life when I can't afford to get the care I need? People don't realise how hard it is to access decent care and the danger if you don't receive any help."

SIA member



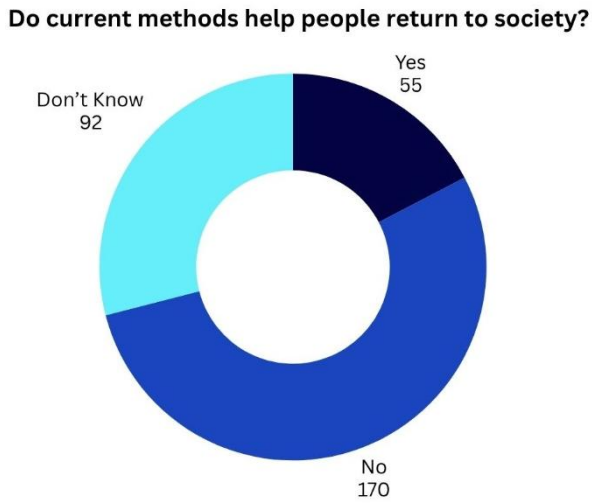
Training and Workforce Standards

Training was identified as a cornerstone for effective SCI care. Nearly all respondents (99%) agreed that standardised training on skin, bowel, bladder, and breathing support should be required. Similarly, 98% supported UK care policies, and 93% endorsed integrating SCI-specific content into medical training.

Key skill areas to be targeted by training and workforce standards included autonomic dysreflexia, pressure ulcer prevention, mental health support, individualised care, and effective communication across providers. The need for team-based coordination and recognition of SCI-specific red flags was repeatedly emphasised by respondents.

Barriers to Reintegration

Only 17% of respondents believed current methods effectively support community reintegration. Nearly all (96%) said a SCI strategy must address access to housing, wheelchairs, and mental health services. The majority rated housing (51%), care (46%), wheelchairs (44%), and employment (44%) as highly significant barriers to reintegration (score of 9 or 10). Respondents also cited structural accessibility, equipment availability, workforce-related pressures, emotional wellbeing, and financial barriers as core challenges.



Only 3% of respondents believed accessible housing is adequate; 62%

said mental health treatment is lacking; and only 11% felt wheelchair access is sufficient. Employment access was also critically low, with 58% citing insufficient opportunity.

Research, Innovation, and Improvement

Almost all respondents (96%) supported a UK research programme to improve rehabilitation, treatment, and reintegration. Most (88%) believed research would enhance care, and 60% expected it to yield cost savings. Suggested innovations that may be targeted by a UK research programme included improved assistive technology, integrated care models, funding for staff and resources, and psychosocial supports. A strong emphasis was placed on co-produced solutions driven by the lived experience of people living with SCI.

The Role of Patient Voice

Patient representation was strongly endorsed: 89% supported a UK network beginning at diagnosis, and 93% agreed with the principle "Nothing about us without us." While some felt early involvement of patient representatives could be overwhelming, the consensus valued patient voice, peer support, and inclusion in decision-making across the board. Better education, digital tools, and shared decision-making were recommended to enhance patient autonomy.

"I was the only disabled person I knew, the only SCI person I knew, the only one who was going through the incontinence, lack of independence. I still felt really alone, which was strange being around family and friends again. But it felt like no one understood what I was going through. I think this was where I reached my lowest point."

SIA member

Consultation alignment

The stakeholder and lived experience consultations reveal a powerful alignment in support of a SCI strategy, with both groups emphasizing its potential to improve outcomes, reduce inequalities, and drive system efficiencies.

Professional stakeholders focused heavily on structural reforms (e.g. standardisation, data integration, and governance), while people with lived experience of SCI brought a more detail-oriented lens to the consultation, highlighting inconsistencies in service access, lack of specialist knowledge in general settings, and everyday barriers to reintegration.

Both groups expressed strong support for UK training standards, integrated rehabilitation pathways, and research-led innovation. People with lived experience of SCI were more vocal in their responses about the emotional and practical realities of living with spinal cord injury, particularly highlighting systemic shortcomings around housing, mental health, and employment.

Both consultations converged on the principle of centring the voices of those with lived experience of SCI, endorsing "Nothing about us without us" as a shared ethos. Together, these perspectives underscore the urgency and legitimacy of a unified, co-produced SCI strategy.

Insight and Next Steps

Draft Theory of Change

Consultation responses and further input from stakeholders has allowed us to produce a draft change model (Appendix 3) outlining a vision for achieving equity, excellence, and empowerment for people with spinal cord injuries (SCI). **This model is not intended to replace a wider and more systematic consultation effort, but rather sets out some preliminary insights that may be useful when developing the approach for a unified SCI Strategy.**

The model is based on five interconnected strands: **Accessible Rehabilitation** (addressing gaps in timely, joined-up rehab services), **SCI-trained Workforce** (improving consistency in clinical knowledge and confidence), **Barrier-free Reintegration** (removing systemic barriers like housing, transport, and discharge planning), **Evidence-based Practice** (using research and cost modelling to shape care and policy), **Lived Experience-led Strategy** (embedding lived experience into all levels of design and delivery).

These strands are mutually reinforcing: for instance, evidence and lived experience inform and advocate for improvements in training and systemic barriers, which in turn enable better access to rehabilitation.

Feedback from a stakeholder evidence cafe validated this model and proposed three additions:

- **Data and infrastructure** (a cross-cutting enabler),
- **Youth-to-adult transitions** (a sub-pathway under reintegration), and
- **Centre accreditation** (under workforce standards).

Recommendations

This consultation has shone a light on broad support among professional stakeholders and those with lived experience of SCI for a unified Spinal Cord Injury Strategy. Based on the consultation responses, **a strategy should engage broadly with the spinal cord injury community to develop recommendations aiming at targeting key areas, including but not limited to accessible rehabilitation, workforce training, barrier-free reintegration, evidence-based practice, data and infrastructure, and youth-to-adult transitions.**

We strongly recommend a SCI strategy:

1. **Gives a voice to those living with Spinal Cord Injury across the UK,** with a specific focus on capturing a wide variety of perspectives and the views of groups that are otherwise underrepresented.
2. **Carefully considers devolution** when developing recommendations. The five strands identified in the draft Theory of Change model all depend on systems that are devolved to different degrees across UK nations, including healthcare, social care, infrastructure, and education. A thoughtful approach to these differences will be essential to develop a strategy that serves people living with spinal cord injury across the UK.
3. Incorporates at its **foundation the huge amount of work that has already been done** in this space by a number of stakeholders across the third sector, government, and the NHS. These include (but are by far not limited to) the 2016 NHS England Service Review for Spinal Cord Injury [24], the Multidisciplinary Association for Spinal Cord Injury Professionals Best Practice[25], National Rehabilitation Pathways, NHSE Service Standards [26], the National Spinal Cord National Database [27], and the SIA/APPG report "A Paralysed System" [28].
4. Address **key priority actions** to deliver integrated, community-led, preventative and value-based care, including establishing national rehabilitation pathways, expanding community care, and addressing reintegration barriers (see 'Key Priority Actions' below).

A SCI Strategy should aim to ultimately drive system-wide reform, aligned with the Government's 10-Year Health Plan to deliver integrated, community-led, preventative and value-based care.

Key Priority Actions

Based on the results of the consultation, wider stakeholder engagement and discussions within the charity coalition, we recommend that a national SCI strategy should drive system-wide reform, aligned with the Government's 10-Year Health Plan to deliver integrated, community-led, preventative and value-based care. We would further like to emphasise the importance of preventative and community-based health promotion, specifically in regard to preventative care through ongoing physical activity, which is vital for long-term health outcomes including secondary complications, supporting psychological health, and improving overall quality of life. Based on this consultation and the established evidence base, we recommend 11 key priority actions.

1. Establish national rehabilitation pathways

There should be clear national standards for spinal cord injury rehabilitation, so everyone knows what to expect. These should set out who is admitted to which service and why, what the minimum level of rehab support should be for each type of injury, how long people should wait for different parts of the care pathway, and what staffing levels are needed. To address the current postcode lottery, extra beds and ventilator facilities should be added to existing centres, a new SCI centre should be developed in an area currently underserved, and outreach services should be re-established at all SCI centres to better support people in rural and remote areas.

2. Expand community and life-long care

People with spinal cord injuries should have access to lifelong care, as outlined in NHS service specifications. This includes follow-up support from local outreach teams linked to SCI specialist centres. Technology based solutions like virtual clinics as well as community centred home-based care should be expanded so that services are easier to access and more responsive, helping reduce the burden of travel for patients and families and prevent readmissions.

3. Recognise spinal cord injury as specialist care through national training standards

Everyone with a spinal cord injury should be cared for by staff who understand their needs. That means recognising that spinal cord injury care is specialist care and setting national training and competency standards for staff working

in hospitals, clinics, and care settings across the NHS. Training should include essential topics like bladder and bowel care, breathing support, skin integrity, and emergency responses such as autonomic dysreflexia. SCI-specific content should also be included in standard medical and nursing education, as in the past, so that all professionals have the right knowledge from the start.

4. Address housing, equipment and reintegration barriers

Too many people face delays leaving hospital or difficulties rebuilding their lives due to poor access to housing, wheelchairs, and care. This not only contributes to delayed hospital discharge but also exacerbates mental health challenges for patients. The NHS Continuing Healthcare (CHC) framework must be applied consistently and fairly, with a mechanism in place to hold local systems to account. National standards should guarantee timely access to accessible housing, wheelchair equipment, and support in the community. NHS and local authorities should also proactively work with charities to deliver peer support, independent living skills and employment assistance as part of the reintegration process.

5. Ensure equitable psychological and mental health support

Psychological health support should be available at every stage of a person's journey with spinal cord injury, from diagnosis through to long-term life in the community. National guidance should require psychological screening, and people should have access to professionals who understand the unique mental health challenges of SCI. Support must be tailored, proactive, and embedded into care pathways rather than offered as an optional extra. To ensure that people with SCI can lead independent and fulfilling lives, there must be a clear commitment to increasing the number of psychology professionals with specialist expertise in SCI, alongside a workforce plan to support this.

6. Strengthen paediatric and transitional care for children and young people

Children and young people with spinal cord injuries must have access to specialist, age-appropriate care throughout their journey. The current provision is patchy and overly reliant on services designed for adults. New paediatric spinal cord injury centres should be established to address geographical gaps and ensure more equitable access. National pathways for care and rehabilitation should be

adapted to meet the developmental, emotional, and educational needs of children and teenagers. Transition to adult services must be managed carefully, with personalised support to ensure continuity of care, mental wellbeing, and social participation. This should include tailored peer support, educational advocacy, and family-focused planning. Paediatric and transitional care should be a clearly defined part of the national SCI strategy, with accountability for its delivery and resourcing.

7. Meet the needs of an ageing population

With life expectancy increasing, there must be a proactive national approach to planning and delivering spinal cord injury services that address the distinct and evolving needs of an ageing population. Older people with SCI often present with complex comorbidities and are more vulnerable to complications, prolonged rehabilitation, and difficulties with discharge and reintegration. Services must be specifically developed and resourced to provide tailored support across the life course, including age-appropriate rehabilitation, preventative care, and community-based interventions that help individuals maintain health, independence and dignity in later life. This approach is fully aligned with the Government's 10-Year Health Plan which emphasises healthy ageing, integrated care close to home, and reducing pressure on hospitals. National planning should include consideration of workforce training, data collection, and new models of care to anticipate and respond to the rising number of older adults living with SCI.

8. Invest in research, innovation and outcome measurement

The Government should fund a national programme of SCI research focused on what improves people's lives: better rehabilitation, reintegration, prevention and innovation in care. There is also a need for research into restoring function, including new technologies. The strategy should include a clear plan for collecting and using outcome data to track progress and hold services accountable. Research should be linked to NHS improvement plans and co-designed with people who have lived experience of SCI.

9. Strengthen data and infrastructure

Accurate data is essential to improving services. A national registry of spinal cord injury cases should be created to track needs, support service planning and guide investment. For instance, a registry would allow charities to use real-time data to better respond to where patients are. SCI alerts should be included in people's digital health

records, so clinicians are aware of their needs. Data systems must be consistent and linked to quality standards, helping ensure good care is provided across all regions.

10. Establish a National Patient Representative Network

A national patient representative network should be established to embed lived experience at every stage of the spinal cord injury care pathway. This network must ensure meaningful involvement from the point of diagnosis, enabling people with SCI and their families and carers to have a consistent voice in decision-making, service planning, and system reform at both local and national levels. The voluntary sector should form the foundation of this network, given that charities already provide essential peer support, advocacy, and community navigation, often filling critical gaps left by under-resourced NHS services. Their strong community links, lived experience-led models, and trusted relationships make them ideally placed to lead this work. This approach aligns with the Government's 10-Year Health Plan, which calls for a shift from centralised to community-led care, greater partnership with civil society and the third sector, and a rebalancing of power towards patients. In line with this vision, the network should also coordinate access to both specialist and local support services, ensuring that lived experience informs the design, delivery, and evaluation of SCI care across the system.

11. Improve governance and accountability

There should be clear leadership within the NHS to oversee the delivery of a national SCI strategy. This includes setting up formal governance structures to link health, housing, social care and the voluntary sector. Progress must be measured and reported publicly every year, with transparency on where improvements are being made and where further action is needed.

In conclusion, the Government should commit to publishing a full National Spinal Cord Injury Strategy within the next 12 to 24 months. This strategy must build on the findings of this consultation and the forthcoming report from the All-Party Parliamentary Group for Spinal Cord Injury's current inquiry into the need for a national strategy, be co-produced with lived experience, and align with the NHS 10-Year Plan. It should help shift post-discharge services from being hospital-led to community-based over the long term, make full use of digital technology, and put prevention and personalised care at the centre of the system.

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Appendix 1: Physical and Psychological Challenges for people living with SCI

A 2022 study found that over 95% of individuals with SCI reported at least one secondary health problem[29]. The most common physical challenges faced by individuals with SCI include bladder, bowel, and sexual disfunction, loss of sensation, muscle spasms, chronic pain, respiratory issues, pressure sores, autonomic dysreflexia, and thermoregulation issues[30].

Physical Challenges

Bladder and Bowel Dysfunction

The majority of people with SCI experience bladder and bowel dysfunction, and managing neurogenic bladder and bowel is among the most critical challenges in their care [31]. Bowel and bladder management are the top two areas of concern for people with SCI[17]. Genitourinary complications are the primary cause of re-hospitalizations in this population and are the fifth leading cause of mortality for people with SCI [32]. Similarly, bowel dysfunction is the second most frequently reported complication among individuals with SCI and the fourth leading reason for re-hospitalization [33]. Bowel incontinence is widespread, and bowel care is time-consuming, with over 20% of individuals reporting it lasting over 60 minutes in one study [34].

Further bladder and bowel dysfunction significantly impacts quality of life and reduces social integration [35]. For instance, a 2018 study of the SCI community revealed that bowel management was a problem for 78% of individuals, affecting personal relationships and a person's ability to leave their home [36]. An effective bowel care routine is therefore key to people living with SCI. However, recent research has shown that over 70% of people with SCI have not changed their bowel care in the past 5 years, primarily due to a lack of support stemming from lack of time to prioritise bowel care and limited healthcare resources [37] .

Bowel care can be neglected in non-specialist medical settings due to inadequate staff training, which can have life-altering, and in some cases life-threatening consequences[38]. The Spinal Injuries Association is leading the Paralysed Bowel Care Campaign to bring these issues to the forefront and support NHS Trusts to achieve the appropriate standards of care.

Sexual Dysfunction

Sexual impairment is highly prevalent within the SCI population. Research indicates that 90% of men with SCI experience erectile dysfunction [39] , and that a similar majority of female individuals with SCI also experience sexual dysfunction[40]. The extent of sexual impairment is often dependent on the type of SCI [41]: common symptoms include erectile, endocrine, and sexual dysfunction, abnormal semen emission and ejaculation [42], lack of vaginal lubrication, pain during intercourse, and dysfunction in the areas of orgasm, desire, and satisfaction [40].

Although sexual activity may decline after injury, sexual interest remains a priority for many individuals with SCI [43], and numerous people report positive sexual adjustment [4445].

Chronic Pain

60%-80% of people living with SCI report chronic pain [46], and pain management was a key concern for 37% of people with SCI[17]. Chronic pain following a SCI can take several forms, including musculoskeletal, visceral, and neuropathic pain.

Musculoskeletal pain is the most common type of pain following a SCI [47] and often results from muscle spasms, abnormal use of limbs. It presents as a dull, aching sensation that often responds to physical therapy, non-steroidal anti-inflammatory drugs (e.g. ibuprofen or aspirin), or opioids [48].

Neuropathic pain is often characterized by a sharp, burning sensation occurring below, at, or above the injury level, and can also manifest as hyperalgesia (increased sensitivity to pain) or allodynia (pain in response to stimuli that would not ordinarily cause pain, such as gentle touch) [46]. Unfortunately, neuropathic pain is often resistant to conventional treatments, and its underlying mechanisms are still not fully understood, making management challenging[49].

Lastly, visceral pain is felt in the abdomen as dull cramping and is typically linked to peripheral inputs from the vagus nerve in a region with intact nerves[50]. It is the least common type of

chronic pain following injury, with a recurrence of around 5%, and it often has delayed onset, typically appearing over 4 years after injury[51].

Muscle Spasms

Involuntary spasms (spasticity) of the lower limbs are common in people living with SCI, with over 65% of individuals reporting spasticity when being discharged following a traumatic SCI [52]. Muscle spasms can be treated with medication [53], although these are less effective when managing severe cases and are often associated with serious side effects, including blurred vision and drowsiness. Botulinum toxin (botox) injections are also available to treat localized muscle spasms [54].

Wounds and pressure injuries

People with SCI are at increased risk of developing pressure injuries, which can lead to the development of serious infection of the bone marrow (osteomyelitis) [55,56]. Osteomyelitis stemming from pressure ulcers can be extremely serious if not fatal, accounting for over 10% of deaths in people with SCI [57]. While surgical options are available for treating osteomyelitis, failure rates are high and median survival time is limited to 7 years even after successful surgeries[58].

However, recent studies have highlighted micropore particle technology (MPPT) as a highly effective option to treat pressure injuries, achieving a 100% closure rate of acute and chronic wounds and controlling the risk of infection[59,60].

Psychological Challenges

Psychologically, SCI can have devastating effects and often triggers depression, anxiety, and social withdrawal [23]. 47% of people with SCI in the UK reported experiencing mental health problems [23], and 69% reported that their mental wellbeing was difficult to manage[17]. Depression, post-traumatic stress disorder, and suicidal ideation have all been shown to affect people with SCI more often than the general population, and to be deeply interconnected both with each other and with pain levels[61].

Depression and anxiety

Around 20%-40% of people with SCI also receive a depression diagnosis [62], and up to 30% have high levels of anxiety, which does not diminish within the first 2 years after injury [63]. Pain was reported as a contributing factor to depression and anxiety[23], as did low heart-rate variability

(HRV), suggesting a strong link between the physiological response to SCI and psychological repercussions[64]. Unfortunately, effective self-management interventions for pain and depression in people living with SCI are not yet fully understood, and there is a pressing need to develop new multi-faceted interventions to serve this population[65]. Importantly, a 2012 study evidenced the remarkable resilience of individuals with SCI in coping with anxiety and depression in the long term [66].

Post-traumatic stress disorder

Moreover, 14%-34% of individuals with SCI report post-traumatic stress disorder symptoms (PTSD)[67], with reported rates up to 60% in the US[68]. PTSD has also been reported to be interconnected with pain levels in the early months following SCI, and to be a predictor for chronic pain two years after injury, highlighting the importance of early interventions targeting both[69,70].

Self-harm

In 2021, 28% of people living with SCI reported having suicidal thoughts (compared to 8% in the general population) [23], with this figure rising to 39% in 2024[17]. Studies have also identified that suicide is 2-6 times more prevalent in people with SCI than in the general population[71], with up to 11% of deaths in people with SCI being due to suicide[72].

People living with SCI who experience suicidal thoughts have been shown to have poorer physical and mental health overall, as well as lower levels of social adaptation and functional status, which suggests that interventions tackling physical and mental health as well as quality of life might help reduce suicidal thoughts for the SCI community[73].

Appendix 2: Social Challenges for people living with SCI

Spinal Cord Injury also leads to a plethora of deeply interconnected social challenges, including employment problems, social isolation and loneliness, and accessibility issues[74].

Employment

Only between 30%-40% of people with a SCI in the UK are in employment[75], which compares unfavourably with other Northern European countries[76]. However, employment rates for people with SCI remain low across the world [77]. Moreover, recent research indicates that individuals with SCI who are in employment see an average reduction in earnings[76].

International research identified barriers to returning to work for people living with SCI included personal factors (personal support system, physical intensity of pre-injury work, social integration, independence in using transportation), healthcare factors (increased mobility, functional independence), and workplace factors (including workplace accessibility issues, benefits loss, availability of vocational training and job placement services)[78,79].

These figures are to be understood within a broader context of high unemployment rates among disabled people in the UK. In 2024, the disability employment rate was 53.0%, compared to 81.6% for non-disabled people[80].

Social isolation and loneliness

People living with SCI are at an increased risk of social isolation and loneliness [81]. Research has indicated that education on these issues and peer-to-peer support groups, together with individualized programs specifically targeting people with SCI might be important components to address social isolation during rehabilitation[82]. Research has also highlighted how employment and family relationships can, among another factors, mitigate social disconnectedness and perceived loneliness in individuals living with SCI[83]. For instance, 91% of people with SCI mentioned family connection as key to their mental wellbeing in a 2024 UK-wider report[17].

Research from the charity Back Up recently identified active involvement with the spinal cord injured community as an important factor in maintaining a good quality of life for people with SCI [84].

Accessibility issues

Individuals with SCI often face societal stigma and physical barriers that prevent full participation in community life. Reports highlight issues ranging from inaccessible public transport to fragmented care planning, all of which contribute to exclusion and loss of autonomy [85].

Accessing wheelchairs, medical care, equipment and living aids were among the top concerns for people with SCI [17]. For instance, 2017 research into the experiences of people with SCI who use a wheelchair has highlighted that the process of accessing a suitable wheelchair is often complex, financially burdensome, and very time consuming [86]. 39% of surveyed users reported paying for their wheelchair themselves, and 48% stated it took over a year to find a wheelchair that met their needs, with 7% of respondents indicating they have never been satisfied with their chair[86].

Accessible housing has also been identified as key to the health and well-being of people with SCI[87,88]. However, in 2020 it was reported that just under 2% of homes in England were built for wheelchair users[89], and only 9% of homes in England have basic accessibility features, including wide doorways, level access, and a bathroom at entrance level [90]. Additionally, struggle to adapt existing homes to be wheelchair accessible: currently, support to fund adaptations in England is limited to £30,000 (up to £36,000 in Wales and £25,000 in Scotland) through a Disabled Facilities Grant, although access to funding is often limited by the complexity of the process [91].

Accessing medical care and achieving wellbeing are a significant barriers for many people living with SCI. For instance, while physical activity has been highlighted as an essential part of recovery, people with SCI often facing significant barriers in accessing exercise or a therapist qualified to supervise exercise[92]. Additionally, a recent campaign from the Spinal Injuries Association has identified women's health as an area where SCI individuals encounter significant barriers to access, including limited access to breast cancer screening equipment, limited access to resources to support with sexual dysfunction, and inaccessible inspection platforms in GP surgeries [93].

Additional needs were identified for people living with SCI who can walk (up to 75% of those with an incomplete injury

[94]), with a specific focus on changing perceptions of the impact of an invisible disability and offering support for the increased levels of pain and fatigue that can be associated with walking after a SCI[95].

Appendix 3: Change Model

This draft change model sets out the vision, mission and strategic objectives put forth to inform the SCI Strategy, which we hope will be relevant to all of the UK's health systems. This explains how change is expected to happen through the following five strands of activity.

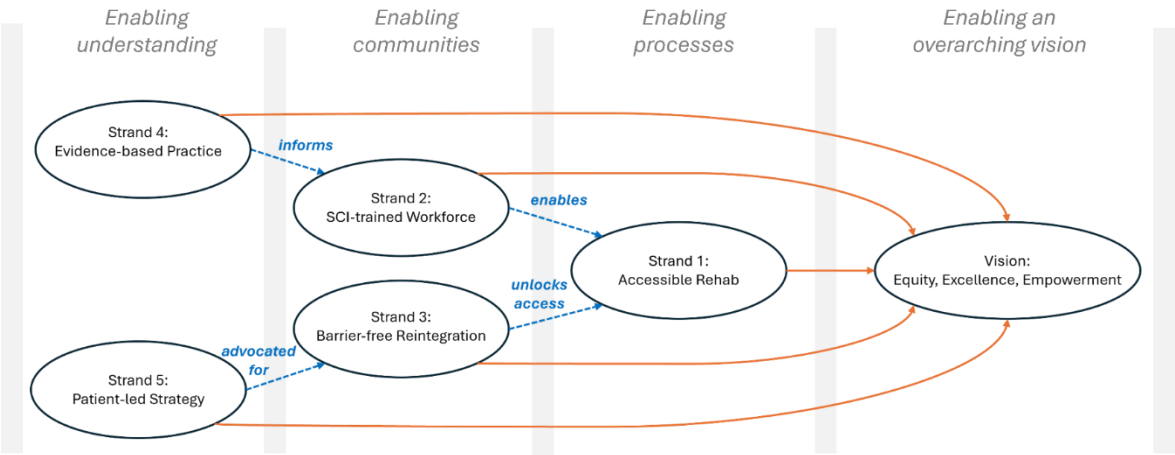
- **Strand 1 – Accessible Rehabilitation**: Derived from widespread feedback about inequitable access to timely, joined-up rehabilitation services post-injury.
- **Strand 2 – SCI-trained workforce**: Raised by both professionals and patients regarding inconsistent clinical knowledge and confidence across providers.
- **Strand 3 – Barrier-free reintegration**: Includes housing, transport, CHC, and discharge planning, identified as major systemic gaps in both survey responses.
- **Strand 4 – Evidence-based practice**: Recognised need to better use evidence, cost modelling (e.g. pressure ulcers), and innovation to inform policy.
- **Strand 5 – Patient-led strategy**: Strong emphasis across consultation on embedding lived experience in design, delivery, and accountability mechanisms.

These five strands were:

- Confirmed by the stakeholder survey (lived experience and SCI stakeholder versions)
- Framed in the UK Strategy Consultation Document.
- Translated into the Theory of Change and Logic Model format, to show how each contributes to long-term systemic change.

The following figure illustrates how each strand directly contributes towards the vision of achieving equity, excellence and empowerment for people with a SCI, but they vary in the change they enable and how they represent different pints in a broader interconnected pathway to system-level impact.

- Strands 4 & 5 are enabling change in understanding through the provision of evidence-based practices and patient-led strategies.
- Strands 2 & 3 'informed by' and 'advocated for' by strand 4 & 5 (respectively) are enabling change in communities.
- Strand 1 is 'enabled' and 'unlocked access' by strand 2 & 3 (respectively) enables change in processes.



Above: Theory of Change with vertical lines representing stages of enablement and dashed lines the relationship between the five strands: informing, advocating, enabling, and unlocking access.

Below: Explaining the interdependencies of the five strands.

From Strand	To Strand	Relationship	Rationale
Strand 4: Evidence-based Practice	Strand 2: SCI-trained Workforce	Informs	Ongoing SCI research informing the generation of clinical evidence ((Strand 4) informs training content and care standards for professionals (Strand 2).
Strand 5: Patient-led Strategy	Strand 3: Barriers-free Reintegration	Advocates for	Patient-led forums (Strand 5) advocates for lived experience by pushing for reforms in CHC, housing, and discharge processes targeted in Strand 3.
Strand 2: SCI-trained Workforce	Strand 1: Accessible Rehab	Enables	A skilled SCI-trained workforce (Strand 2) enables the delivery of timely, high-quality rehabilitation services as outlined in national standards (Strand 1).
Strand 3: Barrier-free Reintegration	Strand 1: Accessible Rehab	Unlocks access	Addressing transport, housing, and discharge barriers (Strand 3) unlocks access to improved physical and logistical access to rehabilitation services (Strand 1).

Feedback received via the two evidence cafés confirmed the legitimacy of the five strands and proposed the following three additions. These are not new strands. The first is a cross-cutting enabler of all five strands and the latter two are thematic sub-pathways:

- Data, metrics and infrastructure (cross-cutting enabler, especially in the case of research, training and rehabilitation). Participants called for national dashboards, an SCI registry (traumatic + non-traumatic), and integration with NHS digital reforms.
- Youth-to-adult transitions (sub-pathway to Strand 3 – Reintegration, as a transition-related risk). Highlighted gap, particularly in paediatric SCI care continuity — risk of lost support post-18.
- Centre accreditation (sub-pathway to Strand 2 – training and standards, expanded to include centre-level standards). UK "kitemark" scheme and benchmarking to address variation across the 11 SCI centres. Sit within Strand 2.

Taken together, the five strands and their interdependencies outline a clear and coordinated pathway toward system-wide transformation. They demonstrate how strategic enablers (e.g. data, training, lived experience) must work in tandem with service delivery reforms (e.g. rehabilitation access, social reintegration) to achieve long-term outcomes. What follows are a set of UK recommendations that build directly on these interdependencies. They are presented in the logical order in which they appear in the Theory of Change model above (from left to right). These explain the actionable steps that would be required to operationalise the change logic and address the most pressing gaps surfaced through consultation.