Minutes of the APPG for Spinal Injuries

Spinal Injuries APPG – Inquiry Session 3: Why Do We Need a National Strategy for Spinal Injuries?

Date: 16 June 2025
Location: Portcullis House, Westminster

Chair: Andy McDonald MP, Chair of the APPG for Spinal Cord Injuries

Co Chair: John Glen MP

1. Opening Remarks

Andy McDonald MP introduced the third session of the APPG Inquiry focused on systemic gaps, clinical failures, and the structural inadequacies in the current provision of care for people living with spinal cord injuries (SCI) in the UK.

2. Evidence from Witnesses

2.1 Alexander Rouse – Clinical Lead, London SCI Network

- Outlined a three tier approach to how to address a lack of knowledge around SCI within the NHS in order to keep people with SCI safe while in NHS settings.
- Shared the story of Steve, a ventilator-dependent SCI patient discharged with the aim of spending Christmas at home. He later died from pneumonia following multiple failings in general hospital care, including:
    - Extended delays in A&E.
    - Lack of specialist input.
    - Absence of trained carers and appropriate equipment.
- His case highlights:
    - Dangerous gaps in post-discharge care.
    - Inadequate training in non-specialist settings.
    - A lack of coordination between local hospitals and SCI centres.

Key Quote: “If you don't do the first episode of care properly, the cost—financially and in human terms—grows exponentially over the patient’s lifetime.”

2.2 Carol Adcock – Spinal Injuries Association

- Addressed the lack of training and knowledge within general nursing practice and the lack of hospital policies around SCI care.
- Emphasised that Steve's story is not an isolated case.
- General hospitals frequently:
    - Refuse to seek help from SCI centres or SIA.
    - Demonstrate dangerous knowledge gaps in managing SCI patients.
    - Rely on outdated, generic practices.
- SIA must often advocate to even secure basic, safe care for individuals.

Key Concern: "Staff sometimes say, 'We don't do that here, we're not allowed,' when it comes to spinal-specific care."

2.3 Dr. Ali Jamous – President, ISCoS (International Spinal Cord Society)

- Expressed concern over declining engagement of spinal centres post-discharge.
- Described how SCI centres have been marginalised by trusts due to financial pressure or misaligned priorities.
- Noted a critical breakdown in:
    - Cross-service coordination (GPs, ambulances, hospitals).
    - Response from spinal centres to patients/families.

Key Insight: "Spinal injury centres need to take responsibility. When patients and NHS professionals stop calling, it's often because no one answered in the past."

- Highlighted the fragmented and inefficient geography of spinal centres:
    - No strategic rationale behind the current distribution.
    - Beds cut without alternatives being created.
    - Delays to admission now average 95 days.
- Stressed the harm caused by reduced training and removal of specialist spinal education programmes:
    - Junior doctors no longer rotate through SCI centres.
    - SCI increasingly misclassified as general rehabilitation.

2.4 ISCoS SCI Toolkit Launch

- ISCoS is launching a **Spinal Cord Injury Toolkit** in Gothenburg in 2025.
- It provides:
    - Clinical and organisational standards.
    - Policy, finance, and workforce planning guidance.
    - A continuous quality improvement cycle adaptable to national and local needs.

- Toolkit is free, co-designed with people with lived experience, and includes:
    - Implementation support via trained international experts.

Recommendation: The UK should **adopt the ISCoS Toolkit** to form the foundation of a National SCI Strategy.

2.5 John Glen MP

- Reflected on his experience in HM Treasury:
    - Identified **lack of accountability** as a central issue.
    - Policies are often conflicting, with no single empowered leader.
- Challenged the cultural norm of resisting external input in hospitals.
- Advocated for:
    - Referral systems based on specialist expertise.
    - Strategic reconfiguration of spinal centres using **clinical evidence**, not **political pressures**.

2.6 Further Testimony: Funding, Planning, and Service Integration

- **Ali Jamous:**
    - Expressed frustration with trust executives diverting SCI funds to cover deficits.
    - Called for a **national spinal register** (similar to head injury) to inform planning and accountability.
    - Emphasised co-location with trauma centres—currently rare but effective.
- **Carol Adcock:**
    - Explained how SCI centres are moved between directorates depending on trust deficits.
    - Training budgets are minimal and consumed by mandatory training (e.g., fire safety), leaving no room for spinal-specific education.
- **Alexander Rouse:**
    - Asserted that spinal centres are not just buildings—they represent unique expertise and interdisciplinary care.
    - Emphasised that rigid mapping or centralisation can damage continuity of care if not grounded in clinical logic.
- **John Glen MP:**
    - Stressed the need for strong leadership and evidence-based decision-making.
    - Political resistance to centre consolidation must be overcome.

3. Key Outcomes

Theme	Findings
Patient Safety	Serious and repeated failures in non-specialist hospitals lead to preventable harm and death.
Coordination	Spinal centres, GPs, ambulances, and hospitals often operate in silos with poor communication.
Funding & Capacity	Budgets for SCI care are raided by trusts, and bed cuts are made without compensating increases elsewhere.
Training Gaps	Specialist training is underfunded and deprioritised. Junior clinicians lack exposure to SCI-specific care.
Data Deficits	Absence of a national SCI register obstructs planning, policy, and service evaluation.
System Design	Centre locations are often historically or politically determined, not clinically justified.
Toolkit & Reform	The ISCoS Toolkit offers a ready-to-implement, evidence-based framework for national reform.

4. Recommendations

National Strategy & System Reform

- Establish a **National SCI Strategy** based on the ISCoS Toolkit.
- Create a **national SCI register**, mandated across NHS trusts.
- Conduct a strategic review of spinal centre distribution, including:
    - Consolidation based on trauma centre co-location.
    - National population needs.
    - Minimum standard access times.

Funding & Accountability

- Ringfence budgets for SCI within trusts.
- Stop SCI funding being absorbed into unrelated deficit management.
- Ensure clear leadership structures and ministerial accountability for SCI care.

Workforce & Training

- Restore spinal injury training rotations for junior doctors and nurses.
- Fund **SCI-specific education programmes**, including dedicated fellowships.
- Protect training budgets for low-incidence, high-need conditions.

Service Coordination

- Ensure automatic referral pathways to SCI centres for community and hospital providers.
- Promote cultural change within general hospitals to respect SCI expertise.

- Ensure post-discharge patients are proactively followed up by spinal centres.

Monitoring & Quality Improvement

- Adopt the **ISCOS Toolkit** as a national quality standard.
- Establish a framework for service audit, evaluation, and continuous improvement across all SCI centres.
- Include people with lived experience in service co-design and monitoring.

5. Closing Remarks

Andy McDonald MP (Chair):

- Expressed thanks to all participants.
- Acknowledged the informal but deeply informative tone of the session.
- Committed to developing strong, clear recommendations for ministers based on this evidence.

“Poor practice is expensive. Good care saves money, and more importantly, lives. The need for a national spinal strategy is now undeniable.”

Next Steps

- Further sessions to hear from additional stakeholders.
- Consolidation of findings into an APPG report.
- Development of formal recommendations to government.

Minutes prepared by the APPG Secretariat