

Setting the SCI agenda in Europe

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Background

An information-gathering project carried out among the European Spinal Cord Injury Federation member countries in 2006 – 2007 inspired the formulation of the ESCIF policy statement that calls for:

1. the establishment of compatible SCI registers in all European countries
2. the promotion of SCI centres of excellence
3. the integration of peer-counselling and peer-support services in rehabilitation
4. proactive support for families of persons with SCI

Four ESCIF policy working groups have been investigating the current situation and practice and formulating benchmarking guidelines and recommendations for "best practice" in each of the four areas – **from the perspective of the consumer.**

1. The member organisations of ESCIF agree that regional and/or national registers should be established in all European countries

Benefits of SCI registers for persons with SCI	Comparable, accurate, and accessible statistics will:
Benefits in finance and monitoring	1. Facilitate and improve the allocation of resources for treatment, rehabilitation and research, as well as for mobility aids, transport, home adaptations etc. 2. Facilitate comparison of national policy and political interventions. 3. Enable an evidence-based social and health policy by monitoring the consequences of political decisions and their effect on outcomes.
Social benefits	Reveal the extent of unmet needs in both the health and social sectors.
Funding benefits	Lead to increased visibility making it easier to get funding for research, medical and clinical facilities, as well as financial support for the SCI organisations.
Research benefits	Overcome the problems of small national samples and provide statistically reliable results.
Clinical benefits	1. Provide a tool that will ensure uniformity of the patient information gathered by the centres during rehabilitation and follow-up. 2. Allow comparison of e.g. rehabilitation outcomes, medical and surgical interventions within and between countries.
Political benefits	Help organisations to target their political activities, lobbying and campaign work more effectively.
Prevention	Enable governments and organisations to channel efforts to prevent/reduce the incidence of SCI based on reliable figures on the demographic and geographical distribution of SCI and its causes.

The group has studied existing registers in Europe and elsewhere (Table 1)

The group is currently working to identify:

- **what** information should be included in an accessible national register
 - **how** this data can be gathered in a clinical setting without creating an overload of administrative tasks.
- One major consideration is how a national register could be aligned with the SCI data sets.

2. ESCIF will work to promote the centralisation of treatment, rehabilitation and life-long care of persons with SCI and the creation of dedicated centres of excellence

Tables 2 and 3 show the response from member organisations to the ESCIF questionnaire in 2007 regarding destinations of acute SCI patients and their primary rehabilitation. It is apparent from the tables that the acute treatment and rehabilitation of persons with SCI differs widely from country to country. Provision for follow-up care is even more erratic.

The ESCIF policy statement outlines the underlying arguments for a centralised SCI treatment, rehabilitation and care system. Centres of excellence can provide a centre and focus not only for treatment and care, but also for research, training of personnel, information and support for persons with SCI and their families, family doctors, local hospitals etc.

The group recognises that geographic features will play a role in the logistics of treatment, rehabilitation and care of persons with SCI. It has considered the issue of "critical mass" which is an accepted parameter in other specialisations. Its current recommendation is: **quality over distance!** A major task is to recommend solutions to the problems of follow-up care.

The intermediate report from the working group emphasises that the reintegration of persons who sustain a spinal cord injury into the community can only be achieved by:

"A seamless approach ... to address the medical, vocational, social and community effects of SCI. It is not enough to train people to dress and manage their bowel, bladder and skin care and transfers to and from the wheelchair. We have to give people a reason for applying these skills."

Such a holistic, coordinated approach to rehabilitation can best be achieved in a centralised system.

3. + 4. Peer-support and proactive support for families

These two groups are working to create a "tool-box" of current practices, ideas and recommendations for support models and activities designed to inspire the national organisations and national healthcare authorities. A crucial point is that such activities need ongoing funding. The proposals will be presented at the next ESCIF congress at Stoke Mandeville in May 2010.

Next steps ...

ESCIF is fully aware that its recommendations will benefit from a close collaboration with SCI healthcare professionals in Europe. We would like to open the discussion to include researchers, therapists and medical personnel. Working together, we can create a pan-European platform from which we can exert pressure on the healthcare authorities in each country.

If you have comments, proposals, or criticisms – input of any kind – and would like to contribute to or be kept up-to-date with this work, please contact the project coordinator, Jane Horsewell, at vice-president@escif.org.

Please visit www.escif.org to read more about ESCIF and its activities, to read the report from the information gathering project and the ESCIF policy statement.

The four working groups include representatives from the following European countries:



Table 1. SCI registers in ESCIF countries: 2009¹

Country	Nat. register	No register	Shared
Austria		✓	
Belgium		✓	
Bosnia-Herz.		✓	
Croatia	✓		
Denmark		✓	
England		✓	
Finland		✓	
Germany	✓		
Ireland	✓		
Italy		✓	
Lithuania		✓	
Montenegro		✓	
Netherlands		✓	
Portugal		✓	
Rumania	✓ ²		
Scotland	✓		
Slovenia	✓		
Spain		✓	
Sweden			✓ ³
Switzerland		✓	

1. In some countries (e.g. Denmark and Spain) the rehabilitation units keep patient databases
2. Rumania has devised an SCI database but currently has problems with data-protection issues
3. Sweden forms part of the Nordic Spinal Cord Registry – with Norway

Table 2. Acute care – destinations of new SCI patients with estimated % (where given)

Country	Specialised hospital	SCI unit or ward	Neurosurg. ward	Trauma ward	Non – spec. ward
Austria			✓	✓	
Belgium		60		20	20
Croatia	✓		✓	✓	
Denmark		✓	✓		
Finland			50	50	
Germany		80	5	15	
Ireland	100				
Italy		50	25	25	
Netherlands				✓	
Portugal		✓			
Scotland	✓		✓	✓	
Slovenia	✓	✓		✓	
Spain	40	15	10	10	25
Sweden		✓		✓	
Switzerland	50	25	25	✓	✓
England & Wales	✓	✓	✓	✓	

Table 3. Primary rehabilitation of SCI patients with estimated % and no. of beds (where given)

Country	Specialised SCI hospital (1)	SCI unit or ward in gen hospital	SCI rehab centre (2)	Generalist rehab unit	Beds available in 1 or 2
Austria			85%	15%	180
Belgium		60%		40%	126
Croatia			90%	10%	35
Denmark			90%	10%	67
Finland			60%	40%	43
Germany	✓	✓	✓	✓	?
Ireland	100%				50
Italy		50%	25%	25%	500
Netherlands			✓	✓	?
Portugal	✓		✓	✓	?
Scotland	✓			✓	48
Slovenia			99%	1%	70
Spain	✓	✓	✓	✓	650
Sweden		✓	✓	✓	?
Switzerland	60%	35%	5%		235
England & Wales	75%	✓	✓	✓	400

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