



Swiss Spinal Cord Injury Study (SwiSCI) Questionnaire 2 2017

Note:

This is the English Reference questionnaire of the SwiSCI Community Survey 2017 intended to be used for research and communication purposes, but it has not been used as such for data collection. The SwiSCI Community Survey 2017 has only been conducted with questionnaires in the official Swiss languages German, French and Italian.

Working life

In this section we would like to ask you some questions about your professional situation after the onset of the spinal cord injury.

1. Did you receive vocational integration services after your spinal cord injury?

- No
- Yes, please specify:

Check all that apply

- Vocational counselling *Support and guidance with the selection of a future job, occupation or education and on the labor market*
- Job Coaching *Professional support during the phase of work integration*
- Courses, Acquisition of general, not job-related skills *e.g., language or computer courses*
- Vocational training or re-training *Training towards a specific occupation, e.g. training as a clerk or a CAD drafter*
- School or vocational education *Taking up a new apprenticeship or a new study*

2. After your discharge from initial inpatient rehabilitation, how long did it take before you started or resumed paid work (incl. work attempts)?

- I never worked after initial rehabilitation >>> *go to question 56*
- I started working immediately after initial rehabilitation
- I resumed paid work after (✍)..... years and (✍)..... month after initial rehabilitation

The following four questions refer to your first paid job after the onset of your spinal cord injury.

3. What was the name or title of your first paid job after spinal cord injury onset? *Please be as specific as possible, e.g., not just 'clerk' but 'bank clerk'; not just 'manager' but 'sales manager'*

✍

4. Did you pursue this job with the same employer as before your spinal cord injury onset?

- Yes
- No

5. Did you ever change your job after having taken up your first paid job after spinal cord injury onset?

This also includes job changes within an institution

- Yes
- No >> *go to question 7*

6. What were the reasons for the job change?

Check all that apply

- Job did not match my interests
- Physical overload
- Cognitive over- or underload (incl. missing professional expertise)
- Psychological overload e.g. Problems in dealing with strain or responsibility
- Lack of possibility to arrange my work tasks independently
- Problems with the accessibility of the workplace e.g. to or within the building
- Problems with the commute e.g. poor reachability of the workplace, long commute
- Problems with work colleagues
- Problems with supervisor
- Professional advancement or promotion
- More lucrative job offer
- Other, namely: *✍*

7. Are you currently engaged in paid work?

- Yes
- No, but I worked again after spinal cord injury onset >> *go to question 32*
- No, I did not work anymore after spinal cord injury onset >> *go to question 56*

8. For how long are you working in your current job?

✍ Years *✍* Month

9. How many persons are you leading either directly or indirectly in your job?

- None
- 1-5 persons
- 6-10 persons
- 11-19 persons
- 20 or more persons

How much problems do you have with the following things in your job?

		1 <i>No problem</i>	2	3	4	5 <i>Extrem problem</i>
10.	How much of a problem is getting things done as required at work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11.	How much of a problem do you have in accessing your workplace? <i>e.g., access to the building, your office or the toilets</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How well are your needs regarding the following aspects met at your job?

	Completely	To a large extent	To some extent	To a small extent	Not at all	I don't have such a need
12. Do you have the assistive devices that you need for work? <i>e.g., assistive computer devices, adjustable desks or arm/hand braces or prosthetics</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Independence in arranging your work tasks <i>e.g. independent decision making what to do when</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Further education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Support from work colleagues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Support from supervisor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions refer to your present job. For each statement, please indicate whether you strongly agree, agree, disagree or strongly disagree

	Strongly disagree	Disagree	agree	Strongly agree
17. Considering all my efforts and achievements, I receive the respect and prestige I deserve at work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Considering all my efforts and achievements, my salary is adequate.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. My job promotion prospects are poor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. My job security is poor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. I am under constant time pressure due to a heavy work load.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. I have many interruptions and disturbances while performing my job.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. I am currently thinking about looking for a new job.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. How often do you experience stress at work?	<input type="radio"/> Always <input type="radio"/> Mostly <input type="radio"/> Sometimes <input type="radio"/> Rarely <input type="radio"/> Never			

25. How good would you generally rate your job performance?



	<i>Much higher than required</i>	<i>Higher than required</i>	<i>Just right</i>	<i>Lower than required</i>	<i>Much lower than required</i>
26. How well do your abilities match the <i>physical</i> demands of your job?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. How well do your abilities match the <i>cognitive</i> demands of your job?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. How well do your abilities match the <i>psychological</i> demands of your job? <i>e.g. dealing with strain or responsibility</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

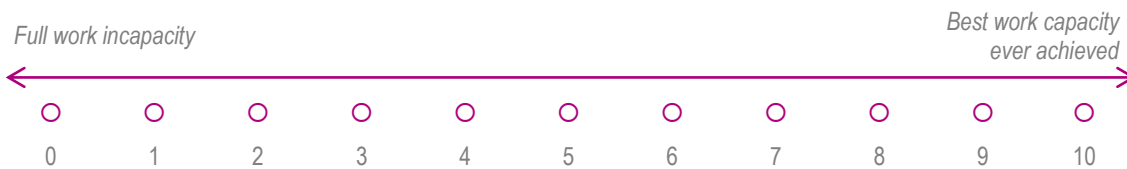
29. How well does your job match your interests?

- Not at all
- Somewhat
- Partly
- Predominantly
- Completely

30. How satisfied are you with your job overall?

- Extremely satisfied
- Very satisfied
- Rather satisfied
- Partly satisfied/partly dissatisfied
- Rather dissatisfied
- Very dissatisfied
- Extremely dissatisfied

31. How many points would you give for your current work capacity if you compare it with your best work capacity ever achieved after onset of your spinal cord injury?



>> Go to question 56

>> The following Questions 32-55 are only for persons who are currently not engaged in paid work.

>> If you did not work anymore after your spinal cord injury onset, please go to Question 56. The following Questions refer to your last job after onset of your spinal cord injury.

32. For how long were you working in your last job?

..... Years Months

33. How many persons were you leading either directly or indirectly in your job?

- None
- 1-5 persons
- 6-10 persons
- 11-19 persons
- 20 or more persons

How much problems did you have with the following things in your job?

	1 No problem	2	3	4	5 Extrem problem
34. How much of a problem did you have in accessing your workplace? <i>e.g., access to the building, your office or the toilets</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35. How much of a problem was getting things done as required at work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How well were your needs regarding the following aspects met at your last job?

	Completely	To a large extent	To some extent	To a small extent	Not at all	I don't have such a need
36. Did you have the assistive devices that you needed for work? <i>e.g., assistive computer devices, adjustable desks or arm/hand braces or prosthetics</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37. Independence in arranging your work tasks <i>e.g. independent decision making what to do when</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38. Further education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39. Support from work colleagues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40. Support from supervisor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate how much you agree with the following statements regarding your last job.

	Strongly disagree	disagree	agree	Strongly agree
41. Considering all my efforts and achievements, I received the respect and prestige I deserved at work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. Considering all my efforts and achievements, my salary/income was adequate.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. My job promotion prospects were poor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. My job security was poor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45. I was under constant time pressure due to a heavy work load.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46. I had many interruptions and disturbances while performing my job.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. I was thinking about looking for a new job.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

48. How often did you experience stress at work?

- Always
- Mostly
- Sometimes
- Rarely
- Never

49. How good would you generally rate your job performance at that time?



The following questions relate to the requirements of your last job.

	Much higher than required	Higher than required	Just right	Lower than required	Much lower than required
50. How well did your abilities match the <i>physical</i> demands of your job?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51. How well did your abilities match the <i>cognitive</i> demands of your job?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52. How well did your abilities match the <i>psychological</i> demands of your job? e.g. dealing with strain or responsibility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

53. How well did your job match your interests?

- Not at all
- Somewhat
- Partly
- Predominantly
- Completely

54. How satisfied were you with your job overall?

- Extremely satisfied
- Very satisfied
- Rather satisfied
- Partly satisfied/partly dissatisfied
- Rather dissatisfied
- Very dissatisfied
- Extremely dissatisfied

55. In which year were you last engaged in paid work?

 (e.g. 2012)

Medical Services

56. **Who were the health care providers you visited, or who visited you in your home, in the last 12 months.** *e.g. for check-up visits, follow-up, routine treatment or because of acute health problems .*

Check all that apply

Number of visits in the last 12 months

- | | |
|---|--------------|
| <input type="checkbox"/> Primary care physician / general practitioner | <i>.....</i> |
| <input type="checkbox"/> Rehabilitation physician / spinal cord injury physician | <i>.....</i> |
| <input type="checkbox"/> Other specialist physician <i>e.g., surgeon, gynecologist, psychiatrist, ophthalmologist</i> | <i>.....</i> |
| <input type="checkbox"/> Nurse or midwife | <i>.....</i> |
| <input type="checkbox"/> Dentist | <i>.....</i> |
| <input type="checkbox"/> Dental hygienist | <i>.....</i> |
| <input type="checkbox"/> Psychologist | <i>.....</i> |
| <input type="checkbox"/> Speech therapist | <i>.....</i> |
| <input type="checkbox"/> Occupational therapist | <i>.....</i> |
| <input type="checkbox"/> Physiotherapist | <i>.....</i> |
| <input type="checkbox"/> Chiropractor | <i>.....</i> |
| <input type="checkbox"/> Masseur | <i>.....</i> |
| <input type="checkbox"/> Alternative medicine practitioner <i>e.g. naturopath, acupuncturist</i> | <i>.....</i> |
| <input type="checkbox"/> Pharmacist | <i>.....</i> |
| <input type="checkbox"/> Home health care worker | <i>.....</i> |
| <input type="checkbox"/> Other, please specify: <i>.....</i> | <i>.....</i> |
| <input type="checkbox"/> Other, please specify: <i>.....</i> | <i>.....</i> |
| <input type="checkbox"/> I did not visit any health care provider in the last 12 months | |

57. **Over the last 12 months, have you been an in-patient in a hospital, rehabilitation facility or another care, not counting cure stays?** *Count all stays where you have stayed overnight.*

- Yes:
..... times
..... total number of days
- No

58. **Have you been to a hospital outpatient clinic or polyclinic in the last 12 months?**

- Yes, please specify:
Check all that apply
- As emergency, unplanned: *.....* times
- For planned treatment: *.....* times
- No

59. Have you been a patient at one of the Swiss Paraplegic Centres over the last 12 months?

- No
- Yes, please specify:

Check all that apply

	<i>REHAB Basel</i>	<i>Uniklinik Balgrist</i>	<i>SUVA Clinique Sion</i>	<i>SPZ Nottwil</i>	<i>Site Plein Soleil Lavigny</i>	<i>Ambulatorium Bellinzona</i>
For a check-up visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For outpatient treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For an inpatient hospital stay	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

60. Do you receive support at home for everyday activities, such as housework or self-care?

- No
- Yes, by the following persons:

Check all that apply

- | | |
|---|--|
| <input type="checkbox"/> Partner / Spouse | Number of hours per week: <i>/</i> |
| <input type="checkbox"/> Children | Number of hours per week: <i>/</i> |
| <input type="checkbox"/> Parents | Number of hours per week: <i>/</i> |
| <input type="checkbox"/> Siblings | Number of hours per week: <i>/</i> |
| <input type="checkbox"/> Friends | Number of hours per week: <i>/</i> |
| <input type="checkbox"/> Spitex | Number of hours per week: <i>/</i> |
| <input type="checkbox"/> Assistance | Number of hours per week: <i>/</i> |
| <input type="checkbox"/> Other persons, please specify: <i>/</i> | Number of hours per week: <i>/</i> |
| <input type="checkbox"/> Other institutions, please specify: <i>/</i> | Number of hours per week: <i>/</i> |

61. What compensation do you receive for your care support?

Check all that apply

- Helplessness Compensation
- Care allowance health insurance, accident insurance, military insurance
- Supplementary benefits
- Assistance contribution (IV)
- Private insurance services
- Others, namely: */*
- I do not receive any financial support for care services

62. Have you ever applied for an assistant's allowance?

- Yes
- No; why not? */*

63. Who is your first point of contact for health problems regarding your spinal cord injury?

- General practitioner
- Specialist with own practice
- Specialist at one of the four paraplegic centres
- Others, namely: */*

Currently, there are four big outpatient clinics in Switzerland specialized in spinal cord injury (Basel, Nottwil, Sion and Zürich). Please imagine the following scenario:

In the future, there is an additional smaller outpatient clinic that will be situated closer to your home town than the four big outpatient clinics. This smaller outpatient clinic provides the same expertise in paraplegia as the four big outpatient clinics. The smaller outpatient clinic offers less diagnostic and therapeutic services than the four big outpatient clinics. If needed, the smaller outpatient clinic can refer you to one of the bigger outpatient clinics.

64. Which of the following statements is true in your case?

- I would prefer to go to one of the four big outpatient clinics.
- I would prefer to go to the closer smaller outpatient clinic.

65. Do you have a personal GP?

- No >> please go to question 68
- Yes

66. How long is the way to your personal GP?

Vehicle driving time: 

67. How satisfied are you with the services of your personal GP?

- Very satisfied
- Rather satisfied
- Neither satisfied nor dissatisfied
- Rather dissatisfied
- Very dissatisfied
- I do not use the service

68. How satisfied are you with the services of the specialist paraplegic centres?

- Very satisfied
- Rather satisfied
- Neither satisfied nor dissatisfied
- Rather dissatisfied
- Very dissatisfied
- I do not use the service

69. How satisfied are you with the services of the hospitals?

- Very satisfied
- Rather satisfied
- Neither satisfied nor dissatisfied
- Rather dissatisfied
- Very dissatisfied
- I do not use the service

70. How satisfied are you with the services of Spitex?

- Very satisfied
- Rather satisfied
- Neither satisfied nor dissatisfied
- Rather dissatisfied
- Very dissatisfied
- I do not use the service


For your last visit to a health care provider, how would you rate the following:		<i>Very good</i>	<i>Good</i>	<i>Neither good nor bad</i>	<i>Bad</i>	<i>Very bad</i>
71.	...your experience of being treated respectfully?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
72.	...how clearly health care providers explained things to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
73.	...your experience of being involved in making decisions for your treatment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		<i>Very satisfied</i>	<i>Satisfied</i>	<i>Neither satisfied nor dissatisfied</i>	<i>Dissatisfied</i>	<i>Very dissatisfied</i>
74.	In general, how satisfied are you with how the health care services are run in your area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

75. In the last 12 months, have you needed health care but did not get it?

- No
- Yes. Which reasons best explain why you did not get the health care you needed?

Check all that apply

- Could not afford the cost of the visit
- There was no service
- No transport available
- Could not afford the cost of transportation
- You were previously badly treated
- Could not take time off work or had other commitments
- The health care provider's drugs or equipment were inadequate
- The health care provider's skills were inadequate
- You did not know where to go
- You tried but were denied health care
- You thought you were not sick enough
- Other, please specify: 

Supply of assistive devices

76. Name up to five technical aids that are particularly important for you:

1)  (Free text field)

2)  (Free text field)

3)  (Free text field)

4)  (Free text field)

5)  (Free text field)

What are your current information needs in the following three areas?

	No need	Very low	Rather low	Rather large	Very large
77. Procurement of aids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
78. Availability of aids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
79. Use and maintenance of aids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the following, the quality of the provision of assistive devices will be discussed. Please indicate to what extent the following statements are correct for you.

	Not true	Hardly true	It's more like	That's right
80. I have the equipment I need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
81. I get good advice about aids.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
82. I go to a lot of trouble to get my aids.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
83. Some of my aids are of insufficient quality.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
84. The maintenance of my aids is insufficient.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
85. My aids cost me a lot of money.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
86. I have to do without certain aids due to high costs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please enter in the following table the availability and your needs of the mentioned assistive devices.

The following selection of assistive devices is based on results of the SwiSCI 2012 survey.

	Need of the aid		Availability of the aid		Frequency of use			
	<i>I have need</i>	<i>I have no need</i>	<i>At my disposal</i>	<i>Not at my disposal</i>	<i>Less than once per month</i>	<i>1-3 times a month</i>	<i>1-6 times a week</i>	<i>daily</i>
87. Electrical support <i>e.g. e-motion</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> » go to question 88	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
88. Wheelchair power unit <i>e.g. Swiss-Trac, wheel-e</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> » go to question 89	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
89. Sports wheelchair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> » go to question 90	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
90. Walking frame	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> » go to question 91	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
91. Lift / hoist / Patient lift	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> » go to question 92	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
92. Ceiling lift	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> » go to question 93	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
93. Arm splint	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> » go to question 94	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
94. Electrical stimulation to improve the ability to walk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> » go to question 95	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
95. Electrical support <i>e.g. e-motion</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> » go to question 96	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please enter in the following table the availability and your requirements of the mentioned assistive devices or structural measures.

	Need of the aid		Availability of the aid	
	<i>I have need</i>	<i>I have no need</i>	<i>At my disposal</i>	<i>Not at my disposal</i>
96. Environmental monitoring devices <i>e.g. Yesmes, Omni, speech control</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
97. Wheelchair-accessible kitchen worktop	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
98. Wheelchair-accessible sink	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
99. Height-adjustable kitchen worktop	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions are about tools that do not yet exist.

100. For which tasks of daily life do you have problems, which could be greatly facilitated in the future by a new type of aid?



101. What could this tool look like?



102. Which of the following activities have you carried out for private purposes on the Internet in the last three months?

Check all that apply

- Participate to a social network, e.g., Facebook, Twitter
- Use services related to travel and accomodation
- Play video or computer games
- Search for health-related information
- E-Banking *pay bills through your bank or postal account, check an account statement, etc.*
- Make an appointment with a doctor via the website of a hospital / medical practice


103. What new online services related to your spinal cord injury would you like to see?



104. Have you ever received direct help from the Swiss Paraplegic Foundation?

- No >> *weiter zu Frage 107*
- Yes, namely

Check all that apply

- Apartment adaptation
- Support of mobility e.g. car adaptation
- Adaptation of the workstation
- Purchase of sports equipment
- Purchase of equipment
- Other, please specify: 

How do you assess the impact of all the direct support you have received from the Swiss Paraplegic Foundation in terms of independence and participation in social life?

	No improvement	Minor improvement	Significant improvement	Very big improvement
105. Independence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
106. Participation in social life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Quality of life

The next questions are about how you rate your quality of life over the last 14 days. Please keep in mind your standards, hopes, pleasures and concerns.

107. How would you rate your quality of life?

- Very poor
- Poor
- Neither poor nor good
- Good
- Very good

	<i>Very dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither satisfied nor dissatisfied</i>	<i>Satisfied</i>	<i>Very satisfied</i>
108. How satisfied are you with your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
109. How satisfied are you with your ability to perform your daily living activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
110. How satisfied are you with yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
111. How satisfied are you with your personal relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
112. How satisfied are you with the conditions of your living place?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions include a set of words that describe various feelings and perceptions. Please indicate to what extent you felt this way during the last week. Read each word and tick the box with the most appropriate answer next to the word. It is not important in which concrete situation you have felt like that in the past week.

I was / I felt...	<i>Very slightly or not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>Quite a bit</i>	<i>Extremely</i>
113. Upset	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
114. Hostile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
115. Alert	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
116. Ashamed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
117. Inspired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
118. Nervous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
119. Determined	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
120. Attentive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
121. Afraid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
122. Active	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Optimism and personal experience

123. Are you often plenty of strength, energy and optimism?

Never Always

←—————→

○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○

0 1 2 3 4 5 6 7 8 9 10

The following questions are about personal views and experiences. Please tick the box that best describes your view.

	1 Not at all	2	3	4	5 Completely
124. How confident are you that you can maintain contact with people who are important to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
125. How confident are you that you can maintain good health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
126. Do you worry about what might happen to you in the future? <i>e.g., thinking about not being able to look after yourself, or being a burden to others in the future</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
127. Do you feel that you will be able to achieve your dreams, hopes, and wishes?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
128. Do you think that living with your spinal cord injury has made you a stronger person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
129. Do you get to make the big decisions in your life? <i>e.g., deciding where to live, or who to live with, how to spend your money</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
130. Do you feel included when you are with other people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
131. Do you have the feeling that you lack contact with other people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
132. Do you feel isolated from others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

133. In the last 12 months, have you experienced any major adverse life event?

e.g., a serious health condition or accident, a serious conflict with other persons, divorce or death of a loved one

- No
- Yes, please specify: 

Mood

Please read the following statements carefully and tick the box which best describes how you felt in the past week.

134. I still enjoy the things I used to enjoy.

- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

135. I can laugh and see the funny side of things.

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

136. I feel cheerful.

- Not at all
- Not often
- Sometimes
- Most of the time

137. I feel as if I am slowed down.

- Nearly all the time
- Very often
- Sometimes
- Not at all

138. I have lost interest in my appearance.

- Definitely
- I don't take as much care as I should
- I may not take quite as much care
- I take just as much care as ever

139. I look forward with enjoyment to things.

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

140. I can enjoy a good book or radio or TV program.

- Often
- Sometimes
- Not often
- Very seldom

Evaluation of own skills

Please read each statement carefully and tick the box that best describes you.

	<i>Not at all true</i>	<i>Hardly true</i>	<i>Moderately true</i>	<i>Exactly true</i>
141. If someone opposes me, I can find the means and ways to get what I want.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
142. I am confident that I could deal efficiently with unexpected events.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
143. Thanks to my resourcefulness, I know how to handle unforeseen situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
144. When I am confronted with a problem, I can usually find several solutions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
145. I can usually handle whatever comes my way	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Below is a list of statements dealing with your general feelings about yourself. Please indicate how strongly you agree or disagree with each statement.

	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
146. I feel that I have a number of good qualities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
147. I certainly feel useless at times.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
148. I feel that I'm a person of worth, at least on an equal plane with others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
149. I take a positive attitude toward myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Life goals

The following questions each consist of two opposing statements concerning aims and sense of life. The numbered boxes stand for the increments between these opposites. Please tick the box which in this moment best describes your view.

150. In life, I have:



151. My personal existence is:



152. In achieving life goals, I have:



153. I have discovered:



Support from others

If necessary, in your opinion, to what extent can the following people provide you with practical help, this means concrete help or useful advice?

Even people who do not need any help should consider possible ways in which they could get support; practical help = for example doing the shopping for them when sick, taking them to the doctor or giving useful advice in case of problems or when looking for specific information.

Please tick „not applicable“ if these persons don't exist.

		<div style="display: flex; justify-content: space-between;"> Not at all to a great deal </div>											
		0	1	2	3	4	5	6	7	8	9	10	n/a
154.	Partner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
155.	Family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
156.	Friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

To what extent can the following people be available in case of need and show understanding, by talking with you.

Even the persons who do not need any help should consider possible ways in which they could get support.

Please tick „not applicable“ if these persons don't exist.

		<div style="display: flex; justify-content: space-between;"> Not at all to a great deal </div>											
		0	1	2	3	4	5	6	7	8	9	10	n/a
157.	Partner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
158.	Family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
159.	Friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Pain

The following questions are about pain.

>> In case you did not experience any pain during the past week, please proceed with question 166.

160. Please rate your pain by circling the number that best describes your pain at its worst in the last week.

No pain Pain as bad as you can imagine

0 1 2 3 4 5 6 7 8 9 10

161. What kind of pain did you experience during the past week?

Check all that apply

- Pain of the musculoskeletal system (*muscles, joints, bones*) above or at level of your lesion (e.g.: *Pain in your shoulders, hands, neck*)
- Pain of internal organs (e.g.: *bowel, bladder, kidneys, abdomen*)
- Pain due to spasm
- Neuropathic pain above the lesion level
- Neuropathic pain at the lesion level
- Neuropathic pain beneath the lesion level (*phantom pain*)
- Headache, toothache
- Other, please specify:

162. Please indicate the localization(s) of the pain of your musculoskeletal system (muscles, joints, bones):

Check all that apply

- | | |
|---------------------------------------|---|
| <input type="checkbox"/> Head | <input type="checkbox"/> Abdomen |
| <input type="checkbox"/> Neck | <input type="checkbox"/> Hip |
| <input type="checkbox"/> Back / spine | <input type="checkbox"/> Buttocks |
| <input type="checkbox"/> Shoulder | <input type="checkbox"/> Thigh |
| <input type="checkbox"/> Upper arm | <input type="checkbox"/> Knee |
| <input type="checkbox"/> Elbow | <input type="checkbox"/> Lower leg |
| <input type="checkbox"/> Forearm | <input type="checkbox"/> Ankle joint / foot |
| <input type="checkbox"/> Wrist / hand | <input type="checkbox"/> Others, please specify: |

Mark the box beside the number that describes how, during the last week, pain has interfered with your:

163. General Activity

Does not interfere Strong interference

0 1 2 3 4 5 6 7 8 9 10

164. Mood



165. Sleep



Activities of daily living

The following section is about problems you experience in your life. Please take both good and bad days into account.

In the <u>last 4 weeks</u> , how much of a problem have you had...	1 No problem	2	3	4	5 Extreme problem
166. ... carrying out daily routine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
167. ... handling stress?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
168. ... doing things that require the use of your hands and fingers, such as picking up small objects or opening a container?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
169. ... getting where you want to go?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
170. ... using public transportation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
171. ... using private transportation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
172. ... looking after your health, eating well, exercising or taking your medicine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
173. ... getting your household tasks done?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
174. ... providing care or support for others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
175. ... interacting with people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
176. ... with intimate relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
177. ... doing things for relaxation or pleasure?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
178. ... with shortness of breath during physical exertion?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	1 No problem	2	3	4	5 Extreme problem
179. Are you able to sit unsupported? <input type="radio"/> No <input type="radio"/> Yes → How much of a problem is sitting for long periods such as 30 minutes?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
180. Are you able to stand unsupported? <input type="radio"/> No <input type="radio"/> Yes → How much of a problem is standing for long periods such as 30 minutes?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

These questions ask about your ability to do activities that involve mobility. Select the response that best describes your ability to do the activity without help from another person but using the equipment or devices you normally use (e.g., transfer boards lifts, hospital bed).

Are you able to...	<i>Without any difficulty</i>	<i>With a little difficulty</i>	<i>With some difficulty</i>	<i>With much difficulty</i>	<i>Unable to do</i>
181. ...get up off the floor from lying on your back?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
182. ...push open a heavy door?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
183. ...moving from sitting at the side of the bed to lying down on your back?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Discrimination

184. Have you ever been discriminated against because of your spinal cord injury?

- Yes
- No >> *Question 186*

185. Have you contacted an appropriate body about this?

- Yes

To whom did you turn?

Check all that apply

- Disability organisation or other specialist office *e.g. SPV, Pro Infirmis, Inclusion Handicap*
- Authorities *e.g. cantonal health or social department*
- Employer
- Others, please specify: *✍*

Has the problem been solved?

- Yes
- partly
- No

- No

Check all that apply

- I solved the problem myself.
- I didn't know exactly how to approach the problem.
- I'm believing that no agency or organization can solve the problem.
- It was too much work for me.
- Other, please specify: *✍*

Search for health information

186. How confident are you that you have or can get the information you need to minimize the occurrence of spinal cord injury related complications?

- Not at all
- Little
- To some extent
- Very
- Completely

187. Are there aspects related to your spinal cord injury that you would like more information about?


- Yes, about what topics



- No

188. What sources do you mainly use to obtain spinal cord injury related information?

Check all that apply

- Other people with SCI
- Patients' organizations
- Healthcare professionals *e.g. doctors, nurses, social workers*
- Online media
- Print media
- Other, please specify: 

Please feel free to add comments and remarks here: