



UEMS PRM Section & Board

Clinical Affairs Committee

New accreditation procedure

Programme No 4

PRM Programme for patients with Spinal Cord Injury

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Content

I. IDENTIFYING DATA.....	3
II. SUMMARY	4
III. GENERAL FOUNDATIONS OF THE PROGRAMME	5
A. PATHOLOGICAL AND IMPAIRMENT CONSIDERATIONS	5
1. <i>Aetiology and pathogeny</i>	5
2. <i>Natural history and relationship to impairment</i>	5
3. <i>Medical diagnosis and prognosis</i>	6
4. <i>Treatments</i>	7
B. ACTIVITY LIMITATIONS.....	7
C. PARTICIPATION RESTRICTIONS	7
D. SOCIAL AND ECONOMIC CONSEQUENCES	7
1. <i>Epidemiological data</i>	7
2. <i>Social data</i>	8
3. <i>Economic data</i>	8
E. MAIN PRINCIPLES OF YOUR PROGRAMME	9
IV. AIMS AND GOALS OF THE PROGRAMME.....	10
A. TARGET POPULATION	10
1. <i>Inclusion/exclusion criteria</i>	10
2. <i>Referral of patients</i>	10
3. <i>Stage of recovery</i>	10
B. GOALS OF THE PROGRAMME	10
1. <i>In terms of body structure and function</i>	10
2. <i>In terms of activity</i>	11

3.	<i>In terms of participation</i>	11
V.	ENVIRONMENT OF THE PROGRAMME	12
A.	CLINICAL SETTING	12
B.	CLINICAL PROGRAMME	12
C.	CLINICAL APPROACH	13
D.	FACILITIES	13
VI.	SAFETY AND PATIENT RIGHTS	14
A.	SAFETY	14
B.	PATIENT RIGHTS	14
C.	ADVOCACY	15
VII.	PRM SPECIALISTS AND TEAM MANAGEMENT	16
A.	PRM SPECIALISTS IN THE PROGRAMME	16
B.	TEAM MANAGEMENT	16
VIII.	DESCRIPTION OF THE PROGRAMME	18
A.	ASSESSMENT	18
1.	<i>Diagnosis (related to ICD)</i>	18
2.	<i>Impairment</i>	18
3.	<i>Activity and participation</i>	19
4.	<i>Environmental and personal factors</i>	19
B.	INTERVENTION	19
1.	<i>Time frame of the programme</i>	19
2.	<i>PRM specialist intervention</i>	19
3.	<i>Team intervention</i>	19
C.	FOLLOW UP AND OUTCOME	20
1.	<i>Review and progress through the programme</i>	20
2.	<i>Criteria for progress measurements</i>	20
D.	DISCHARGE PLANNING AND LONG TERM FOLLOW UP	20
IX.	INFORMATION MANAGEMENT	22
A.	PATIENT RECORDS	22
B.	MANAGEMENT INFORMATION	22
C.	PROGRAMME MONITORING AND OUTCOMES	22
X.	QUALITY IMPROVEMENT	24
A.	WHICH ARE THE MOST POSITIVE POINTS OF YOUR PROGRAMME ?	24
B.	WHICH ARE THE WEAK POINTS OF YOUR PROGRAMME ?	24
C.	WHICH ACTION PLAN DO YOU INTEND TO IMPLEMENT IN ORDER TO IMPROVE YOUR PROGRAMME? .	24
1.	<i>Extrinsic improvements</i>	24
2.	<i>Intrinsic improvements</i>	24
XI.	REFERENCES	25
A.	LIST OF REFERENCES	25
B.	DETAILS ABOUT NATIONAL DOCUMENTS	26

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II. Summary

Spinal Cord Injury (SCI) is a complex and catastrophic injury, difficult to treat with devastating medical, social, emotional, psychological, financial and economic consequences affecting not only the patient, but also his/her partner, family members, friends, employer and the community in general (1). These effects can however be alleviated by multidisciplinary and dedicated approach of experienced team in spinal centres.

Spinal Unit of Special Medical Rehabilitation Hospital in Varazdinske Toplice is the national rehabilitation centre for spinal injured patients, admitting almost all patients with traumatic and the majority of non-traumatic SCI patients, extending its services and co-operation to all major surgical departments in the country, and conducting research (2-4). It has been certified as a Training Centre by the UEMS PRM Board and is carrying on educational activities for all profiles of medical staff on the national level. In Croatia, a country of 4.2 million inhabitants (5,6), a single spinal centre is sufficient for these needs.

Patients are admitted early after surgical management and stabilisation, which is within two weeks post-injury for paraplegics and within one month for tetraplegic patients, unless respiratory unstable or ventilated, or with serious co-morbidity.

Multiprofessional team approach includes understanding of each others' professional languages, learning about the patient's impaired and dynamic pathophysiology, familiarising with the presentation of symptoms and signs in the sensory impaired patient, understanding the reasons and importance of a holistic multidisciplinary approach and management, and understanding the real needs of the patient and varying priorities at different times after injury. The team consists of PRM physicians, nurses, physical therapists, occupational therapists, psychologist, speech therapist and other team members as necessary, e.g. urologist, neurologist, and kinesiologist (committed to sports for disabled people).

The focus of the programme is the simultaneous treatment of fractured spine and multi-system dysfunction, together with the rehabilitation of all the malfunctioning systems of the body and the simultaneous attention of the non medical effects on the patient/partner/family members. Although initially impairment of body functions and structures are in focus, the main concern then becomes centered on activity limitations and participation restriction along the course of rehabilitation, which may last from 3 – 6 months, depending of the level and completeness of injury, as well as co-morbidity and complications. The adequate management of all the body systems affected by the paralysis results in near normal functioning, minimising morbidity, mortality, hospitalization and costs, while maximising health, quality of life and productivity of the individual.

The unit performs **follow up assessment** of the individual with spinal cord injury, which is likely to result in: early diagnosis of inevitable complications of which the patient may not be aware due to the loss of feeling, early treatment of such complication before morbidity sets in, and minimal disruption to the life of the patient. Furthermore, these follow up assessments are frequently a good way to prevent avoidable complications caused by faulty equipment or disturbed psycho-social environment, thus reducing costs of treatment and enhancing quality of outcomes in the short and long terms. We use the ASIA impairment scale, the Standard Neurological Classification of Spinal Cord injury and the Barthel index of functionality. They are followed by specific assessments for: 1) the bladder function including a systematic urological screening with ultrasound, completed with urodynamics for selected patients; 2) the bowel function; 3) walking and transfer activities (WISCI, parts of SCIM) and 4) performance in daily activities.

III. General foundations of the Programme

A. PATHOLOGICAL AND IMPAIRMENT CONSIDERATIONS

1. *Aetiology and pathogeny*

The mechanism of spinal injury may consist of hyperflexion, hyperextension, rotation, luxation, or combined forces with direct immediate damage to the cord especially in high velocity trauma such as motor vehicle accidents or gunshot injuries. Immediate lesions of the nervous tissue can be followed by secondary damage due to oedema and anoxia of the spinal cord. The degree of motor and/or sensory loss is determined by the location and severity of the cord damage, producing anterior, posterior, central spinal cord injury, Brown-Sequard syndrome, or conus and cauda equina (horse-tail) syndromes.

The spinal cord may also be affected by non-traumatic events such as vascular injuries, tumours, infections, acquired degenerative narrowing of the spinal canal, disc herniation, multiple sclerosis and similar neurological diseases.

Along with the assessment of neurologic lesions, it is important in the case of a trauma to evaluate: i. the spine instability, involving bone fractures as well as disc and ligament tears; ii. the possibility of a double injury; iii., e other injuries to the body from head and brain injury, extra-vertebral fractures and visceral lesions..

Bradycardia and hypotension are indicative of spinal cord injury and may direct ways of acute and rehabilitative management of patients. Impaired sympathetic system and unopposed vagal stimulation cannot cope with excessive fluid input or early verticalization, which both may further destabilize already a vulnerable spinal cord injured site.

2. *Natural history and relationship to impairment*

The neurological level of injury is defined by the most distal level where key muscles are graded with 3/5, provided that the proximally adjacent group of muscle is graded 5/5.

Functional residual ability can be better predicted by the manual testing of 10 key muscles on each side of the body. The neurological examination between 72 hours and 1 week following injury may predict neurological and functional recovery.

Recovery prognosis - Subject to physiological and biomechanical stability, the majority of patients with motor or at least sacral sparing 72 hours following the injury will regain motor power sufficient to walk again. Patients with complete injury have about 10% chances of recovery. Further recovery may be expected within the zone of partial preservation, especially if the fracture level is below the neurological level of lesion and in non-functioning myotomes with existent pin-prick sensation.

The functional capacity of the patient is very dependant on the metameric level of the tetra/paraplegia:

- In high complete tetraplegia (C1-C4) patients have little or no movement of their upper extremity, besides movement of head and neck, and possibly shoulder shrug. While a C4 tetraplegic person may not require long-term mechanical ventilatory support, patients with C1-C3 injuries are likely to need it, because of the loss of innervation to the diaphragm. The physiological status of all this group of patients is insecure and they require total and permanent assistance..
- Patients with C5 and C6 tetraplegia remain with active elbow flexion (and wrist extension with tenodesis action in C6) enabling the use of assistive devices in feeding and grooming, and some activities in upper extremity dressing. Both may

1 use manual wheelchairs with grip enhancements, but also power wheelchair for
 2 long distances and uneven surfaces. For dressing, transfer mobility, bowel and
 3 bladder management these patients require assistance, although some individuals
 4 with C6 injury may function independently, even in driving adapted vehicles.

- 5 • Patients with C7 extend their elbows. With the use of assistive devices, they may
 6 achieve independence in feeding, dressing, bathing and grooming, bed mobility,
 7 transfers and community manual wheelchair propulsion (besides very uneven
 8 surfaces as curbs). Male patients may achieve independence in bladder
 9 management, while female may need help for intermittent catheterisation. Patients
 10 may use computers and phones, which opens vocational perspective for them.

- 11 • Patients with C8 tetraplegia have also good hand grasp and release function, for
 12 complete self-care and independent driving of adapted vehicles.

- 13 • Individuals with thoracic or lumbar neurological level of injury regain potential for
 14 independent activities of daily-living including advanced transfer skills (e.g. from the
 15 floor to the wheelchair) and community skills. Patients with lower thoracic and
 16 lumbar injury may stand by using bilateral HKAFO or KAFO orthoses and crutches
 17 and even become community ambulators. Increased ambulatory potential starts
 18 with T11 neurological level of injury, while for community ambulation functional hip
 19 flexion and knee extension should be present as in L2 and L3 injury.

20 **Incomplete patients** may benefit from body-weight supported treadmill training, while
 21 functional electrical stimulation may help to both complete and incomplete patients in
 22 achieving ventilation, tasks in self-care activities or ambulation. Tendon transfer surgery
 23 may promote one more distal level.

24 **Spasticity** may sometimes benefit to some daily routines (e.g. turning, standing). But for a
 25 majority of patients, increased spasticity alters daily activities and/or can lead to further
 26 complications including skin abrasion, pressure sore, infection, bone dislocation and
 27 fractures.

28 **Pressure sores** result from inadequate medical management or, later-on self-care. They
 29 also present significant vital risk if not properly treated, conservatively and/or surgically.

30 **Bladder dysfunction** endangers the patients' life since it threatens the upper urinary tract.
 31 Its good management is vital, but also an important condition of the patient's quality of life.

32 **Early bowel managements** has a similar impact on the patient's health and comfort.

33 **SCI-induced osteoporosis** is multifactorial. Its prevention is necessary to avoid
 34 pathological fractures.

35 **Haemodynamic instability and vegetative** disturbances are mainly observed in
 36 tetraplegic and high paraplegic patients.

37 **3. Medical diagnosis and prognosis**

38 **Patients with acute SCI in transferred to regional SCI specialized surgical centres.**
 39 Assessments include radiography (x-ray, MRI, CT) of the spine, assessment of
 40 cardiovascular and respiratory system, abdomen including bladder and urinary system,
 41 assessment of level of consciousness and psychosocial assessment of cognitive functions.

42 **Diagnosis of level and completeness of lesion** is made according to ASIA (American
 43 Spinal Injuries Association) impairment scale (7). Decision on surgical or conservative
 44 management depends on the degree of spine instability and progression of neurological
 45 impairment, which must be regularly repeated.

46 **Prognostic indicators** relate to the ASIA scale for the completeness of injury whereas
 47 complete injury remains complete in 96% of patients, while incomplete patients usually
 48 improve to a great extent so two thirds of them are able to ambulate at the end of
 49 rehabilitation period. Both groups of patients are in need of focused rehabilitation efforts, to
 50 compensate for lost functionality and overcome limitations imposed by impairments.

4. *Treatments*

Intensive care of SCI patients includes ensuring biomechanical and physiological stability to save the remaining spinal fibres and prevent and cure early complications. In cases of traumatic SCI, NASCIS II scheme is used (8). Surgical management unfortunately prevails to the active physiological conservative management in Croatia, where major concern of surgeons is biomechanical stability, while exposing injured cord to further disturbances as hypoxia, hypotension, hypertension, hypothermia etc. during surgery, which may be potentially as damaging to the cord as was the injury itself. There is no evidence that surgical decompression achieves better or earlier neurological recovery than conservative management in humans with incomplete injury; or that the surgery is any more beneficial to humans with complete traumatic injury (9).

Expert and early simultaneous conservative management can minimise both the short and long-term impact of the injury on the patient and family members.

B. ACTIVITY LIMITATIONS

Activity prognosis according to Neurological status and other factors has been described above in chapter A2.

SCI patients are presented with paralysis of trunk and limbs, vegetative and immunological dysfunction rendering them susceptible to infections, disturbances of eliminatory functions, anaesthesia endangering skin integrity and easily leading to pressure sores, reactive depressive state, if not properly treated with increased morbidity and mortality. They are unable to move by themselves, needing help for turning in bed, sitting, transferring to wheelchair, eating and grooming, if arm and hand functions are impaired as are in tetraplegic patients. Patients, in majority of cases young people are becoming totally disabled and dependent of others for the simplest of human needs and to survive.

This loss of control of primary body functions needs to be compensated first, so the programme can address more complex issues of activities and participation. Some limitation of activities would definitely restrict some participation potential and realisation (e.g. in professional life), while others may be overcome by careful choice of methods and equipment used in rehabilitation.

C. PARTICIPATION RESTRICTIONS

Spinal cord injury profoundly affects every role of the patient's premorbid life – the more complete and proximal the level of injury is, the more disturbed are these functions. Difficulties leading to restriction of participation are visible in all ages and both sexes. Younger individuals have difficulties in completing educational efforts not only because of some physical barriers but also because sometimes the whole purpose and the direction of their education have to be redefined or completely altered.

This is extremely difficult in patients and relatives who don't easily accept the reality of the injury and paralysis. Many years may be wasted in futile attempts to improve the neurological status, instead of undergoing career change and adequate education.

Participation in professional life may be aggravated in low-educated patients with no potential to re-qualify for suitable sitting job; they lose their job and end up in early retirement, losing their supportive role for themselves and their families. Besides this vocational restriction, keeping other social involvement and hobbies becomes complicated since most of the available time is consumed for the patient's medical needs.

D. SOCIAL AND ECONOMIC CONSEQUENCES

1. *Epidemiological data*

1 **Spinal Unit of the Special Hospital for Medical Rehabilitation in Varaždinske Toplice**
2 has conducted medical rehabilitation of SCI patients for decades. Since 1991, a computer
3 follow-up and database register of that population have been introduced.

4 **The overall incidence of traumatic SCI is approximately 100 new cases per year.**
5 Incidence during the war years (1991-1995) increased up to 30/million in Croatia. It is now
6 20/million for surviving traumatic SCI admitted for rehabilitation into the Spinal Unit. Eighty
7 percent of patients are male in young adulthood (10,11). In Croatia, a south-eastern
8 European country with 4.2 million inhabitants, with diverse landscape and increasing traffic,
9 road traffic accidents account for approximately 40% of all traumatic SCI. With 1.3 million
10 registered vehicles (roughly 1 per every 3 persons) and the incidence of 13 deaths in
11 traffic/100.000 inhabitants, Croatia is within the limits of European Union statistics (5). The
12 rest of traumatic cases includes falls, diving or sports accidents, acts of violence or work-
13 related injuries.

14 **An equal or perhaps even higher numbers of non-traumatic SCI cases** in need of
15 rehabilitation services should be added, even though their referral to our centre is not as
16 systematic as for traumatic SCI. They include spinal cord neoplasm and infarction and
17 excluding progressive neurological diseases e.g. multiple sclerosis, amyotrophic lateral
18 sclerosis and such. Even some patients with cancer-related SCI may benefit from PRM
19 programme of care, to be assessed and prescribed with rehabilitation aids, started with PT
20 and OT programme and continued by home-base physical therapy. These programmes are
21 usually shorter in length of stay than average.

22 Some respiratory compromised patients (e.g. in neurological level of injury of C3 and
23 above) may not be admitted to our spinal centre. Unfortunately, there is no dedicated place
24 for rehabilitation of ventilatory-dependent SCI patients in Croatia. Those patients undergo a
25 limited rehabilitation through a long-term surgical management in intensive care units.
26 Eventually, they receive mobile ventilators to be transferred to their homes, if they survive
27 up to that stage.

28 We used to care for children with SCI in the past. But the contract between our Spine
29 Centre and the Croatian Institute of Health Insurance has recently changed and now
30 children with newly acquired SCI are rehabilitated in another centre.

31 There is no clear indication of the **prevalence of SCI in Croatia**, but regarding available
32 data from the US model systems (12,13), approximately 3500 SCI people may live in
33 Croatia today and they will need special PRM services throughout their life-time.

34 **2. Social data**

35 Spinal cord injury patients originate from all parts of the society, although predominantly
36 affecting younger male individuals, who have not finished their education yet and/or started
37 to work. Only half of the patients are married at the time of injury and that contributes even
38 more to the social aspect of the injury. Older patients, likely to suffer from SCI after a fall,
39 need assistants or home adjustments, which is costly to them and the health system,
40 especially if their salaries or incomes are low.

41 Therefore spinal injury is not only a medical but in some cases also a social issue, and
42 Centres for Social Welfare are called upon to take care of them. In Croatia, these centres
43 are obliged to resolve these issues if the patient has neither family nor personal resources.
44 A legal tutor is being appointed by the court (anyone of the family, if available; or the Centre
45 itself). The patient's property (if any) is transferred for compensation to the institution which
46 provides care to him/her.

47 Yet, a majority of patients are discharged to a private residence. There is no apparent
48 relationship between the severity of injury and nursing home admission. Indeed, admission
49 may be caused by other factors (i.e. family cannot take care of person, medical
50 complications, etc.) Nursing home admission is more common among elderly persons.

51 **3. Economic data**

52 Spinal cord injury is a great economic burden to the family and society. Data from The
53 University of Alabama National Spinal Cord Injury Statistical Center of March 2002 claimed

1 an initial hospitalization costs following injury of \$140.000 average; first year expenses for a
 2 SCI injury (all groups) of \$198.000; first year expenses for paraplegics of \$152.000, first
 3 year expenses for tetraplegics of \$417.000; average lifetime costs for paraplegics at age of
 4 injury of 25: \$428.000; average lifetime costs for tetraplegics at age of injury of 25: \$1.35
 5 million. The percentage of SCI people unemployed eight years after injury was 63% (12).
 6 Compensations for loss of future earnings, handicap, pain etc. which may be found eligible
 7 in the court may add to these figures.

8 Croatia does not keep statistics on expenses of SCI patients.

10 E. MAIN PRINCIPLES OF YOUR PROGRAMME

11 All Croatian patients are transferred for rehabilitation to the Spinal Unit of the Special
 12 Medical Rehabilitation Hospital in Varazdinske Toplice within the already mentioned time
 13 frame.

14 **Treatments** include multiprofessional team approach in Spinal Unit from the day of
 15 admittance. The patient is seen by PRM specialist who addresses the neurological, multi-
 16 system and functional issues and leads the total management of the patient. Physical
 17 therapists use means of physical / kinesiotherapy in the gym and in the pool to prevent
 18 range of motion limitations, improve balance and stability, verticalisation and ambulation,
 19 while analgesic electrotherapy and sometimes peloids (mudpacks) may be used. The use
 20 of bio-feed-back and isokinetic exercise (subject to additional payment) represent added
 21 value to the programme. Occupational therapists improve posture, transfer, activities of
 22 daily living and functioning; evaluate equipment (e.g. wheelchairs, hand splints and
 23 orthoses) and housing. All treatments should have ICF in mind and addressing not only
 24 body functions and structures but also the limitation of activities and restriction of
 25 participation. Nurses are assessing and treating eliminatory functions, bladder and bowel
 26 management, skin integrity and adequate diet in early catabolic stage of the injury.
 27 Intermittent catheterisation is a golden standard for neurogenic bladder management and
 28 the patient who is ready and willing to learn can be sufficiently educated in self-
 29 catheterisation within several days. Psychologist is providing evaluation and psychological
 30 support to every patient and his/her family, with emphasise given to the patients whose
 31 injuries are results of suicide attempts and/or are already known to have history of
 32 psychosis or drug addiction.

33 **Body functions** which are dealt with are: Skin protection – pressure sores care, urinary
 34 safety: to save the upper tract, to prevent retention, to control bladder emptying; digestive
 35 control; respiratory function; locomotor function: sitting, standing, and walking; osteoporosis
 36 and fracture prevention.

37 **Activity restoration** to deal with includes transfers, movements, sphincter control.

38 **Participation restoration** include re-establishing of family and friends network, return
 39 back to home and job, leisure activities.

41 **Goals**

42 Main goals of the programme are return of the patient to productive life, diminishing sequels
 43 of neurological injury and improvement of functional abilities, so the patients stays as
 44 healthy as possible, and that avoidable complications are being prevented.

46 **Operative mode**

47 The programme is being defined in multiprofessional team organized under supervision of
 48 PRM physician, providing medical, psychological, partially social and professional
 49 rehabilitation. Short and long-term goals are discussed on daily and weekly basis.

IV. Aims and goals of the Programme

A. TARGET POPULATION

1. *Inclusion/exclusion criteria*

Inclusion criteria – patients who have sustained spinal cord injury or disease resulting in complete or incomplete para/tetraplegia.

2. *Referral of patients*

Direct access to the PRM programme	No
Referral from general practitioners	Yes
Referral from other specialists	Yes
Referral from specialists in PRM	Yes

Inpatients are referred from PRM physicians, vertebral surgeons, neurosurgeons, orthopaedic surgeons or neurologists in acute care facilities. Inpatients admitted for check-up are referred by PRM physicians, surgeons or neurologists through their general practitioners. Patients may be referred as outpatients through their general practitioners.

3. *Stage of recovery*

Within two weeks of onset	Yes
2 weeks to 3 months after onset	Yes/No
3 months or longer after onset	Yes/No

Patients who are ventilatory independent and stable are being transferred to Spinal Unit within 2 weeks of injury/disease leading to SCI. Patients with co-morbidity or who are ventilator dependent may need more time. Early interventions within their respective intensive care units (e.g. respiratory, weaning, early bladder and bowel management) are managed by referring hospitals PRM staff.

B. GOALS OF THE PROGRAMME

1. *In terms of body structure and function*

ICF code	ICF label
s1200	Structure of spinal cord
b760	Control of voluntary movement functions
b755	Involuntary movement reaction functions
b730-b749	Muscle functions
b710-b729	Functions of the joints and bones

The main goals of the programme, with respect to body structure and function, are to maintain stability of spinal column and protection of sensitive spinal cord and spinal canal structures, to regain voluntary movements below the injury level and upgrade muscle strength, posture and stability above the injury level

1

2. In terms of activity

ICF code	ICF label
d410-d429	Changing and maintaining body position
d430-d449	Carrying, moving and handling objects
d450-d469	Walking and moving
d510	Washing oneself
d520	Caring for body parts
d530	Toileting
d540	Dressing
d550	Eating
d560	Drinking
d570	Looking after one's health
d630	Preparing meals

2

3

The main goals in terms of activity include self-care and self-mobility in activities of daily living.

4

3. In terms of participation

ICF code	ICF label
d810	Informal education
d840	Apprenticeship (work preparation)
d9100	Informal associations
d9200	Play

5

6

7

The main goal of participation after spinal cord injury is to regain former lifestyle in vocational and avocational activities and performance. It may require further education and career change, different hobby and sport activities.

8

V. Environment of the programme

A. CLINICAL SETTING

Individual practice or part of a doctor's group practice	No
Individual practice in a private hospital	No
Part of a local (public) hospital	No
Part of a regional hospital (or rehabilitation centre)	Yes
Part of a university or national hospital	No

The Spinal Unit of 50 beds provides SCI management within the context of a rehabilitation centre (1100 beds, 500 dedicated to different PRM programmes of care), using its diagnostics (including laboratory, radiology etc), but having an intrinsic context in terms of multiprofessional teamwork pattern. The Unit collaborate with the nearby General Hospital (15 km) for emergency management e.g. respiratory failure, while neurological, urological, neurosurgical, traumatologist (vertebral surgeon) consultants are available on weekly or monthly basis within the Unit. Management of urinary tract of pulmonary infections is done within the Unit, which is most capable of patient-care with respect to skin integrity care or bladder and bowel management, which may be difficult in other settings (1).

B. CLINICAL PROGRAMME

Inpatients in beds under PRM responsibility	Yes
Inpatient beds belonging to other departments	No
Day programme (most of the day in outpatient setting, not home)	No
Outpatient clinic (assessment and/or treatment, for up to 3 hours/day)	No
Community based (in the patient's home or workplace or other relevant community location, e.g. sports centre)	No

The Spinal Unit has 50 beds, allocated for SCI patients, led by PRM specialists, within the multiprofessional rehabilitation team. Inpatients occupy all beds. At follow-up, patients return as inpatients for 21 days. In the meantime, they are entitled for assessment in outpatient general PRM outpatient department. There is an open communication between local PRM departments and general practitioners and the Spinal Unit, starting before the patients are discharged to their homes. Discharge notes include prescription of future activities for GPs, including prescription of home-based physical therapy, of necessary rehabilitation aids and of future follow-up plans.

C. CLINICAL APPROACH

Uniprofessional	No
Multiprofessional	Yes

PRM specialists, physical therapists, occupational therapists, rehabilitation nurses, psychologist, *social worker** and others work in interdisciplinary rehabilitation team.

*Unfortunately the facility and the programme have no social worker at this moment.

D. FACILITIES

Does your programme have a designated space for :	
For assessments and consultations ?	Yes/No
For an ambulatory or day care programme ?	No
For inpatient beds ?	Yes
For therapeutic exercises ?	Yes
For therapeutic exercises ?	Yes
For training in independence and daily living ?	Yes
For vocational and/or recreational activities ?	Yes

No day care programme is available although PRM consultations may be obtained through the outpatient service of the Centre. Vocational activities are performed through occupational therapy in a limited way.

VI. Safety and patient rights

A. SAFETY

The safety concerns of persons in the unit where the programme takes place, relate to :	
Emergencies (fire, assault, escape)	<u>Yes</u>
Medical emergencies	<u>Yes</u>
Equipment	<u>Yes</u>
Handling of materials	<u>Yes</u>
Transports	<u>Yes</u>
The safety of persons in the programmes of your unit is provided by :	
Written standards from National Safety Bodies	<u>Yes</u>
Written standards from National Medical Bodies	<u>Yes</u>
Unit-specific written rules	<u>No</u>
Periodic inspection	
Internal	<u>Yes</u>
External	<u>Yes</u>

All safety concerns, with set of rules for the above mentioned issues, are imposed by national laws or bodies, and within the Statutes of the Centre. The maintaining of protocols is checked on yearly basis. Periodic inspections are subject of internal as well as external control.

B. PATIENT RIGHTS

Has your programme adopted a formal policy or statement of patients' rights?	<u>Yes</u>
Does this statement specify the influence that the patient should have in the formulation and implementation of the programme?	<u>Yes</u>
Is the statement known to all personnel involved in delivering the programme?	<u>Yes</u>
Is this checked periodically?	<u>No</u>
Is the statement made known to and is available to all persons visiting your unit?	<u>Yes</u>

Patient rights are imposed and controlled through the Patients' Rights Act (Narodne novine 169/2004) of 2004. It is discussed and pursued through the management of quality within the centre, by all staff members.

1 Some of the laws, including constitutional rules, and papers (in Croatian) are listed below:

2 1. Health Care Act (Zakon o zdravstvenoj zastiti), Narodne novine, 1/97, 121/03.

3 2. Patients' Rights Act (Zakon o zastiti prava pacijenata), Narodne novine, 169/04.

4 3. Constitution of Republic of Croatia (Ustav Republike Hrvatske), Narodne novine 56/90, 8/98,
5 124/00, 41/01.

6 4. Rusinovic - Sunara D.M.A. M.D.; Lugovic G., M.A.; prof. Belicza B., Ph.D., M.D.; Liovic J.,
7 nurse; Radovancevic Lj., Ph.D.,M.D; Croatian Association for Patients' Rights, Split, Croatia,
8 Congress Proceedings, 15th World Congress on Medical Law, Sydney, Australia, page
9 934. - 940., 1 - 5 August 2004.

10 5.Criminal Act (Kazneni zakon), Narodne novine 110/97, 27/98, 50/00, 129/00, 11/03, 190/03,
11 105/04.

12 C. ADVOCACY

13 **Give at least one example of how your organisation advocates for people your programme deals with:**

Negotiating SCI management with Croatian Institute for Health Insurance in terms of availability of services, diagnostics and rehabilitation aids/devices	<u>Yes</u>
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Actions within Ministry of Health and Social Welfare – project of overall SCI management	<u>Yes</u>
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14 The Spinal Unit within The Rehabilitation Centre is constantly negotiating its services in
15 rehabilitation of SCI patients in terms of availability, duration and effectiveness of treatment
16 and long-term follow-up. We have succeeded in establishing multiprofessional team for
17 total management of medical as well as some non-medical issues within rehabilitative care
18 for SCI patients. We are in contact with all major surgical departments throughout our
19 country, in order to discuss and maintain optimal surgical (both operative and conservative)
20 and rehabilitative care for the patients.

21 The Committee for Management of Spinal Cord Injury Consequences (Povjerenstvo za
22 zbrinjavanje posljedica spinalnih ozljeda), consisting of four professionals, including
23 applicants for accreditation (Ivan Dzidic and Sasa Moslavac) has been established within
24 the Ministry of Health and Social Welfare of Croatia, to define a health-care service for
25 spinal cord injury/disease patients in the country. We have produced a comprehensive
26 document – project, which is now being investigated within the Ministry.

VII. PRM Specialists and team management

A. PRM SPECIALISTS IN THE PROGRAMME

Does your PRM physician have overall responsibility and direction of the multiprofessional team?	Yes
Does your PRM physician have overall responsibility and direction of the rehabilitation programme, not only medical responsibility?	Yes
Does he/she have a European Board Certification in PRM?	Yes
Does he/she meet National or European CME/CPD Requirements?	Yes
Number of CME or EACCME points earned in the last 3 years :	60*
The two primary functions for the PRM specialist in your Programme are to :	
Treat comorbidity	No
Assess the rehabilitation potential of the patient	Yes
Analyse & treat impairments	No
Coordinate interprofessional teams	Yes

The Croatian Medical Chamber is regularly licensing and re-licensing all Croatian practising physicians. The requirement is to obtain 20 credits each year through a comprehensive set of rules that define credits for all activities (papers, presentations etc.).

The PRM physician is responsible for the supervision and for direct actions of the multiprofessional team in the total rehabilitation programme. The applicants hold European Board Certification in PRM and also fulfil national CME/CPD requirements. The national license has to be renewed on 6-years basis under strict rules, and delivered by regulatory body – Croatian Medical Chamber.

Primary functions of PRM specialists are the assessment of rehabilitation potential and coordination of the multiprofessional team. Early in the acute phase, emphasis may be put on the treatment of co-morbidity and complications due to multisystem dysfunction and haemodynamic instability inherent to spinal cord injury patients' population.

B. TEAM MANAGEMENT

Which rehabilitation professionals work on a regular basis (minimum of once every week) in your programme ? (give the number)	
Physiotherapists	8, full-time
Occupational therapists	3, full-time
Psychologists	1, full-time
Speech & Language therapists	2, full-time
Social workers	

Vocational specialists	
Nurses	20, full-time
Orthotists/prosthetists assistive technicians/engineers	1, part-time
Other (please specify)	
How often does your staff receive formal continuing education (mark as is) ?	
In team rehabilitation :	<u>Not regularly</u>
In their own profession :	<u>Every year</u>
Do team activities in your rehabilitation programme include the following ?	
Is the patient at the centre of a multiprofessional approach?	<u>Yes</u>
Do you always give informed choices of treatment?	<u>Yes</u>
Do you regularly promote family involvement?	<u>Yes</u>
Does your organisation of multi professional team working include :	
Holding regular team meetings with patient's records only (more than 2 members)	<u>No</u>
Holding regular team meetings (more than 2 members) with the presence of the patients	<u>Yes</u>
Joint assessment of the patient or joint intervention	<u>Yes</u>
Regular exchanges of information between team members	<u>Yes</u>

- 1 Every professional has its own set of rules for continuing education which are defined
- 2 through the rules of chambers (medical, nurse, PT, OT, psychologist). The Patient is within
- 3 the centre of multiprofessional approach and assessed on daily basis through regular visits
- 4 and intermittent team meetings. Regular exchange of information between team members
- 5 is ensured at formal and, equally important, at many informal levels, under influence of local
- 6 culture and tradition of information exchange.

VIII. Description of the programme

A. ASSESSMENT

Besides PRM specialists, physical and occupational therapists are also educated to perform assessments, to be able to observe any change in motor and sensory state in patients. Nurses are educated to generally discriminate between cervical or high thoracic level of injuries and thoraco-lumbar or more distal injuries; and between anaesthetic skin and preserved sensory, so the care is adjusted to these levels of injury and dysfunction. Nurses also assess and treat eliminatory functions and educate patients in self-care with respect to these.

1. *Diagnosis (related to ICD)*

Main diagnosis are paraplegia and tetraplegia, being flaccid or spastic, depending on the time from injury, presence of spinal shock or exaggerated reflexes including pathological ones. ICD relation to these diagnoses is G82 family, from G82.0 to G82.5.

2. *Impairment*

a) **Clinical assessment**

Clinical assessment is done by a PRM specialist at admission. We use the following scales and classifications :

- ASIA (American Spinal Injury Association) impairment scale defines lesion level and completeness (7), where "A" represents complete injury with total motor and sensory loss below the injury level, while "B" - "E" stand for incomplete injury with residual sensory ("B") or motor ("C", "D", "E") function, with "D" and "E" representing useful motor function with ambulatory capability, although not always achieved,
- Standard Neurological Classification of Spinal Cord Injury is used to quantify motor and sensory loss, using key muscles and key sensory points, and define level of injury and clinical syndromes (anterior, posterior, central cord, conus medullaris, cauda equina syndromes). Neurological level of injury is the most caudal segment with preserved motor and sensory function. Key muscles are assessed by MMT (Manual Muscle Testing),
- SCIM (Spinal Cord Independence Measure),
- Barthel's index of functionality.

Clinical examination of patients is done by an experienced examiner - PRM specialist. It has been demonstrated that there are variability between examiners and that sometimes repeated examinations are necessary (14,15). Therefore it is done routinely every week in the early phase (including spinal shock) and then repeated on monthly basis with final examinations before discharge.

b) **Diagnostic tools (instrumental assessment)**

Urodynamic assessment. Filling cystometry is routinely performed in all SCI patients in order to define bladder capacity and intravesical pressure, thus setting up the bladder management programme. Filling cystometry is the method by which the pressure/volume relationship of the bladder is measured during bladder filling. Procedure is performed with Dantec Etude urodynamic machine at non-physiological filling rate. A double-lumen 8F catheter is inserted transurethrally into the bladder. Cystometric capacity (CC) and leak point intravesical pressure (Pves LPP) at terminal detrusor overactivity (a single, involuntary

detrusor contraction, occurring at cystometric capacity, which cannot be suppressed and results in incontinence) are recorded. The urodynamic evaluations conform to the International Continence Society standardisation (16).

Bowel and anal assessment. Anal sensation, anal reflex and bulbo-cavernous reflex are assessed, as part of the clinical examination. Bowel routines are investigated during history taking, and the plans for bowel management are shaped and followed.

Respiratory assessment includes pulse oxygenation monitoring in some cases, management of tracheotomy tubes, aspiration and decanilation.

EMG assessment is sometimes needed when peripheral lesion is suspected or monitored.

Thrombophlebitis detection (by ultrasound) is not available.

Walking assessment: WISCI, LEMS, 10mWT and 6minWT.

3. *Activity and participation*

a) *Capacity evaluation (what somebody can do)*

WISCI (Walking Index for Spinal Cord Injury) is measured to assess ambulatory potential in patients who are able to walk (17,18). Barthel's Index is used to assess the level of functional independence/dependence for ten Activities of Daily Living (ADLs) primarily related to personal care and mobility in a clinical setting. Although it is not dedicated to spinal cord injury patients and rather used in stroke patients with modifications (19), we are obliged to use it for Croatian Institute of Health Insurance Committees requirements and to determine the final length of stay in rehabilitation facility.

b) *Performance (what somebody is actually doing)*

SCIM (Spinal Cord Independence Measure) comprehensively assesses functional recovery, starting with feeding, bathing, dressing and grooming, respiration, sphincter management and use of toilet, mobility indoor and outdoor, including transfers and ambulation (20-22). The assessment is done at admission and before discharge, and done by occupational therapists, physical therapists and nurses with the supervision of PRM specialist.

4. *Environmental and personal factors*

Environmental and personal factors are not assessed but discussed with patients, providing educational and advisory role.

B. INTERVENTION

1. *Time frame of the programme*

The programme is maintained within a 3-6 months time-frame. The exact period of time for each patient is decided in accordance with the completion of rehabilitation goals and by approval of Croatian Institute of Health Insurance Committee.

2. *PRM specialist intervention*

PRM specialist has the pivotal role in clinical examination, setting-up of short and long-term goals, prescribing and coordination actions of multiprofessional team members, writing prescriptions and discharge letters, prescribing rehabilitation and orthotic aids. Interventions include performing certain procedures like change of tracheotomy tubes are pressure sores debridement, that are also part of mandatory skills trainees have to perform during their training in the Unit.

3. *Team intervention*

1 **Physiotherapy** in the gym and in the pool is used to assess and train patients in balance,
 2 sitting, standing, transfers, mobility, verticalisation, ambulation, strength training and
 3 maintaining range of motions. Other forms of therapy including bio-feed-back and
 4 electrotherapy, thermal therapy, ultrasound, magnetotherapy and balneotherapy may be
 5 used. Although these are scarcely referenced in the literature, the use of these therapies is
 6 indicated in treating some complications (e.g. complex regional pain syndrome) of SCI.

7 **Occupational therapy** deals with ADL training, splinting, transfers, use of devices for hand
 8 function, adjustment and use of adapted environment, home modifications, kitchen and
 9 bathroom skills and driving assessment.

10 **Nurses** promote care of skin integrity, eliminatory functions including use of intermittent
 11 catheterisation within bladder programme and reflex evacuation within bowel programme,
 12 and education of patients and relatives.

13 **Dietician** may address specific needs in early (catabolic) phase in severely injured patients
 14 or later to prevent obesity.

15 **Psychologist** is evaluating patients and estimating their need for increase psychological
 16 treatment and, in some cases, psychiatric treatment.

17 **Speech therapist** helps patients with high cervical lesions, post-intubated or
 18 tracheotomised patients, and those who have concomitant brain injury and dysphasia, to
 19 regain articulation, and also promote swallowing in some patients with dysphagia.

20 **Fertility/Sexual function** are assessed in interview by PRM physician and psychologist.
 21 Furthermore, "postal stamp" test may be used to assess psychogenic/reflex nocturnal
 22 erection. Patients may be prescribed with sildenafil or similar phosphodiesterase type 5
 23 inhibitor (23) for erectile dysfunction, and referred to knowledgeable urologist in University
 24 department in Zagreb for vibro-ejaculation or electro-ejaculation procedures within fertility
 25 programme.

26 C. FOLLOW UP AND OUTCOME

27 1. *Review and progress through the programme*

28 The comprehensive evaluation should include a review of records and history-taking,
 29 physical examination, evaluation of bowel and bladder programme with urologic studies,
 30 skin condition, medications taking, blood work and analysis, physical and occupational
 31 therapy evaluations for motor/sensory changes, posture, transfers, activities of daily living
 32 and functional tests, equipment evaluation, psychosocial evaluation and counselling,
 33 radiological studies, team conferences and reports documenting the results and
 34 recommendations.

35 2. *Criteria for progress measurements*

36 Admission and discharge measurements and periodical measurement needed for Croatian
 37 Institute of Health Insurance Committee include Barthel's index and written notes by PRM
 38 specialist to explain specific individual needs of patients, especially with respect to
 39 rehabilitation aids.

40 D. DISCHARGE PLANNING AND LONG TERM FOLLOW UP

41 Discharge is planned at approximately 3 months after admission for paraplegic and 6
 42 months after admission for tetraplegic patients. It includes enhanced communication to
 43 relatives and local community to address specific needs of each patient after the discharge.
 44 Discharge note includes written recommendations for their GPs for continuity of PRM
 45 activities including physical therapy and nursing care, if necessary. Patients then may be
 46 referred to local PRM departments for further treatment or for home-based physical
 47 therapy.

1 Following initial inpatient rehabilitation, patients are re-admitted for their first re-evaluation at
2 12 months post discharge, to make certain that discharge plans have been carried out, and
3 that patients are staying healthy and have established relationships with local providers for
4 ongoing care. After the first re-evaluation patients undergo annual re-evaluations for the
5 first 3-5 years, or until such time as patients have established a consistent record of healthy
6 routines and participation in the community.

7 Once the re-evaluations indicate that patients have consistently demonstrated their ability to
8 manage their complex and chronic conditions, a reduction in frequency is possible to every
9 other year, or sometimes longer, depending on the patient and the expertise of their local
10 providers. As patients age with spinal cord injury, especially into their 2nd and 3rd decade
11 of injury, their medical and functional conditions can change dramatically, and may require
12 a resumption of annual evaluations. Many of the costly complications associated with the
13 aging process are preventable, if identified early.

IX. Information management

A. PATIENT RECORDS

Do the rehabilitation records have a designated space within the medical files ?	<u>Yes</u>
Do you have written criteria for :	
• Admission	<u>Yes</u>
• Discharge	<u>Yes</u>
Do your rehabilitation plans include written information about aims and goals, time frames and identification of responsible team members ?	<u>Yes</u>
Do you produce a formal discharge report (summary) about each patient?	<u>Yes</u>

B. MANAGEMENT INFORMATION

Does your programme show evidence of sustainability ?	
• Established part of public service :	<u>Yes</u>
• Has existed for more than 3 years :	<u>Yes</u>
• Has received national accreditation (where available) :	<u>Yes</u>
How many new patients (registered for the first time) are treated in your programme each year :	100
In your day care or inpatient programme : 100	
• What is the mean duration spent in therapy by patients on this programme	111 days
• How many hours a day do the patients spend in therapy.	5 hours
Give the mean duration of stay spent in the programme :	

C. PROGRAMME MONITORING AND OUTCOMES

Does your programme have an overall monitoring system in addition to patient's records ?	<u>No</u>
Are the long term outcomes of patients who have completed your programme regularly monitored ?	
• Impairment (medical) outcomes :	<u>Yes</u>
• Activity/Participation (ICF) outcomes :	<u>No</u>

• Duration of follow up of the outcomes :	12 months longer
Do you use your outcome data to bring about regular improvements in the quality of your programme's performance?	Yes
Do you make the long term overall outcomes of your programme available to your patients or to the public ?	Yes

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Unfortunately, the accreditation system in Croatia is still in a preliminary phase and not mandatory yet. We monitor medical outcomes in long-term follow-up on yearly basis. Besides empirical, at this moment we do not use structured data to improve quality of programmes, however, with SCIM monitoring for past 2 years, we will be able to extract good as well as weak points in the programme and try to improve the performance.

Our activities are presented to the PRM meetings and within the documents of the regional government. Several references are listed below:

1. Dzidić I, Moslavac S. Functional skills after the rehabilitation of spinal cord injury patients: observation period of 3 years. *Spinal Cord* 1997; 35: 620-623.
2. Moslavac S. Put do samostalnosti, prirucnik za osobe s ozljedom ledne moždine (SCI patients manual), Varaždinske Toplice, 1998.
3. Moslavac S, Moslavac A, Dzidic I. Survey of patients with spinal and (or) spinal cord injury: Varaždinske Toplice, 1991–1996. Abstract Book, First Croatian-Israeli symposium with international participation, Varazdinske Toplice, 1998.
4. Dzidic I, Moslavac S, Moslavac A. Osteoporosis after spinal cord injury: Croatian study. Abstract book. 38th Annual Scientific Meeting of International Medical Society of Paraplegia, Copenhagen, 1999.
5. Cop R, Potrebica S, Moslavac S, Moslavac A, Sekelj-Kauzlaric K, Kejla Z. Complications during rehabilitation in elderly patients with spinal cord injuries. Abstract book, 3rd Congress of the Croatian neurosurgical society, Zagreb, June/2002.
6. Moslavac S. Spinal cord injury management in Croatia 1991 – 2001. Book of Abstracts, Third ISPO Central and Eastern European Conference, Dubrovnik, October, 2002.
7. Cop R, Jelic M, Moslavac S, Potrebica S, Kejla Z, Cikac T, Topoljnjak D. Research approach program to spinal cord injury patients in Croatia in last decade. *International Journal of Rehabilitation Research, Proceedings of the 8th Congress of European Federation for Research in Rehabilitation*, Vol. 278, suppl. 1, June 2004: 92.
8. Katalinic N, Mijic S, Cop R, Moslavac S, Potrebica S, Kejla P, Pticar R, Rasan Lj. Analysis of life activities of patients after spinal cord injuries in Croatia. Abstracts Book. 43rd ISCoS Annual Scientific Meeting, Athens, 2004.
9. Moslavac S, Cop R, Dzidic I. Rehabilitation of patients with tuberculous spondylitis and spinal cord injury in Croatia. Abstracts book. 44th ISCoS Annual Scientific Meeting, Munich 2005.
10. Moslavac S, Moslavac A, Cop R, Dzidic I, Kejla Z. Heterotopic Ossification and Etidronate Treatment in Spinal Cord Injury Patients in Ten Cases. Abstracts Book. 45th ISCoS Annual Scientific Meeting, Boston, 2006.
11. Moslavac S. Evaluation of neurogenic bladder in patients with spinal cord injury. *Neurol Croat* 2007; 56: 102-106.
12. Moslavac S, Dzidic I, Kejla Z, Tomas D. Hemodialysis-associated amyloidosis with cervical spinal cord compression and incomplete tetraplegia: a case report. *Spinal Cord* 2007;45:799-801.
13. Moslavac S, Dzidic I, Kejla Z. Neurogenic detrusor overactivity: comparison between complete and incomplete spinal cord injury patients. *Neurourol Urod* 2008;27:504-506.
14. Moslavac S, Dzidic I, Kejla Z. Neurological Outcome in Road Traffic Accidents with Spinal Cord Injury. *Coll Antropol* 2008; 32:583-586.
15. Moslavac S. Long-term follow-up after spinal cord injury. Abstract Book. 5th World Congress of the International Society of Physical and Rehabilitation Medicine. p. 38, Istanbul, Turkey, 2009.
16. Kučina M, Moslavac S. Spinal Cord Independence Measure III: odraz rehabilitacijskog postupka i funkcionalnog napretka osoba s ozljedom kralježničke moždine. *Neurol Croat* 2010;59(supl.1):108.

X. Quality improvement

A. WHICH ARE THE MOST POSITIVE POINTS OF YOUR PROGRAMME ?

The most positive points are

- the multiprofessional team approach to spinal injured/lesioned patients,
- the team focused on acute rehabilitation and post-discharge follow-up of near total country's incidence of traumatic and majority of non-traumatic SCI patients,
- the communication with surgical wards and spinal (neuro, orthopaedic) surgeons throughout the country, as well as with country institutions as are the Ministry of Health, the Croatian Institute for Health Insurance, the Croatian Medical Chamber, the Croatian Medical Association and the Croatian Society of PRM. Spinal Unit has been accredited as UEMS PRM Board Training Centre.

B. WHICH ARE THE WEAK POINTS OF YOUR PROGRAMME ?

There is not enough clinical audit, the staff are not sufficient, there is a shortage of some state-of-the-art physical and occupational therapy equipment (e.g. treadmill exercises, functional electrical stimulation, etc).

The communication with primary care physicians and community is insufficient, as well as the preparation of patients to return to productive life and previous life-style.

C. WHICH ACTION PLAN DO YOU INTEND TO IMPLEMENT IN ORDER TO IMPROVE YOUR PROGRAMME?

1. *Extrinsic improvements*

We would like to improve communication with the society, including primary care physicians, to enable better "soft-landing" of the patient to his/her community.

We need a social worker to negotiate social affairs with the community, so that the patient's right resulting from the newly acquired medical conditions will be fully achieved.

2. *Intrinsic improvements*

We intend to:

- start a legal support to our patients, giving them advice and legal help to pursue compensations and guidance through the judicious system.
- start an internal audit of workflow, urological and surgical on-site management,
- and to improve accommodation for patients.

XI. References

A. LIST OF REFERENCES

1. El Masry WS: Management of patients with Spinal Injuries: "Philosophy and Practice", Fiz med rehabil, suppl. 2004, p 15-2, Opatija, Croatia.
2. Dzidić I, Moslavac S. Functional skills after the rehabilitation of spinal cord injury patients: observation period of 3 years. *Spinal Cord* 1997; 35: 620-623.
3. Moslavac S, Dzidic I, Kejla Z. Neurogenic detrusor overactivity: comparison between complete and incomplete spinal cord injury patients. *Neurourol Urod* 2008;27:504-506.
4. Moslavac S, Dzidic I, Kejla Z. Neurological Outcome in Road Traffic Accidents with Spinal Cord Injury. *Coll Antropol* 2008; 32:583-586.
5. Statistical Yearbook 2004, Central Bureau of Statistics, Croatia.
6. DeVivo MJ, Fine PR, Maetz HM, Stover SL. Prevalence of spinal cord injury: An estimation employing life table techniques. *Arch Neurol* 1980;37:707-8.
7. Maynard FM, Bracken MB, Creasey G, Ditunno JF, Donovan WH, Ducker TB, et al. International standards for neurological and functional classification of spinal cord injury. *Spinal Cord* 1997; 35: 266-74.
8. Bracken MB, Shepard MJ, Collins WF. et al. A randomized controlled trial of methylprednisolone or naloxone in the treatment of acute spinal cord injury. *N Engl J Med.* 1990; 322: 1405–1411.
9. El Masri W. Management of Traumatic Spinal Cord Injuries: current standard of care revisited. *ACNR* 2010;10:37-40.
10. DeVivo MJ, Krause JS, Lammertse DP. Recent trends in mortality and causes of death among persons with spinal cord injury. *Arch Phys Med Rehabil* 1999;80:1411-9.
11. Berkowitz M, Harvey C, Greene CG, Wilson SE. *The Economic Consequences of Traumatic Spinal Cord Injury.* New York: Demos Publishers, 1992.
12. The National SCI Statistical Center. *Spinal cord injury: Facts and figures at a Glance.* Birmingham: University of Alabama at Birmingham National SCI Center, April, 1999.
13. Lasfargues JE, Custis D, Morrone F, Carswell J, Nguyen T. A model for estimating spinal cord injury prevalence in the United States. *Paraplegia* 1995;33:62-8.
14. Mulcahey MJ, Gaughan J, Betz RR, Vogel LC. Rater agreement on the ISCSCI motor and sensory scores obtained before and after formal training in testing technique. *J Spinal Cord Med.* 2007;30 Suppl 1:S146-9.
15. Chafetz RS, Gaughan JP, Vogel LC, Betz R, Mulcahey MJ. The international standards for neurological classification of spinal cord injury: intra-rater agreement of total motor and sensory scores in the pediatric population. *J Spinal Cord Med.* 2009;32(2):157-61.
16. Abrams P, Cardozo L, Fall M, Griffiths D, Rosier P, Ulmsten U et al. The standardisation of terminology of lower urinary tract function: Report from the Standardisation Sub-committee of the International Continence Society. *Neurourology and Urodynamics.* 2002;21:167-178.
17. Ditunno JF Jr, Ditunno PL, Graziani V, Scivoletto G, Bernardi M, Castellano V, Marchetti M, Barbeau H, Frankel HL, D'Andrea Greve JM, Ko H-Y, Marshall R and Nance P. Walking index for spinal cord injury (WISCI): an international multicenter validity and reliability study. *Spinal Cord* 2000;38:234-43.

- 1 18. PL Ditunno and JF Dittuno. Walking index for spinal cord injury (WISCI II): scale
2 revision. *Spinal Cord* 2001;39:654-56.
- 3 19. Surya S, Vanclay F, Cooper B. Improving the sensitivity of the Barthel Index for stroke
4 rehabilitation. *Journal of Clinical Epidemiology*, 1989;42 (8):703-9.
- 5 20. Catz A, Itzkovich M, Agranov E, Ring H, Tamir A. SCIMF Spinal Cord Independence
6 Measure: A new disability scale for patients with spinal cord lesions. *Spinal Cord* 1997;35:
7 850-6.
- 8 21. Itzkovich M, Gelernter I, Biering Sorensen F, Weeks C, Laramie MT, Craven BC et al.
9 The Spinal Cord Independence Measure (SCIM) version III: reliability and validity in a multi-
10 center international study. *Disabil Rehabil* 2007;29:1926-33.
- 11 22. Catz A, Itzkovich M, Tesio L, Biering-Sorensen F, Weeks C, Laramie MT et al. A multi-
12 center international study on the spinal cord independence measure, version III: rasch
13 psychometric validation. *Spinal Cord* 2007; 45:275-91.
- 14 23. Cop R, Potrebnica S, Kejla Z, Vagic N, Moslavac S, Dzidic I. Use of sildenafil (Viagra) in
15 patients with lumbar spine injury. Abstract book, 40th Annual Scientific Meeting of
16 International Medical Society of Paraplegia, Nottwill, Switzerland, 2001.
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18 **B. DETAILS ABOUT NATIONAL DOCUMENTS**

19 Unfortunately, there are no national guidelines concerning spinal cord injury rehabilitation.
20 This is included in the PRM segment of health care and delivered through a network of
21 inpatient rehabilitation beds imposed by Ministry of Health.

22 This network is obtained and maintained through the payment system of the Croatian
23 Institute for Health Insurance, which dictates staff and budget for every bed. However,
24 these rules don't match all the standards which are necessary to maintain these kinds of
25 services. Furthermore, the Ministry of Health is obliged to propose bylaws for
26 comprehensive rehabilitation (e.g. spinal cord injury, traumatic brain injury). Unfortunately,
27 this has not been done yet.

28