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PRM Programme for patients with Spinal Cord Injury in the post-acute phase.

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Content

I.	SUMMARY	4
II.	GENERAL FONDATIONS OF THE PROGRAMME	5
A.	PATHOLOGICAL AND IMPAIRMENT CONSIDERATIONS	5
1.	<i>Etiology</i>	5
2.	<i>Natural history and relationship to impairment</i>	5
3.	<i>Diagnosis approach and prognosis</i>	6
4.	<i>Impairment treatment principles</i>	6
B.	ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS	6
C.	SOCIAL AND ECONOMIC CONSEQUENCES	7
1.	<i>Epidemiological data</i>	7
2.	<i>Social data</i>	7
3.	<i>Economic data</i>	7
D.	LEGAL FRAMEWORK.....	9
III.	DESCRIPTION OF THE PROGRAMME	10
A.	ENVIRONMENT OF THE PROGRAMME	10
1.	<i>Clinical setting</i>	10
2.	<i>Clinical programme</i>	10
3.	<i>Clinical approach</i>	10
4.	<i>Facilities</i>	10
B.	TARGET POPULATION.....	11
1.	<i>Inclusion criteria</i>	11
2.	<i>Criteria for refusal</i>	11
3.	<i>Referrals of patients</i>	11
4.	<i>Stage of recovery before admission</i>	11
5.	<i>Early management before admission</i>	12
C.	GOALS.....	13
1.	<i>In terms of body structure and body function (impairment)</i>	14
2.	<i>Activities and participation</i>	14
3.	<i>In terms of participation</i>	15
D.	CONTENT OF THE PROGRAMME	15
1.	<i>General scheme and time frame</i>	15
2.	<i>Role of PRM specialist</i>	15
3.	<i>Specific role of each team member in SCI rehabilitation programme</i>	16
4.	<i>Diagnostic and assessment tools</i>	16
5.	<i>Specific therapeutic interventions</i>	17
E.	DISCHARGE PLANNING AND LONG TERM FOLLOW UP	18
1.	<i>Discharge criteria</i>	18
2.	<i>How patients are managed after the programme?</i>	19
IV.	ADDITIONAL INFORMATION ABOUT PRM ORGANIZATION	20
A.	SAFETY AND PATIENT RIGHTS.....	20
1.	<i>Safety</i>	20
2.	<i>Patient rights</i>	20
3.	<i>Advocacy</i>	20
B.	PRM SPECIALISTS AND TEAM MANAGEMENT	21
1.	<i>PRM Specialists in the Programme</i>	21
2.	<i>Staff devoted to this programme</i>	21
3.	<i>Team management</i>	21
C.	INFORMATION MANAGEMENT	22
1.	<i>Patient records</i>	22
2.	<i>Data about general organization</i>	22
3.	<i>Programme monitoring and outcomes</i>	23
V.	QUALITY IMPROVEMENT	25

A.	WHAT ARE THE MOST POSITIVE POINTS OF YOUR PROGRAMME?	25
B.	WHAT ARE THE POINTS TO IMPROVE IN YOUR PROGRAMME?	25
C.	WHAT ACTION PLAN DO YOU INTEND TO IMPLEMENT IN ORDER TO IMPROVE YOUR PROGRAMME? ...	25
1.	<i>Extrinsic conditions that you wish to obtain</i>	25
2.	<i>Intrinsic improvement of the programme</i>	25
VI.	REFERENCES	26
A.	LIST OF REFERENCES	26

I. Summary

Spinal cord injury (SCI) instantly changes the person's life and the further consequences affect the person him/herself, his/her family, relatives and society.

During the last 25 years a modern, comprehensive rehabilitation system for SCI patients has been established in Latvia. One single SCI centre is sufficient for 2 million inhabitants of Latvia. Rehabilitation is provided by certified physical and rehabilitation medicine physicians and rehabilitation professionals in multidisciplinary team approach.

Reported global incidence of traumatic SCI lies between 10.4 and 83 per million inhabitants per year. (1)The median calculated from these data for the Western Europe region is 16 per million inhabitants per year. Limited amount of data are available from Eastern Europe. (2)

All SCI patients with rehabilitation potential are the target population for SCI rehabilitation program in NRC "Vaivari". Rehabilitation starts in acute setting and continues in the dedicated SCI rehabilitation program in the National Rehabilitation center „Vaivari". The main goal is to improve patient activity and participation.

Rehabilitation usually starts on the 10-14th day post injury, when the patient is medically stable and able to participate in an intensive rehabilitation process. In case of serious complications, rehabilitation is temporary suspended.

All patients are included in a long term continuous follow up program. The follow up is usually implemented once a year after first rehabilitation course.

Rehabilitation team consists of experienced experts – PRM doctor, physiotherapist, occupational therapist, nursing staff, psychologist, social worker and nutritionist. Other necessary consultants, such as an orthopedic technician, urologist, and surgeon are available. First treatment for newly injured paraplegic people lasts for 30-45 days and 45-60 days for tetraplegic patients. A follow up program, usually with a yearly control, starts after discharge.

A multidisciplinary team managed by a PRM physician, works together with the patient and his/her family to set realistic rehabilitation goals and provide relevant care. They do their best to maximize recovery, to prevent avoidable complications and to achieve maximum independence of SCI patient within the limitations of his/her disability.

Patients are assessed with International Standards of Neurological Classification of SCI (ISNCSCI) and Spinal Cord Independence Measure (SCIM). Data are collected in a uniform manner with respect to International SCI Data set, International SCI Lower Urinary Tract Function Basic Data Set and Autonomic Standards Assessment form.

Specialists of our rehabilitation team perform an efficient, respectful and cost effective model of SCI rehabilitation.

Cooperation with nongovernmental organizations and local government social services is used to achieve the goals. Family members and their relatives are involved in the rehabilitation process.

This SCI rehabilitation program has been introduced into the curriculum of the University study process for medical residents and functional specialists. Training of specialists is carried out in NRC "Vaivari" SCI rehabilitation department.

II. General foundations of the Programme

Specialized SCI rehabilitation program provides comprehensive and patient-focused rehabilitation services for inpatient, outpatient and follow-up care with aim to empower people with SCI and their families to achieve optimal quality of life continuing into the community (focusing on increasing self-reliance and gaining independence).(5)

Rehabilitation is provided by certified PRM physician and rehabilitation specialists in multidisciplinary team approach.

Patients with traumatic spinal cord injuries and patients with non-traumatic spinal cord injuries benefit from the same rehabilitation program in a SCI rehabilitation program. It is effective to admit and rehabilitate patients with injuries resulting from both traumatic and non-traumatic etiology in the same specialized setting (7).

A. PATHOLOGICAL AND IMPAIRMENT CONSIDERATIONS

1. Etiology

SCI can result from different mechanisms leading to tissue damage: 1) destruction by direct trauma; 2) compression by bone fragments, hematoma, or disk material; 3) ischemia from damage or impingement on the spinal arteries. (4)

The spinal cord can be radically disrupted by injury. But there are also many heterogeneous conditions in causes and outcomes, which can result from contusion, compression, penetration or maceration of the spinal cord. SCI leads to the death of cells, including neurons, oligodendrocytes, astrocytes and precursor cells and any resulting cavities and cysts may interrupt descending and ascending axonal tracts, although circumferential white matter is often spared. (6)

SCI is a dynamic process. Immediate lesions of the nervous tissue can be followed by secondary damage due to vasogenic oedema and anoxia of the spinal cord. In all acute cord syndromes, the full extent of injury may be not initially apparent. Incomplete cord lesions may evolve into more complete lesions. (4)

2. Natural history and relationship to impairment

The degree of motor and/or sensory loss is determined by the location and seriousness of cord damage. **ASIA Impairment Scale (AIS)** is used in grading the degree of impairment:

A = Complete. No sensory or motor function is preserved in the sacral segments S4-S5.

B = Sensory incomplete. Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5, and no motor function is preserved more than three levels below the motor level on either side of the body.

C = Motor incomplete. Motor function is preserved below the neurological level and more than half of key muscle functions below the single neurological level of injury have a muscle grade less than 3 (Grades 0–2).

D = Motor incomplete. Motor function is preserved below the neurological level, and at least half (half or more) of key muscle functions below the neurological level have a muscle grade >3.

E = Normal. If sensation and motor function as tested with the ISNCSCI are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E. Someone without a SCI does not receive an AIS grade (9-13).

Besides those levels, special anatomic types consist of, incomplete SCI produce anterior, posterior, central spinal cord injury, Brown-Sequard syndrome or conus medullaris and Cauda Equina (horse-tail) syndromes. (9-13)

Diagnosis approach and prognosis

Functional outcomes may vary with individuals, depending on such factors as the level and completeness of the injury, neurological recovery (or loss), associated medical complications (pain, spasticity, contractures, cardiac disease, musculoskeletal injury), the amount of rehabilitation training that the patient receives, the rehabilitation team's level of expertise, as well as the patient's motivation, age, and family and financial resources.

An important objective of acute SCI rehabilitation is to maximize patient functional outcomes. Completeness of injury and neurologic level of injury are important factors in predicting functional outcomes after SCI. (23, 24, 27) Incomplete SCI tend to indicate a more favorable prognosis. Tetraplegia is clearly more functionally impairing than paraplegia, depending on the degree of motor-sensory sparing.

Functioning prognosis is better if the time lapse from the injury to the rehabilitation department admission is shorter.(15)

The more incomplete the injury is, especially on initial examination at 72 hours to 1 week after the injury has occurred, the more favorable the potential for neurological recovery.

Neurological recovery usually plateaus in the first 3-6 months (although changes have been reported more than one year after injury). The use of orthotics and assistive devices can sometimes facilitate patient's functional abilities. (11-13)

Comprehensive and detailed neurological examinations that are yearly repeated form an important component of patient assessment and of neurological and functional outcome prediction. Key elements of the examination include motor and sensory testing, which allow the designation of a neurological level of injury and of the completeness of injury. In addition, rectal examination is required to assess motor and sensory functions of the pelvic floor. (14)

3. Impairment treatment principles

When acute SCI occurs, the patient is transported to the emergency room and undergoes surgery, if necessary. After the vital signs and the patient status are stabilized, the rehabilitation process can begin. In traumatic SCI, adequate timing of medical treatment and rehabilitation is essential for the recovery of functioning. The concept of "post-acute rehabilitation" can be understood as the rehabilitation process being initiated as soon as possible after acute medical management. (15)

In the rehabilitation of SCI patients, specific therapies and management, such as physical and occupational therapy, bladder and bowel management should be carried out simultaneously. Medical treatments for symptoms including orthostatic hypotension, pain, and spasticity, are also required.

Therefore, a comprehensive evaluation on the patient's medical, functional, and social status is necessary before planning the rehabilitation goals. (5) In the comprehensive evaluation of SCI, the problem list oriented approach is known to be more useful than the individual approach by each rehabilitation team member.

B. ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS

Changes of physical state cause the functioning problems led activities limitations and participation restrictions typically related to mobility, self-care, household and leisure activities, employment difficulties, maintaining social relationships and being active members of the community.

Higher level and more severe SCI (based on AIS) exhibited the strongest association with more activity limitations. (32)

1 Assistive technology for mobility, including wheelchairs, plays an important role in
2 community participation among persons with SCI.

3 **C. SOCIAL AND ECONOMIC CONSEQUENCES**

4 **1. Epidemiological data**

5 Reported worldwide incidence of SCI lies between 10.4 and 83 per million inhabitants per
6 year. (1) In Western Europe, reported rates are: Denmark (9.2 per million), Finland (13.8 per
7 million), France 19.4 per million, Germany 10.7 per million, Greece 33.6 per million,
8 Greenland 26 per million, Iceland 20 per million, Ireland 13.1 per million, Italy 19 per million,
9 Israel 15.9 per million, Netherlands 7.5 per million, Norway 26.3 per million, Spain 12.1 per
10 million, Switzerland 15 per million. The median calculated from these data for the Western
11 Europe region is 16 per million (2)

12 One-third of patients with SCI are reported to be tetraplegia and 50% of patients with SCI to
13 have a complete lesion. The average age of patients sustaining their injury at is reported as
14 33 years old, and the sex distribution (men/women) as 3.8/1. The causes of these injuries
15 ranging from motor vehicle accidents and community violence to recreational activities and
16 workplace-related injuries.(1-3).Limited amount of data are available from Eastern Europe.
17 New Estonian data are combined with regional data for Russia show the main causes of
18 TSCI in Estonia and Russia (Novosibirsk and Saint Petersburg) were falls (median 40%) and
19 land transport (median 25%) (2)

20 Available published data from Latvia (30) on epidemiological profile of traumatic spinal cord
21 injury and medical complications show results from 134 medical records of patients with
22 traumatic spinal cord injury during the primary rehabilitation in PRM program for patients
23 with Spinal Cord Injury in post-acute phase of National Rehabilitation Centre "Vaivari" from
24 January 2011 to December 2014. All SCI patients' rehabilitation is centralized in this
25 specialized in-patient rehabilitation program, which covers all 2 million of Latvian
26 population.¹⁶ Over this period the mean age of patients with traumatic spinal cord injury was
27 41.81 years and male to female ratio was 5:1. The leading cause of traumatic spinal cord
28 injury were falls (37.3%), followed by road traffic accidents (29.1%), sport and leisure
29 activities (18.7%), other causes (7.5%), unidentified causes (5.2%), and assault (2.2%). The
30 most common medical complications were the following: pain (76.9%), spasticity (47.8%),
31 urinary tract infections (44.8%), pressure ulcers (24.6%) and orthostatic hypotension
32 (14.2%). Degree A of impairment according to ASIA accounted for 26.1% cases, degree B–
33 26.1%, C – 18.7%, D – 26.9%, and E – 2.2%.

34 **2. Social data**

35 Life expectancies for persons with SCI are still significantly below life expectancies for those
36 with no SCI and have not improved since the 1980's. Mortality rates are significantly higher
37 during the first year after injury than during subsequent years, particularly for severely injured
38 people. In the past, the leading cause of death among people with SCI is used to be renal
39 failure. Today, the more frequent causes of death for this population are pneumonia and
40 septicemia. (26)

41 Whether a person returns to work after SCI, is greatly influenced by his/her educational level.
42 Although this is true for the general public, it is especially important for the SCI population.
43 The more educated a person is at the moment of injury, the more he/she is likely to return to
44 work. The rates of employment also depend of functional status. People with paraplegia are
45 employed more frequently (32.8%) than those with tetraplegia (24.7%). More specifically, the
46 chance to return to work for people needing ADL assistance (18.2%) is less than a half of
47 the chance for those who do not require assistance (42%) (16).

48 **3. Economic data**

49 SCI has an impact on multiple systems. SCI has been classified among the five most
50 expensive hospital diagnoses. SCI onset is life-changing and a lengthy program of SCI

1 rehabilitation is needed to train patients to use their remaining abilities and to support
2 “adjustment” to a changed body and life situation.(16)

3 Significant costs are incurred throughout the life of a person with SCI, including initial
4 hospitalization and acute rehabilitation, home and vehicle modifications, and recurring costs
5 for durable medical equipment, medications, supplies, and personal assistance.

6 The level and extent of injury are important factors contributing to first-year costs. People
7 with high tetraplegia incurred over 3 times the charges that people with incomplete motor
8 paraplegia. (16)

1

2 D. LEGAL FRAMEWORK

3 After a spinal cord injury, patients are usually admitted to spine surgery or neurosurgical
4 departments in University hospitals or regional hospitals.

5 Rehabilitation starts in acute setting and continues in the dedicated SCI rehabilitation
6 program in the National Rehabilitation centre „Vaivari”. This usually starts on the 10-14th day
7 post injury , when the patient is medically stable and able to participate in an intensive
8 rehabilitation process. In case of serious complications, rehabilitation is temporary
9 suspended.

10 First treatment for newly traumatic injured paraplegic people lasts for 30-45 days and 45-60
11 days for tetraplegia patients. From study conducted in 2015 (29) the mean length of stay is
12 39, 31; min=5, max=104 days. For tetraplegic patients these were on average 43.9 days and
13 for patients with paraplegia – 36.3 days. The longest treatment period is for complete
14 tetraplegic patients – mean length of stay 52.62 days; in contrast to the shortest treatment
15 period of incomplete paraplegic patients, which is mean length of stay 30.86 days.

16 A follow up program, usually with a yearly control, starts after discharge.

17 The follow up program can be implemented on an in-patient or day hospital basis, more
18 rarely – in out-patient clinics. The follow-up program for inpatients lasts for 10 - 14 days
19 (maximum 21 days for high tetraplegia or complicated patients).

20 Patient’s rights are guaranteed in Constitution of the Republic of Latvia: “The State will
21 protect human health and guarantee a basic level of medical assistance for everyone”. (28)

22 Rehabilitation programs in National Rehabilitation center “Vaivari” are financed by state,
23 patient has to pay the “patient’s fee” (5 EUR per day) (with the exception of persons exempt
24 from payments) according to Regulations of the Cabinet of Ministers of Latvia.

III. Description of the Programme

A. ENVIRONMENT OF THE PROGRAMME

1. Clinical setting

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

National rehabilitation centre Vaivari is the only state funded inpatient rehabilitation centre in Latvia with specialized SCI patient rehabilitation programme.

2. Clinical programme

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

23 inpatients beds for newly injured and follow up program.
Distribution of patients within the rehabilitation program is 1:3. It means that $\frac{1}{3}$ of patients are newly injured and $\frac{2}{3}$ of them join the program after a primary rehabilitation course.

3. Clinical approach

Uniprofessional	Yes/No
Multiprofessional	<u>Yes</u>

Multiprofessional rehabilitation approach with involvement of necessary specialists – consultants from other center's programs and University clinics.

4. Facilities

Does your program have a designated space for:	
For assessments and consultations?	<u>Yes</u>
For an ambulatory or day care program ?	<u>Yes</u>
For inpatient beds?	<u>Yes</u>
For therapeutic exercises?	<u>Yes</u>
For vocational and/or recreational activities?	<u>Yes</u>
For training in independence and daily living?	<u>Yes</u>

Accessibility to equipped intensive therapy unit with anesthesiologist on 24-hour duty.

There is a swimming pool, a hydrotherapy complex and a horse riding therapy arena, places for recreational sport activities (minigolf, tennis, bochia)

B. TARGET POPULATION

1. Inclusion criteria

All patients with recent spinal cord injury or impairment caused by trauma or disease, after acute treatment stage, and who have functional disorders, according the international classification of functioning (ICF).

Patients are medically stable and have undergone all the necessary medical treatment, including vertebral column stabilization.

Patients are motivated and have the capacity to understand the goals and results of medical rehabilitation.

All SCI patients are included in a long term continuous follow up program. The follow up is usually implemented once a year after first rehabilitation course.

SCI patients with changes in the functional condition or extra functional disorders are also admitted in the follow up program. Control / monitoring within the follow up program is usually appointed by PRM doctor, sometimes patients can also be entered by primary care doctors or other specialists.

2. Criteria for refusal

Patient's functional disorders are not related to spinal injuries.

The patient is not motivated or is not interested in going through the rehabilitation process.

Patient's mental condition is not appropriate to participate in the rehabilitation.

Severe and/or decompensated comorbidities or complications.

3. Referrals of patients

Direct access to the PRM program	Yes/No
Referral from general practitioners	<u>Yes</u>
Referral from other specialists	<u>Yes</u>
Referral from specialists in PRM	<u>Yes</u>

In exceptional cases, the patient can be directly referred by a general practitioner (GP) if it has not been done during a previous (hospital) stage. Then GP forwards to PRM physician for consultation, and he/she takes a decision on the selection of a rehabilitation setting.

4. Stage of recovery before admission

Within two weeks of onset	<u>Yes</u>
2 weeks to 3 months after onset	<u>Yes</u>
3 months or longer after onset	<u>Yes</u>

A patient is admitted into post-acute program as soon as he/she is medically stable and has no complications, optimally 10-14 days after onset. Delayed starting of the rehabilitation program may occur due to medical complications or to combined injuries, such as a serious head injury, when rehabilitation is started in another setting.

Long term follow up program usually has been carried out once a year for patients who have received a first rehabilitation course.

5.

1 **6. Early management before admission**

2 **a) How are patients selected?**

3 The patients are selected in the hospital by the attending surgeon or neurologist together
4 with the PRM physician who performs the assessment of patient's functioning disorders,
5 rehabilitation potential and indications, who designs the rehabilitation plans in the hospital
6 and for further rehabilitation, and who manages the transfer of the patient to the rehabilitation
7 center. Occasionally, a general practitioner can send a patient to the PRM physician who
8 then completes the assessment of the functioning disorders, potential, indications and admits
9 the patient to the rehabilitation program.

10 **b) Do patients benefit from PRM advice in acute settings?**

11 At the University Clinics, specialized and regional hospitals the PRM services are accessible
12 where patients are consulted and the rehabilitation course has been started in the acute
13 stage and then the patient is sent for further rehabilitation within a specialized program.

14 **c) What alternate solutions are proposed to refused patients?**

15 The refused patients continue the medical treatment and the stabilization of health conditions
16 in the hospital. They take treatment of comorbidities and complications in the hospital setting.
17 Then, they are oriented to Long term Care hospitals or Social Care Centre without intensive
18 rehabilitation or they return back home where they are under the care of their general
19 practitioner and their family. After discharge from rehabilitation program SCI patient with A and
20 B /AIS of the lesion can receive home based rehabilitation provided by physiotherapist and/or
21 occupational therapist with periodical PRM physician supervision. For patients with a low level
22 and C; D/ AIS of the lesion, further rehabilitation is planned as an out-patient course or as a
23 course of rehabilitation in the day care center.

24

25

C. GOALS

Main goals of the program are:

- to reduce impairment
- to provide improvement of functional abilities in activity and participation domains
- to help the patient to return to productive life,
- to prevent secondary complications and avoid re-hospitalization
- to realize educational program for persons with SCI and caregivers.

There is a large variety of functional problems reflecting the complexity of SCI. The ICF can provide a comprehensive framework for the description of functional health in individuals with SCI worldwide.(21-22)

Rehabilitation team lead by PRM doctor set the rehabilitation goal – maximal functional independence measured by SCIM and based on injury level and completeness. The most important predictors of possible independence are injury level and completeness. It determines what level of independency could be achieve and how much assistance will be needed in future

Maximal functional independence allows to decrease the restrictions in activities, participation and environmental factors. The most important criteria besides neurological level are patient's general health condition – existing comorbidities and secondary complications and patient's self- priorities in activities, participating.

The goals can be achieved by training and re-training different skills. Physiotherapist develops mostly gross motor skills and mobility :

- bed mobility,
- transfers mobility,
- wheelchair mobility and walking ability and gait training,
- work with strengthening of the functions of upper extremities,
- improving of motor control,
- body stabilization,
- joint mobility,
- spasticity management,
- monitoring and improving of respiratory system,
- fitness for general body strengthening

Occupational therapist provides training of participating activities of daily living and focus on:

- optimizing upper extremity function and deformities prevention,
- evaluation and recommendation of wheelchair seating and positioning systems,
- teaching to perform activities of daily living,
- training of wheelchair skills in different environment,
- prescribing and adapting of assistive technologies,
- evaluation of physical and environmental barriers in the home and community and recommends modifications,
- engaging in recreational activities,
- new technique and use special equipment for achieving these goals

The functions of the rehabilitation specialists overlap in certain segments and thus allow to achieve the main goal successfully in various ways – the good quality of life possible despite the impairment.

1 **1. In terms of body structure and body function (impairment)**

2 Brief ICF Core set for individuals with SCI in early post-acute context with some additional
3 categories from Comprehensive ICF Core set for SCI individuals (31)

ICF code	ICF label
s120	Spinal cord and related structures
s430	Structure of respiratory system
s610	Structure of urinary system
b730	Muscle power function
b620	Urination functions
b525	Defecation functions
b440	Respiration functions
b735	Muscle tone function
b152	Emotional functions
b810	Protective functions of the skin
	Supplemented with:
b640	Sexual functions
b420	Blood pressure functions
b280	Sensation of pain
b550	Thermoregulatory functions
b280	Sensation of pain

4 In the body structures domain, the relevant item was the spinal cord and related structures
5 (s120) In the body function domain, muscle power functions, urination functions, defecation
6 functions, and sensation of pain were frequently mentioned. These items involve problems
7 which most of the SCI patients suffer from. This is directly influenced by the spinal cord injury
8 itself. (21-22)

9 **2. Activities and participation**

10 Brief ICF Core set for individuals with SCI in early post-acute context

11

ICF code	ICF label
d420	Transferring oneself
d410	Changing basic body position
d445	Hand and arm use
d530	Toileting
d550	Eating
d450	Walking
	Washing oneself
d540	Dressing
d560	Drinking

3. *In terms of participation*

The spectrum and number of ICF categories included in the Brief ICF Core Set seem to fulfill the needs of single health professions who want to get a brief profile of functional problems of a person with SCI. In specific cases when the information provided by categories of the Brief Core Set is not sufficient, additional categories out of the Comprehensive Core Set can be chosen.(31)

ICF code	ICF label
d760	Family relationships
d770	Intimate relationships
d845	Acquiring, keeping, terminating a job
d870	Economic self-sufficiency
d920	Recreation and leisure

4. *In terms of environmental factors*

ICF code	ICF label
E115	Products and technology for personal use in daily living
E120	Products and technology for personal indoor and outdoor mobility and transportation
E120	Products and technology for communication
E310	Immediate family
E355	Health professionals

CONTENT OF THE PROGRAMME

5. *General scheme and time frame*

SCI patients in acute phase have usually been admitted to spine surgery or neurosurgical department of University hospitals or regional hospitals. Rehabilitation has usually been started in an acute setting. Then the process continues in the specialized SCI rehabilitation program of NRC "Vaivari".

The earliest time when the patients can start the rehabilitation in our program is on the 10th day after injury. The average time the patient joins our program is 2-3 weeks after impairment. Lengths of stay for newly injured patients are 30-45 days for paraplegics and 45-60 days for tetraplegics..

The follow up is usually implemented once a year after first post-acute rehabilitation course.

6. *Role of PRM specialist*

The PRM physician evaluates the patient's condition: sets the short and long term goals, works out the rehabilitation plan, performs the treatment and prevention of infections, spasticity, pain, hypotension, hypertension, autonomic dysreflexia, manages the medication therapy and leads the whole multidisciplinary specialist's team. The PRM physician provides education and counselling related to sexuality and fertility.

The PRM physician makes neurological assessment of the injured person using the ISNCSCI and uses his/her knowledge to accurately predict the likely neurological and functional outcomes based on this assessment. (25)

1 The PRM physician invites necessary consultants and organizes medical Council for
2 complicated cases.

3 The PRM physician consults and selects for rehabilitation complicated patients in University
4 hospitals.
5

6 PRM specialists educate patients and caregivers about prevention of secondary
7 complications. Following topics are included in everyday routine work of multidisciplinary
8 rehabilitation team:

- 9 - Skin care management and pressure ulcers prevention
- 10 - Bladder and bowel management
- 11 - Management of autonomic dysreflexia
- 12 - Osteoporosis and heterotopic ossification
- 13 - Sexuality and fertility after SCI

14 Before discharge all the rehabilitation team has discussion about secondary complications
15 with the patient together with his/her family and caregivers.

16 Thematic lectures and discussions about preventing complications are organized by team
17 members twice a month.

18 Once a month discussions about living with SCI are done by experienced person living with
19 SCI

20 **7. Specific role of each team member in SCI rehabilitation programme**

21
22 **Physiotherapists:** evaluation of motor function including voluntary and involuntary motor
23 activity of all muscle groups, spasticity assessment, training for range of motion, walking and
24 standing, balance, treadmill walking with body weight support, physical modalities,
25 physiotherapy activities in swimming pool.

26 **Occupational therapists:** evaluation of upper limb function and specific training for upper
27 limb, splinting and grasp formation, training of daily activities, environmental adaptations
28 advices of technical aids, wheelchair tests and training, recreation activities.

29 **Psychologists:** assessment of personal factors, support, adaptation to new abilities
30 (disability), rebuilding self- esteem.

31 **Social workers:** advice and help in social security fields, cooperation with the family and
32 local municipalities about financial support, house adaptation, returning to school or to work.
33 Founding solutions about the discharge place.

34 **Art therapists (Dance/Movement Therapists and Music therapists):** use of
35 psychotherapeutic concepts of movement and dance or music to support the intellectual,
36 emotional, and motor functions (including respiration functions) of the body.

37 **Nutritionists** consult about energy needs, protein needs, ideal body weight, fluid needs, and
38 fibre needs, especially for those who have pressure ulcers.

39 **The urologist** consults in complicated cases and selects patients for more specific urological
40 investigations and treatment. Perform urodynamic tests, intravesical botulin toxin injections
41 and surgical procedures in other hospital settings.

42 **The nursing staff** provide bowel management, intermittent catheterization. Nurses teach
43 self-catheterization, maintenance of skin integrity and ulcer prevention. They monitor
44 autonomic dysreflexia and autonomic instability. Nurses are responsible for positioning in
45 bed. They teach patients to perform everyday life skills. Nursing staff often has close
46 interactions with family members. (23-25)

47 **8. Diagnostic and assessment tools**

48 **Diagnostic equipment:** X-ray, laboratory, ultrasound, portable ultrasound for residual urine,
49 electrocardiography, electroencephalography, laborator

1 **Tools for clinical assessment** (9-14, 18, 19, 31)

2 Clinical assessments in the post –acute SCI rehabilitation covering different aspects of the
3 bio- psychosocial model of rehabilitation.

- 4 • International Standards of Neurological Classification of SCI (ISNCSCI), which
5 describe the motor level and completeness of injury,
- 6 • The Spinal Cord Independence Measure (SCIM) - independence scale specifically
7 developed for subjects with SCI.
- 8 • Brief and Comprehensive ICF Core Set for Spinal Cord Injury – early post-acute
9 situation
- 10 • Asworth Scale
- 11 • The Barthel Index
- 12 • ADL taxonomy
- 13 • Berg scale
- 14 • Walking index for spinal cord injury
- 15 • Nine-Hole Peg Test
- 16 • Visual Analogue Scale
- 17 • Dynamometry, Goniometry
- 18 • International SCI Data set
- 19 • International SCI Lower Urinary Tract Function Basic Data Set
- 20 • Autonomic Standards Assessment form
- 21 • Depression and cognitive function evaluation tests
- 22 • Classification of in-patient's functional capacity and the required assistance level
23 during patient's stay in rehabilitation ward for nursing
- 24 • Braden's scale is used for assessment of pressure ulcer risk
25 Nurse and nurse assistant provide regular skin check and repositioning every 1,5-2
26 hours patients with high pressure ulcer risk.
27 Every day visual checking has done for cutaneous pressure control.

28 **Instrumental assessment:**

- 29 • Video Gait analysis laboratory for gait assessment.
- 30 • Standing and sitting posture photo fixation.
- 31 • Seating evaluation with shear pressure map and sitting pressure map
- 32 • Spirometer (Care Fusion Micro lab) and Peak flow meter for respiratory function
33 control.
- 34 • Telemetry to evaluate the cardiac function while performing the activities and
35 exercise

36 **9. Specific therapeutic interventions**

- 37 • Botulin toxin injection for spasticity management.
- 38 • Cough Assist machine - a noninvasive therapy for safe removal of secretions in
39 patients with an ineffective ability to cough. High-level SCI often lack the muscle
40 strength and muscle control to create the full inhalation/explosive exhalation required
41 to cough and thereby remove bronchial secretions from the lungs.
- 42 • Endotracheal suctioning for secretion management.

- Management of ventilation depended patients, in cooperation with anesthesiologists
- Vacuum assisted closure for wound care management.
- Robotic devices –EksoGT; Andago, Erigo Pro; Armeo Spring; Armeo Senso; Virtual reality program MiraRehab

D. DISCHARGE PLANNING AND LONG TERM FOLLOW UP

1. Discharge criteria

The patient is discharged after post-acute rehabilitation program on day 45-60 in the case of tetraplegia, on day 30-45 in the case of paraplegia after admittance in the rehabilitation hospital as soon as the short term goals have been reached: assistive aids have been adapted for the needs of the patient, the patient has been taught how to use them, the patient is ready to perform everyday activities, if necessary, the relatives and/or assistants have been trained to help him/her.

Technical assistive aids are provided in the rehabilitation center during the rehabilitation course.

Different types of wheelchairs (passive, active, electrical, verticalized) and walkers, crutches as well as aids for carrying out everyday activities are accessible during rehabilitation and after discharge. The patient's functional condition is evaluated and the decision about the most suitable aids is made during the rehabilitation course .

Patient himself completes submission form for technical aids.

PRM physician, considering the team decision – physiotherapist, occupational therapist , social worker, psychologist and patient's opinion, writes the application addressed to the Technical Assistance Centre.

The Technical Assistance Centre is one of the structural units of National Rehabilitation center.

Newly injured person receives assistive aids out of turn. Generally the wheelchair and pressure relief cushion is provided while the patient is in the rehabilitation center. The wheelchair is being tried and adapted to the individual under the guidance of occupational therapist. Necessary assistive aids are provided from the government budget.

Persons with SCI have an access to wheelchairs – electrical, passive, active, and scooters. If the patient works or studies two wheelchairs are insured from the state budget. If the state's provided wheelchair does not suit the patient, he/ she can choose other option, receive the base funding from state budget and makes the co- payment and thus covers the necessary expenses. Participants of Paralympic sport activities are provided with special wheelchairs.

The social worker of SCI rehabilitation program provides the information about the possibilities to renovate or adapt the apartment or a house when the patient has entered the SCI program.

The social worker communicates with the municipality. Whether the changes and adaptation of the accommodation are implemented before the patient returns from the rehabilitation center very much depends on the municipality. In case the accommodation is not suitable for the patient, the rehabilitation course could be shortly prolonged till the problem is solved.

There are some cases when the patient has to be sent to the social care institution.

Patient's return back to her/his home environment or admission to nursing home has to be arranged.

Social worker before discharge informs the patient about possibilities of vocational reintegration after rehabilitation program. Social worker helps to clear formalities for applying to the State Social Integration Agency for requalification courses and training which are financed from the governmental budget.

Before discharge, patient's evaluation is performed for the necessity to participate in the follow-up program. The follow up program focuses on prevention of secondary complications,

1 functional testing and training. Rehabilitation specialists give attention to psychosocial and
2 sexual problems, as well as involvement in sports and recreation activities. Simultaneous
3 rehabilitation program for newly injured and experienced SCI patients is very helpful.
4 Conformity assessment of technical aids is executed for patients and new technical aids are
5 prescribed where appropriate.

6 Management of urinary disorders is reassessed for all SCI patients, once a year as a routine
7 US scan is executed as to kidneys and urinary bladder, clinical and biochemical tests are
8 performed, urodynamic testing is performed where appropriate, advisory services by
9 urologists and advisors of other specialties are available.

10 Functional changes are assessed. Experienced PRM physician evaluates neurological
11 symptoms. If necessary, in order to exclude syringomyelia, patient will be sent for magnetic
12 resonance imaging.

13 A training program concerning prevention of secondary complications is simultaneously
14 implemented both for newly injured and for experienced SCI patients. Thematic lectures about
15 prevention of secondary complications and discussions are organized by team members twice
16 a month. Support group activities are carried out jointly for newly injured and experienced SCI
17 patients

18 ***2. How patients are managed after the program?***

19
20 Most of SCI patients are discharged to return home where they can live with their relatives.
21 Home assistance is offered by social institutions and visiting nurse services. Those patients
22 who cannot take care of themselves after concluded rehabilitation are accommodated in social
23 institutions.(16)

24 The future rehabilitation plan has been designed in accordance with the level and severity of
25 the lesion. Before discharge from first rehabilitation course, the rehabilitation team make
26 further plan and follow up program together with the patient

27 If the first course, due to various conditions, has not been sufficient, a recurrent rehabilitation
28 course can be planned after a temporary stay at home. Subsequent control of patients in the
29 rehabilitation centre is carried out once a year. In case of changes in the patient's functional
30 condition, a recurrent rehabilitation course is prescribed as necessary. Patient's medical
31 record contains detailed recommendations for the patient and the general practitioner, and
32 also roughly states the time of the next rehabilitation review.

33 After discharge SCI patient with A and B /AIS of the lesion can receive home based
34 rehabilitation provided by physiotherapist and/or occupational therapist with periodical PRM
35 physician supervision. For patients with a low level and C; D/ AIS of the lesion, further
36 rehabilitation is planned as an out-patient course or as a course of rehabilitation in the day
37 care centre.

IV. Additional information about PRM organization

A. SAFETY AND PATIENT RIGHTS

1. Safety

The safety concerns of people in the unit where the program 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 people 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>Yes</u>
Periodic inspection	
Internal	<u>Yes</u>
External	<u>Yes</u>

2. Patient rights

Has your program 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 program?	<u>Yes</u>
Is the statement known to all personnel involved in delivering the program?	<u>Yes</u>
Is this checked periodically?	<u>Yes</u>
Is the statement made known to and is available to all persons visiting your unit?	<u>Yes</u>

3. Advocacy

Give at least one example of how your organization advocates for people your program deals with:
2007 Initiation and participation in Health Ministry Working group of creation of longterm rehabilitation system for ventilation depend patients. 2012 State started to provide financing for ventilation depend patient rehabilitation in NRC "Vaivari". We established system for this group of patients.
2013 participation in Health Ministry Working group of pressure ulcers prevention program.
2013/2014 In collaboration with NGO Latvian Spinal Cord Society -SCI prevention project for Youth (devoted diving accidents)
2013/2014 In collaboration with NGO "Apeirons" and "Verte" project for independent living camp and patient support group
2015-2019 In collaboration with NGO Latvian Spinal Cord Society annually organize "Sport for all"
2019 High intensity rehabilitation course with international leaders with the experience of spinal cord injury and high independence level

1 Our specialists actively address the public and government representatives on specific
 2 needs of this group of patients, call professional associations, nongovernmental
 3 organizations and media attention.

4 **B. PRM SPECIALISTS AND TEAM MANAGEMENT**

5 **1. PRM Specialists in the Programme**

6 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 program, not medical responsibility only?	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:	350 National credit points
The two primary functions for the PRM specialist in your Programme are to:	
Treat comorbidity	Yes/No
Assess the rehabilitation potential of the patient	Yes
Analyze & treat impairments	Yes/no
Coordinate interprofessional teams	Yes

7
 8 Beside the two primary functions of PRM physicians, a lot of work must be done in the
 9 treatment of comorbidity and secondary complications.

10 The leader of the SCI program has to attract attention of other professionals and officials in
 11 order to promote quality of SCI patients care.

12 The National recertification procedure or PRM specialists takes place every 5 years and
 13 requires a minimum of 250 credit points

14 **2. Staff devoted to this program**

15 Which rehabilitation professionals work on a regular basis (minimum of once every week) in your program? (give the number)	
PRM physicians	3
PRM resident doctors	0-2
Physiotherapists	5
Physiotherapists of swimming pool and fitness gym	2
Occupational therapists	2
Psychologists	1
Social workers	1
Nurses	7,5
Nurse assistants	13
Nutritionist	0,5
Art therapist	0,5
Masseur	0,5
Secretary	1
Peer	0,5

16 Consultants from other departments, Outpatient's Clinic and University clinics are also
 17 involved on demand.

18 The rehabilitation team is often complemented with assistive technicians, a speech and
 19 language therapists and plastic surgeons.

Horse riding instructors are also involved in the SCI rehabilitation program on demanded.
Representatives from NGOs are involved for performance of recreation and sports activities.

3. Team management

How often does your staff receive formal continuing education (mark as is)?	
In team rehabilitation:	Every year Every second year Other period <u>Not regularly</u>
In their own profession:	<u>Every year</u> Every second year Other period Not regularly
Do team activities in your rehabilitation programme include the following?	
Is the patient at the center 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 organization of multi professional team working include:	
Holding regular team meetings with patient's records only (more than 2 members)	<u>Yes</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>

Meetings of the multidisciplinary rehabilitation team in patient's absence take place twice a month, and team meetings in patient's presence are also organized twice a month.

C. INFORMATION MANAGEMENT

1. 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>No</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>

Each patient has his or her own medical file, which contains information on all rehabilitation courses (first and follow up). Each specialist has to fill own protocols.

2. Data about general organization

Does your program 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 program each year:	100
In your inpatient program:	
• What is the mean duration spent in therapy by patients on this program	22 Days
• How many hours a day do the patients spend in therapy.	4 Hours
Give the mean duration of stay spent in the program:	31 Days

Primary rehabilitation course for newly injured patients with longer length of stay and follow up program with short lengths of stay.

3. Programme monitoring and outcomes

Does your program have an overall monitoring system in addition to patient's records?	No
Are the long term outcomes of patients who have completed your programme regularly monitored?	
• Impairment (medical) outcomes:	Yes
• Activity/Participation (ICF) outcomes:	Yes
• Duration of follow up of the outcomes:	3-6 months 12 months longer
Do you use your outcome data to bring about regular improvements in the quality of your program's performance?	Yes
Do you make the long term overall outcomes of your program available to your patients or to the public?	No

Patients are followed-up after discharge every year. They undergo a control examination by a PRM physician. A routine urological testing is performed (urine delay measurements, US scanner test, blood and urine analysis).

Adequacy of the prescribed medical technical aids is checked. Likely secondary complications resulting from spinal cord injury are diagnosed and treated. Counselling related to sexual dysfunction is provided.

Some outcome data of our SCI program have been published and presented to international and local professional journals and meetings:

Nulle A Cross talk between bladder and bowel; How to achieve UEMS PRM program accreditation; PRM physicians in Latvia invited speaker of 21 th European PRM congress 2018, Vilnius, Lithuania

Nulle A, Tjurina U, Erts R, Vetra A. A profile of traumatic spinal cord injury and medical complications in Latvia. Spinal Cord Ser Cases. 2017 Dec 6;3:17088. doi: 10.1038/s41394-017-0002-2. eCollection 2017.

Nulle A Epidemiological profile and management of TSCI in Latvia invited speaker of 20 th European PRM congress 2016 Lisbon, Portugal and 7th Baltic Spinal Cord Society 2016 Haapsalu, Estonia

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- 25
- 26

V. Quality improvement

A. WHAT ARE THE MOST POSITIVE POINTS OF YOUR PROGRAM?

Effective patient planning and selection in cooperation with University Clinics and close professional contacts with neurosurgeons, orthopedic surgeons, plastic surgeons. Experienced multidisciplinary, professional staff with few staff turnover and well educated young colleagues.

24 hours/day availability of intensive therapy in anesthesiologist's presence.

Close cooperation with NGO's for recreational and sports activities.

Good technological equipment for rehabilitation

Wide range of sport and recreational activities

B. WHAT ARE THE POINTS TO IMPROVE IN YOUR PROGRAM?

Decrease risk of burn-out syndrome in the staff.

Urodynamic testing accessibility on regular basis.

Spasticity reduction with baclofen pump

Cooperation with the GPs after patients discharge.

C. WHAT ACTION PLAN DO YOU INTEND TO IMPLEMENT IN ORDER TO IMPROVE YOUR PROGRAM?

1. Extrinsic conditions that you wish to obtain

Specialized clinic for bladder and bowel management.

Extension of the spasticity program with Baclofen pump implantation.

Hand surgery consultation for tetraplegia hand

Sports teacher for sport activities (wheelchair basketball) and canoe for balance training in swimming pool and/or at sea.

Locomat technology

2. Intrinsic improvement of the program

Implementation of ICF Core set in clinical practice for assessment and documentation

Implementation of International SCI data core set

Teambuilding and staff training.

Learning workshop about using specific assessment tools for all team members.

Development of Electronic medical records.

Psychological support and staff training

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