Health Sector Transition and Recovery Programme

SIRC PD 6: Report on Community Based Rehabilitation Follow Up

SPINAL INJURY REHABILITATION CENTRE

APRIL 2016

स्पाइनल इन्जरी पुनर्स्थापना केन्द्र
Spinal Injury Rehabilitation Centre
A Project of Spinal Injury Sangh Nepal

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This document addresses the requirements of SIRC's Payment Deliverable 6 under the Health Sector Transition and Recovery Programme:

'200 former and recently discharged patients of SIRC living in affected districts have received follow-up home visit services support'.

This report has been funded by UKaid from the UK Government's Department for International Development (DFID); however the views expressed do not necessarily reflect the UK government's official policies.

Contents

List of Acronyms

ASIA	American Spinal Injuries Association
CBR	Community Based Rehabilitation
HI	Handicap International
IMC	International Medical Corps
IRU	International Rehabilitation Unit
M&E	Monitoring and Evaluation
MDT	Multi-drug Therapy
NGO	Non-Government Organisation
NHSSP	Nepal Health Sector Support Programme
SCI	Spinal Cord Injury
SIRC	Spinal Injury Rehabilitation Centre
TPO	Transcultural Psycho-social Organization Nepal

1. Introduction

Conservative estimates are that around 300 people sustained spinal cord injuries (SCIs) as a result of Nepal's Spring 2015 earthquakes. The Spinal Injury Rehabilitation Centre (SIRC) works to help patients suffering from SCIs get the rehabilitation treatment they need and resettle back home, with an emphasis on helping them become as independent as possible. The rehabilitation process includes care beyond the treatment facility through systematic follow up of each patient in the community. Such inputs aim to ensure that rehabilitation goals are on track, any complications are identified and that the knowledge, skills and confidence of family members and carers to support rehabilitation processes are strengthened.

The rationale for carrying out community rehabilitation visits is to:

- update the post-rehabilitation status of discharged patients
- better understand each patient's living circumstances in the community
- provide necessary guidance, aids, supplies and other assistance as required.

The overall purpose of the assignment was to provide *follow-up home visit support services to 200 ex-SIRC patients living in 14 earthquake affected districts* with specific objectives being to:

- provide patients with basic therapy and teach them self-care techniques
- provide a referral and 'sign-posting' service for patients requiring more intensive care and rehabilitation. This to include referral to district and national hospitals, Handicap International (HI) out-patient/social work services and, as required, referral to the Spinal Injury Rehabilitation Centre (SIRC)
- liaise and work with representatives of local governments and communities, non-governmental organisations (NGOs) and private sector groups to ensure the successful resettlement of injured earthquake victims.

In completing the assignment, the following major tasks were carried out:

- five community based rehabilitation (CBR) out-reach workers were recruited for the 14 affected districts
- home visits were conducted, specialised education and training provided, and essentials such as urinary catheters and consumables supplied
- referrals were organised and ex-patients with SCIs sign posted to other relevant services.
- home visits were complemented with telephonic follow-up and, through this, the provision of further information and advice
- CBR workers carried out a comprehensive evaluation assessment capturing information on the physical, emotional and social wellbeing of ex-patients including economic/vocational assessments
- lessons learned by CBR workers in developing an evidenced based model of CBR services provided by SIRC were documented.

The tools and processes used included:

- the preparation of a CBR an evaluation form for ex-patients during support visits
- an analysis of information aggregated across all 14 districts completed by five CBR workers

- reflections of CBR workers on their support across 14 districts on implementing an evidenced based model for CBR in Nepal
- the identification of CBR workers needs to support the delivery of effective support to 200 ex-patients.

2. Methodology

A single data collection tool was used by the visiting CBR worker during each follow up assessment with patients who had previously been discharged by SIRC. This form is extensive and takes account of the holistic needs of individuals with SCIs including their health, social, vocational, economic and sexual status at the time of the interview. By paying attention to these various aspects of a person's life, a full picture of their health can be drawn to identify gaps, either individually or collectively, which can then be supported by the CBR worker connected to SIRC's support systems. A copy of the form can be found in Annex II.

Each CBR worker followed the same protocol in completing the follow up form on a one to one basis and asked the same set of questions. The information obtained was then returned to a central point at the Social Department at SIRC where all data were entered into a secure and confidential database. As of the end of February 2016, 217 follow up visits with corresponding assessments using this form had been completed. These visits are currently continuing. Within this cohort, the CBR workers were informed by family members that 20 ex-patients had subsequently died and that they could therefore not provide further information beyond that in the initial assessment. The remaining sections of the assessment tool were completed and made available for analysis for 197 individuals.

3. Findings

A detailed and exhaustive analysis of information in the dataset for 217 ex- patients was carried out by the evaluation consultant. To aid the presentation of the findings, the sub components of the assessment tool served as natural dividers for the presentation of results. Data analysis is broken down into the following sections:

3.1 Demographics of Patients

- Admitted to SIRC between 2002-2015
- The largest group in the database was from 2015 (n=32)
- Discharge dates ranged between 2002-2015
- Duration at SIRC as a patient ranged from one week to two years
- 34% of patients were female and 66% male
- Ages ranged from 16 to 91 years of age
- 64% of patients were married, 28% single, 5% divorced and 3% widowed
- 26% had a job outside of the home (not including housewives)

- 35% were principally cared for by their father, followed by 27% by their wife 17% by their husband.

3.2 Accommodation

- 81% of patients were resident in the hills of Nepal
- 19% were from the Kathmandu valley
- The districts in which follow up assessments were completed are outlined in Table 1:

Table 1: Areas in which follow up assessments took place

Area	Number of patients in follow up
Kathmandu	34
Sindhuli	27
Kavre	19
Nuwakot	26
Gorkha	15
Lalitpur	12
Ramechhap	21
Dhading	10
Okhaldhunga	2
Dolakha	7
Siindhualchok	8

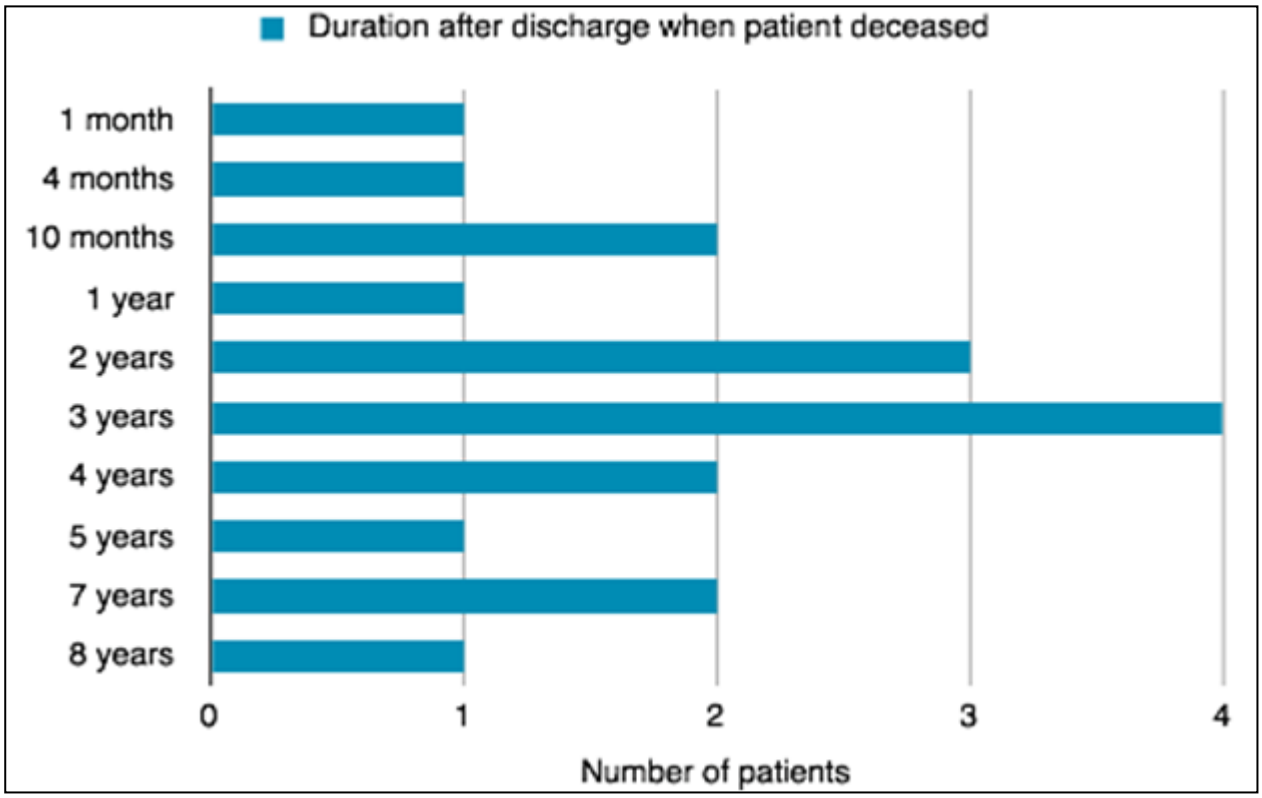
- Thirty five percent were in temporary accommodation including tents. Two of these individuals were injured during the earthquake with the others already having sustained an SCI at the time of the earthquake
- Sixteen percent were living in care facilities such as BIA Foundation or the Khagendra New Life Centre[1]
- Seventy six percent had had their homes adapted to some degree to suit their physical and practical needs
- Fifty five percent had had to move communities but it is unclear if this was due to the earthquake or as a result of their injury, or both
- When asked if home modifications were needed in their houses, 27% stated that these were still required if they were to have access to all parts of their home
- The area identified most frequently as needing to be modified to improve or gain access was the toilet (15%). This was followed by access to a water tap (12%)
- In 31% of cases, access to areas in the home such as the kitchen, porch, bedroom and toilet had already been modified to accommodate the mobility needs of the patient.

[1] http://www.khagendranewlife.com, http://bia-foundation.org/about-bia/

3.3 Deceased Ex-patients

- Figure 1 illustrates the death rate and duration of patients included in this follow up report based on when they were discharged from SIRC. Inspection of the graph shows that the largest number of patients died within three years of leaving the care of SIRC.
- Twenty percent of patients in this group were female and 80% were male, with an average age of 44 (ranging from 23 to 88 years of age).

Figure 1: Time of death after discharge from SIRC



- Ninety five of the deceased ex-patients died as a result of a pressure wound (only one individual was cited as having died from being elderly).

Note: From this point on in the analysis, data for deceased individuals were not available and the total count on which the analysis proceeds is based on 197 ex- patients.

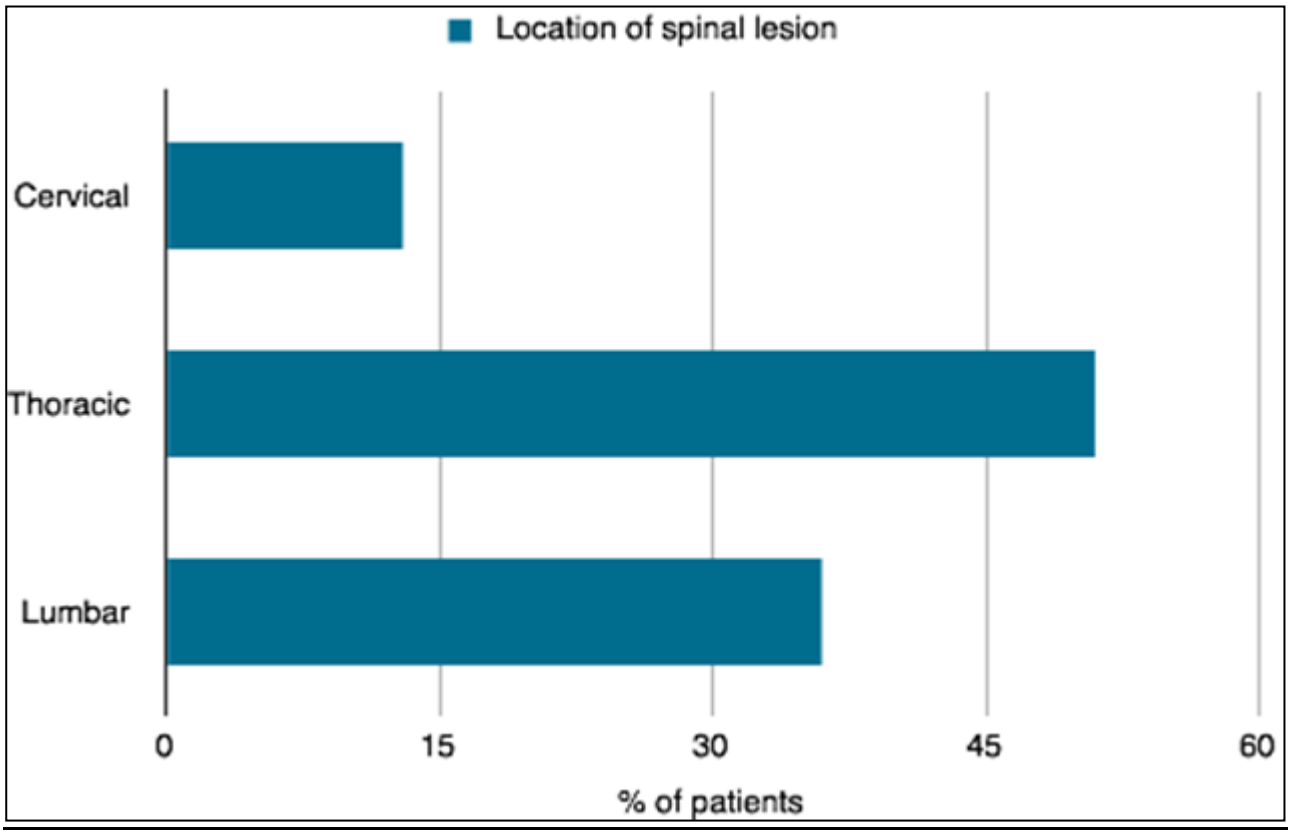
3.4 History of Injuries

- Fifty eight percent of injuries were the result of falls
- Eighteen percent were road traffic accidents (RTAs)
- Twelve percent were due to the earthquakes of April and May, 2015
- Eighty four percent were admitted to a hospital within 24 hours of the injury
- Thirteen percent were taken to hospital between one to three days after the accident

- Seventeen percent reported that they had not received treatment when taken to hospital and there had been a delay in treatment being provided
- When asked about the number of hospitals they were moved from before being admitted to SIRC for rehabilitation, 35% stated two with 27% coming directly to the centre from their primary care provider. Twenty three percent had visited three hospitals prior to SIRC, with a further 9% attending four hospitals and the remaining 6% reporting five or more moves.

3.5 Medical Status Following Injury

Figure 2: Level of injury



- Thirty five percent did not know their diagnosis, including 50% of earthquake affected patients
- Nineteen percent knew their American Spinal Injury Association ASIA score (53% of these scores were classified as ASIA A).
- Fifty two percent were complete injuries and 48% incomplete.

3.6 Interventions

- Eighty nine percent stated that they had surgery as a result of their injury (86% had one operation, while 11% had two and 3% had three operations to attend to their injuries)

- Ninety one percent of these patients had a procedure to insert an internal fixation to immobilise the spine while the bony bridge heals across the two vertebrae. Metal fixation of the spine is considered a temporary splint to hold it while it fuses[2]
- For 44%, surgery took place within weeks of obtaining the injury while 33% stated their surgery occurred within days of being admitted to hospital. For the remainder (23%), the time period was several months
- A small percentage (5%) reported that they had not received rehabilitation of any sort while in the primary care hospital(s).

3.7 Rehabilitation Care (Physical and Mental Health)

- Fifty four percent have ongoing bladder problems
- Twenty six percent used a catheter with 54% of this group getting a new catheter every month
- Fifty three percent had bowel problems
- Forty eight percent stated that they did not do anything to help improve their bowel motions
- Sixty one percent did not practice abdominal massage, 83% did not use digital stimulation, and 65% did not use manual evacuation methods
- Twenty six percent of toilet care is conducted in bed
- Ninety percent reported pain as an issue, however 83% are not taking medication for pain
- There was a predominance of pain in the back and legs
- Forty six percent reported having daily pain while 16% stated their pain was a constant feature in their life
- When asked if pain interfered with daily functioning, 65% agreed that it did
- Ninety five percent did not know about autonomic dysreflexia. Of those who did know what it was, only two knew what to do when it occurred.

3.8 Pressure Ulcers

- Fifty one percent of ex-patients stated that they had a pressure ulcer with 26% of this group currently experiencing a pressure sore
- Of the ex-patients reporting a pressure sore at the time of assessment, 20% were not receiving any treatment.
- Of those who had been getting treatment for the wound, 33% were practising self-management with dressings and the remaining 67% involved family members applying and changing dressings

[2] http://www.spine-health.com/glossary/internal-fixation

- Pressure sores had been ongoing for months and even years in some cases
- The primary locations of the pressure sores were the buttocks (51%) and hips (35%)
- Twenty three percent of patients with a pressure wound had received surgery as treatment with 64% reporting a period of months for the wound to heal following the procedure
- A larger proportion of patients assessed stated that they had developed a pressure ulcer in hospital (53%), marginally more than those who had developed one at home (47%)
- When asked about the length of time it took their first pressure sore to heal, 81% stated that it took months with 8% stating that it took years.

3.9 Mental Health and Wellbeing

- Eighty percent stated that they currently felt depressed or suffered from depression. Only one person indicated that they were on medication for depression and anxiety
- Eighty one percent had experienced flashbacks as a result of their injury and 77% still get these now
- Eighty four percent had seen a counsellor or psychologist for support of whom 91% reported that this was helpful.

3.10 Mobility Status

- Twenty eight percent had wheelchairs in poor condition and in need of repair. The main problems related to tyres and brakes
- A small number indicated their chair had been crushed in the earthquake and could no longer be used
- The largest group of respondents did not know where to get a new wheelchair. Similarly, 21% did not know where to get a new cushion
- Thirty two percent (the largest proportion) go to a local bike shop for wheelchair repairs

3.11 Follow Up

- Three percent said they had received NGO assistance while in the community and for a very small number (three individuals), this was still continuing
- Thirty seven percent had received a follow up from someone within the last three years
- Fifty nine percent had never received a follow up and for eight individuals this meeting with the SIRC CBR worker was their first
- All of those interviewed stated this was a home visit with 50% reporting it as a CBR worker visit

- When asked at the end of the survey which areas needed the most attention the responses were equally divided between 1) bowel and bladder and then 2) depression with each accounting for 35% of responses.

3.12 Family Life and Recreation

- Sixty percent stated that their self-care needs were being met.
- Sixty percent spent their days doing something purposeful and the same percentage took part in some kind of recreational activity
- Seventy three percent believed they are able to assume their role within the family
- Sixty nine percent were comfortable with their personal relationships at the moment
- Fifty six percent had taken trips out of their community for recreational purposes and 61% reported to have a social activities they took part in
- Forty one percent had ongoing contact with other individuals with an SCI
- Twenty seven percent felt included within community life but 73% did not feel they were part of their community
- Thirteen percent had been abandoned by their main caregiver after they had acquired their injury
- Twenty four percent knew someone who had died in the earthquakes.

3.13 Sexual Health

This was the section most likely to have missing data or references from the CBR workers with most patients not wanting to discuss this sensitive topic with other family members present. Of those who did respond, it was clear that the information they had on sexual health following their injury came from SIRC.

3.14 Vocational Information

- Sixty three percent knew that the Government had a disability policy
- Thirty three percent did not have a disability card
- Sixty three percent were in receipt of a disability allowance
- Fifty three percent had not received any vocational training following their injury
- Only 9% of those receiving training had been able to put this to use in terms of employment or economic gain
- The largest request for further training was in the area of tailoring and mobile tailoring although 42% did not want another skill or skills developed.

3.15 Future Actions Requested by Patients

- When asked about employment and other hopes they wanted to comment on, 44% believed that there was no hope for their future
- As an open ended question, participants were free to make any suggestions they would like SIRC to provide support for. The most frequently cited issues were pain (45%), depression and wheelchair issues (each 27%) and bowel and bladder problems (25%). For 51% multiple issues were raised rather than a single concern.

4. Discussion

4.1 Systems to Support and Respond to Patient Needs

Through the designation of five community outreach workers appointed by SIRC, a system was developed which facilitated the identification, meeting and gathering of information on the needs of SCI individuals who had been discharged from SIRC following rehabilitation. The CBR workers made home visit follow ups in the 14 earthquake affected regions. Using a standardised protocol and comprehensive follow up evaluation tool, each CBR worker determined the needs of each patient across a number of key areas such as medical, social, economic, demographic, psychological, vocational, accessibility and community integration.

A two-step process was followed. This began with each worker contacting the patient they were responsible for via telephone where possible to confirm the forthcoming visit. Questions were asked to identify pressing issues that the CBR worker could address during the visit. This would specify equipment or materials to be brought to the patient immediately until a larger follow up assessment could be conducted and a more detailed action plan devised. Examples included; catheters, dressings, Foleys, medications, and xylocaine jelly, etc. The CBR workers also carried mobile phones with them and distributed equipment to needy patients such that follow up communication could be continued with them over the telephone. During home visits, if the CBR worker identified major complications in the patient requiring treatment by specialised services, then they would immediately contact and coordinate with SIRC's Social Department and then send the patient to SIRC for further treatment and the prevention of complications.

Following visits, CBR workers returned to SIRC to provide feedback and devise a detailed action plan in response to urgent and non-urgent needs. These were prioritised and a plan developed for the next home visit.

4.2 Issues Arising from Follow Up Assessments

Analysis of the information provided by patients highlights a number of health, social, vocational and community issues being experienced by SCI patients and requiring attention. The cumulative impact of these issues described by patients and reinforced through direct observations by CBR workers reinforces the need to ensure continuity of care for ex-patients following discharge at key stages of their rehabilitation. The information gathered provides insights into meeting the immediate, intermediate and long term needs of ex-patients and their families.

In addition, learning from both positive and negative patient outcomes has informed service planning and helped both SIRC and ex-patients improve the transitioning process and longer term reintegration into community life.

A detailed and analytic review of the 197 full cases included in the follow up database points to a number of pertinent issues including:

- The debilitating impact of the earthquake on individuals already having an SCI prior to the events of April and May 2015
- The need to revise patient and caregiver education programmes to support the application of knowledge to practice through assessments of patient and caregiver capacity and skills during follow up
- Increased emphasis on knowledge of bowel and bladder management
- Increased distribution of essential equipment such as catheters at designated points of follow up
- Focused education to patients and caregivers using multiple communication mechanics, such as videos, photographs, and practical demonstrations of pressure wound management and actions required to prevent pressure sores and reduce other complications related to SCIs
- Improve patient and caregiver understanding about how pain can be prevented and managed through active measures that reduce complications that can contribute to pain, such as regular turning and relevant exercises
- Strengthen telephonic follow up with patients and increase institutional follow up at SIRC to focus on follow up needs with a special emphasis on counselling and emotional and psychosocial support since patients tend not to be mentally stable after earthquakes
- For patients suffering from depression and stress, another option is to refer them to units set up by Transcultural Psycho-social Organization Nepal (TPO) in various earthquake affected districts. In this regard, a referral pathway established with TPO Nepal should be followed
- Home visits and telephonic services allow patients and caregivers to raise concerns about wheelchair conditions including identifying repairs needed, where these can be made and by whom
- CBR assessments highlight accessibility issues and modifications needed to homes and what actions are needed for patients living in temporary accommodation to improve their independence in daily living functions
- Given the lack of application of skills obtained through vocational training to local labour markets and activities suitable for the level of injury, changes in vocational training activities are needed. An increased emphasis on employability leading to sustained levels of adequate income is required
- Unfavourable community attitudes towards disability and perceptions on future roles for disabled people in the community were affecting the psychological wellbeing of patients by demotivating them. This was reported as contributing to a sense of 'hopelessness' felt by patients about their future with 44% stating that they had no hope for their own future.

4.3 Services Provided by SIRC

The rationale for developing and using such a detailed follow up assessment tool was directly influenced by the multi-disciplinary team approach to rehabilitation practiced at the centre. The intention of the follow up CBR model was to ensure continuity in approach and care from admission and discharge to community

reintegration. This required a clear and frequent communication system that updated multi-drug therapy (MDT) at the centre and directed the response of CBR workers in creating action plans for patients they were supporting. While SIRC's monthly meeting mechanism offered a valuable opportunity to review what was needed by the community team and what changes needed to be made to their working practices, ongoing communication with Heads of Department, in particular their line manager (head of the Social Department), was a critical part of their working approach.

4.4 Coordination with Partners

SIRC organised referrals and sign posted patients with SCIs to other services responsible for various types of care beyond the rehabilitation of their injury. CBR workers liaised closely with key health providers and other organisations to identify the most appropriate and locally available services that could be accessed by ex-patients they were supporting using the SIRC follow up framework and approach.

In order to establish a common referral mechanism among like-minded organisations, SIRC participated in meetings with HI, TPO, International Medical Corps (IMC), and International Rehabilitation Unit (IRU). Three meetings have already been held on the development of an appropriate referral mechanism. A common referral form has been agreed will be used by these organisations when making referrals. This will help to maintain uniformity. The referral mechanism has already been initiated and will be further strengthened to help patients obtain the right treatment at the right place at the earliest possible time.

4.5 Lessons Learned

In response to emerging issues from the follow the 197 SIRC ex- patients, a series of lessons has been highlighted. These potentially have a direct role in affecting change at an individual (patient and family), community, organisational (SIRC, HI, TPO, IMC, and IRU) and sector level (SCI rehabilitation and community based provision). Patient focused action plans like to have immediate impact include service support, equipment provision, referral back to SIRC for enhanced or augmented treatment, or referral to other providers for localised support. Specifically, the following lessons have been drawn from the data that have resulted in affirmative changes to the follow up system being managed by SIRC.

4.5.1 System Changes

There is a need for scaffold learning and support after caregiver and patient education is received at SIRC. Capacities and capabilities of both the caregivers and patients need to be assessed once they have returned to their communities to ensure recommendations including necessary practices are implemented. The increase in materials and resources that CBR workers bring to follow up districts can offer immediate responses to urgent needs as required.

There is also a need for context specific coordination and planning of medical interventions to support nurses in local centres and hospitals to perform quality wound management and reduce the number of pressure sores suffered by patients when they return to their communities. It is also the case that follow up visits for ex-patients every three months following discharge are needed so that staff can stay informed on the health conditions of patients and their re-integration into their communities.

4.5.2 The Role of CBR Workers

It was clear from the feedback received during SIRC's monthly review and learning meetings that a number of challenges were being faced by SIRC staff including who held the primary responsibility for community follow up of SCI patients who had attended the centre. This was caused by a combination of logistical and external factors outside of SIRC's control such as the fuel crisis and impact of the weather on the landscape (landslides) and organisational variables that could be addressed in future project plans.

In the development of the initial project proposal and plans, budget costings were calculated for CBR workers. However it soon became apparent that these costs were not realistic for the sustained mobilisation of these workers. Provision should therefore be made for adequate resource allocations in SIRC's strategic plan where community outreach is a key activity. This should take account of the issues identified and reflect the knowledge gained on sustainable mobilisation of CBR workers and their role in completing a critical part of the care pathway for SCI patients.

Requests were made by CBR staff for additional training to improve knowledge, skills and confidence so that they can have an array of skills and information at their disposal when delivering CBR to a wide range of patients. Through the support of the training team at SIRC, CBR workers need to remain fully versed in appropriate and evidence based practices that are consistent with the MDT approach experienced by patients who were previously treated at the centre. Through ongoing professional development, the CBR team will play a valuable role in the rehabilitation of patients and assuring their longer term health beyond the point of their discharge from the centre.

5. Monitoring and Evaluation

Feedback on the assessment form used by CBR staff indicated that while comprehensive it is very time consuming and demanding to complete. Additional questions were suggested to gather information that was not sought previously and other questions were viewed as very personal and difficult to answer, particularly those on sexual health. As a result, revisions are now being made to the form to ensure that the reflections shared by CBR workers are reflected in the M&E tools and procedures. The intention is to accurately inform action planning for each individual patient in a timely and relevant manner. The assessment tool is the main conduit by which detailed and up to date information about all aspects of an individual's life can be gathered. Analysis of responses and the prioritising of needs to dictate actions relies heavily on the questions asked. In this regard, learning about the M&E tools themselves is an essential part of the overall lesson learning process.

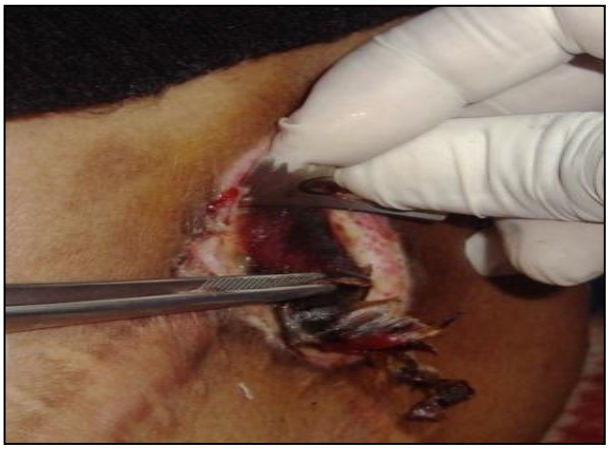
Annex I: Case Study of an ex-patient

Ms X was identified with complications by the CBR worker during home visit follow up and brought to SIRC for further cure and treatment.

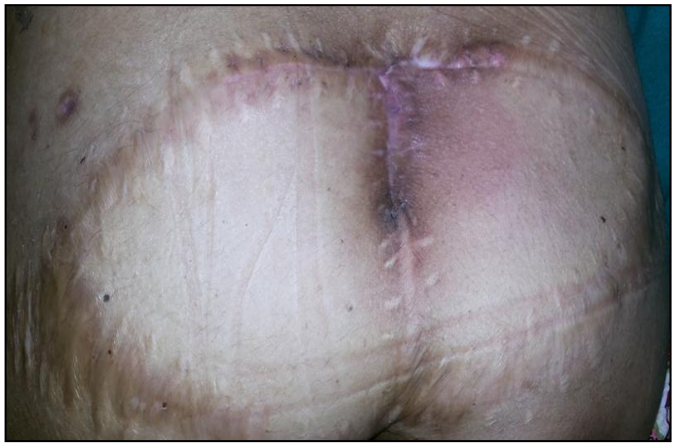
Hospital No: 82/012
Name: Ms. X.
Mode of injury: Fall from cliff
Address: Kavre
AIS: C8 "A"
SIRC Neurological Diagnosis: C5-C6 Dislocation tetraplegic.
Management of patient: Surgically managed at Dhulikhel Hospital

Ms. X is an ex-patient of SIRC. She was initially discharged after completion of four months of rehabilitation. She was successfully living her life until the disastrous earthquake of 25th April, 2015 which destroyed her house. She was compelled to stay live outside the house in a temporary shelter for three months. She had to be frequently moved from one place to other due to repeated aftershocks and, as a result, she developed pressure ulcer at her sacrum.

She was followed up by one of our CBR staff and referred back to SIRC for the further management of the pressure ulcer. After admission at SIRC and initial wound management with daily dressing and positioning she was referred to PHECT NEPAL, Kirtipur for surgical management.



The patient at the community (L) and her pressure sore (R).



Post flap surgery:

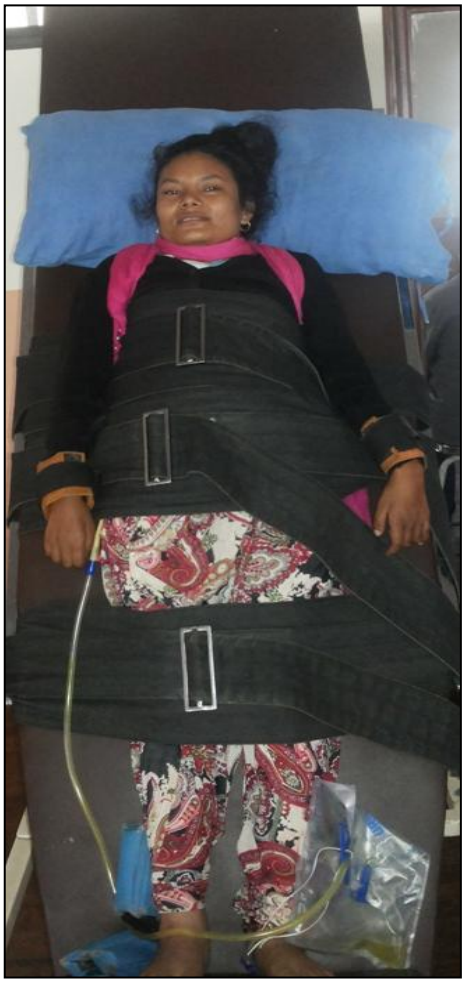
After surgical management, she was bought back to SIRC and is actively participating in comprehensive rehabilitation. The following images show her daily activities at various departments of SIRC:

Occupational therapy department:

a. Dressing and undressing of the upper body.

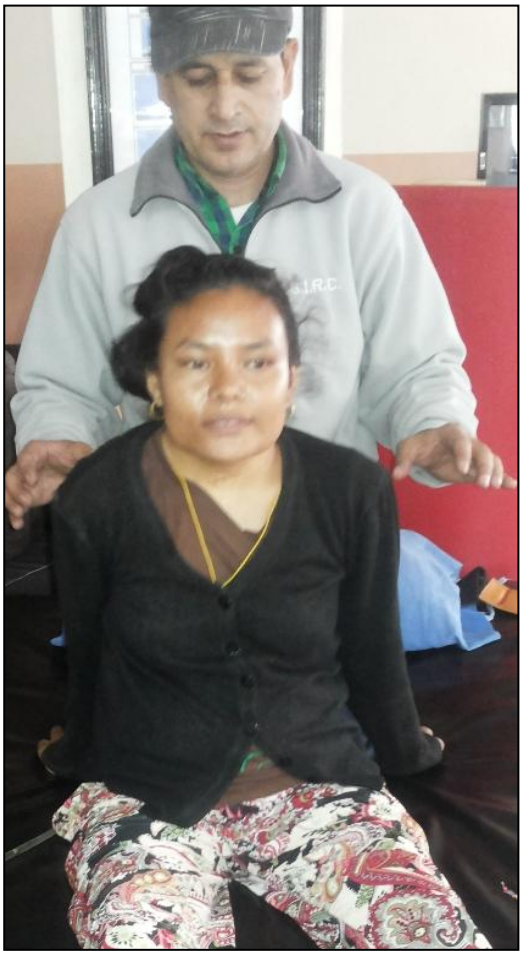
Physiotherapy Department:

b. Tilt table standing for orthostatic hypotension and weight bearing for spasticity management



c. Range of motion exercises of the lower limbs to prevent contractures

d. Balance training in elbow lock position:



Ms. X is independent in bed mobility from supine to side lying with minimal assistance. We are glad to see the improvements in her health condition. The intervention taken by the CBR worker has had a direct impact on Ms. X's health outcomes and the sustainable management of her injury. The case study clearly documents the actions that resulted in the outcomes achieved and is a positive example of the active involvement of CBR in long term rehabilitation and wellbeing.

Annex II: CBR Home Visit Follow up Form

Spinal Injury Rehabilitation Centre

Bhaisepati, Sanga, Kavre

CBR Follow-up Assessment Form

Visit Date: **Examiner Name:**

Patient Name: **Date of birth:**

Age/sex: **SIRC Hospital Number:**

Date of Discharge: **Contact No:**

Married/single/divorced **Job:**

Address: **Postal Address:**

E-mail address: **Livestock**:

Demise: **Cause of demise:**

Name of main family members	Age	Relation	Occupation	Income

Demographics	
Area of Nepal:	
Mechanism of injury	Earthquake/road traffic accident/ fall/violence/non-traumatic/other (if other, describe)
Medical	
Do you know your diagnosis?	Yes/no/don't know
What level of Level of injury do you have	Cervical/thoracic/lumbar/sacral Quadraplegia (tetraplegia)/paraplegia/ don't know
Do you know your ASIA Score?	Yes/no/don't know
If yes, what is it?	A, B, C, D, E
Do you know if you have a complete or incomplete injury (ie; can you feel around your bottom/bum/anus; can you contract the anus)?	Complete/incomplete/don't know
Did you receive hospital treatment immediately after the injury?	Yes/no/don't know
How long did you wait before going to hospital after the injury?	Less than 24 hours
	1-3 days
	4-7 days
	More than a week
What was the name of the first hospital you visited?	
Were you moved to more than one hospital?	Yes/no/don't know
If yes, how many?	
Surgical Intervention – Spinal Cord	
Did you have surgery for the SCI?	Yes/no/don't know
What surgery did you have?	Neck/upper back/lower back/don't know
Did you have metal work (fixation)?	Yes/no/don't know
If yes, what did you have?	Halo/internal fixation/don't know

How long after the injury did you have the surgery?	Days/weeks/months/years
How many spinal operations did you have?	

Rehabilitation	
Did you receive rehabilitation/therapy in a hospital?	Yes/no/don't know
What was the name of the hospital?	
How long did you stay in the rehabilitation/therapy hospital?	Days/weeks/months/years/don’t know
Did you receive NGO assistance in the community?	Yes/no
Do you still receive community care?	Yes/no
Pressure Ulcers	
Have you had pressure ulcers (bed sore, pressure sore, decubitus ulcer)?	Yes/no/don't know
If yes, when?	In hospital/at home/both/don’t know
Please state where (mark all that apply):	Heel(s): R/L/both
	Tail bone (posterior) sacrum
	Buttocks
	Hips (trochanter): L/R/both
	Other (state where):
	Don’t Know
If yes, how long did your first ulcer take to heal?	Weeks/months/years/don’t Know
Did you have an operation to close the pressure sore?	Yes/no/don’t know
If yes, what?	Debridement/skin flap/graft/don’t know

Do you have a pressure ulcer now?	Yes/no/don't know
If you have a PU now, state where:	Heels : R/L/both
	Tail bone (posterior) sacrum
	Buttocks
	Hips (trochanter): L/R/both
	Other (state where) :
	Don't Know
If you have a pressure ulcer, are you receiving treatment?	Yes/no
If yes, from whom?	Doctor
	Nurse
	Hospital
	Clinic
	Pharmacy
	Friend
	Other:
	Don't know
If yes, what treatment (mark all that apply)?	Dressings/Medication
	Other:
	Don't know
Bladder Function/management	
Do you have any trouble with your bladder function?	Yes/no/don't know
If yes, what treatment do you use?	Intermittent catheterization (CIC)
	Indwelling urethral catheter (foley)
	Indwelling suprapubic catheter
	Condom catheter
	Bladder tapping
	Medication

	Nothing
	Don’t know
If using an intermittent catheter, how often do you pass it each day?	Times per day:
If using an intermittent catheter, how often do you get a new catheter?	Every time
	Every day
	Every week
	Every month
	Every year
	Don’t know
If you have an indwelling catheter, how often do you change it?	Every _____ weeks Every _____ months
Where do you get your supplies for catheters?	
How do you clean your catheters?	Clean water, detergent, other:
How do you store your catheters?	Plastic container/cotton bag/sock/other:
Have you had a urinary tract infection while using catheters?	Yes/no/don’t know
If you have had a urinary tract infection, how many?	1-2 per year/more than 2 per year/ don’t know
If yes, how did you treat it? (fluids, medications, local/traditional medicine)	Drink fluids
	Antibiotics
	Other medication
	Traditional healer/ medicine
	Other:
	Don’t know
Do you experience any urinary incontinence?	Yes/no/don’t know
Do you take medication to help with your bladder?	Yes/no/don’t know
If yes, what medication do you take?	Name:
	Don’t know
<u>Bowel Function /management</u>	

Do you have any problems with emptying your bowels?	Yes/no/don't know
If yes, do you do anything to help pass faeces?	Yes/no
Do you take medication for your bowels?	Yes/no
If yes, what is the medication called?	Name: Don't know
Do you drink certain fluids?	Yes/no
Do you eat certain foods?	Yes/no
Do you perform abdominal massage?	Yes/no
Do you use suppositories?	Yes/no
Do you perform digital stimulation?	Yes/no
Do you perform manual evacuation (remove faeces with finger)?	Yes/no
Where do you do your bowel care?	In bed/on toilet/other:
How often do you do this?	Daily/every-other-day/weekly/other:
Do you have faecal incontinence?	Yes/no
Do you have constipation?	Yes/no
Neuropathic Pain & Spasticity	
Do you have any pain?	Yes/no
If yes, where do you have pain?	Head/neck/back/arms/legs/feet Other:
How often?	Sometimes/daily/all the time/other:
If yes, do you use medication to help this?	Yes/no/don't know
If yes, what is the medication called	Name: Don't know
Are you experiencing spasm/stiffness that interferes with your function?	Yes/no/don't know
Are you taking medication for spasms/muscle stiffness?	Yes/no/don't know
If yes, what is the medication called?	Name: Don't know
Do you have any difficulty getting the medication?	Yes/no/don't know

Tetraplegic/Quadriplegic and patients with T6 and above only – Autonomic Dysreflexia	
(For T6 and above interviewees) Do you know about autonomic dysreflexia symptoms (sudden intense headache, sudden sweating, vision changes, flushing, and goose bumps)?	Yes/no
(For T6 and above interviewees) Do you get autonomic dysreflexia symptoms (sudden intense headache, sudden sweating, vision changes, flushing, and goose bumps)?	Yes/no/don't know
(For T6 and above interviewees) Do you know what to do?	Yes/no If yes, please state :
Mental Health	
Have you ever seen a psychologist and/or received counseling since your injury?	Yes/no/don't know
If you did receive psychological support, how often?	Once/daily/weekly/monthly/don't know
For how long?	Once/days/weeks/months/don't know
Who was this?	Psychologist/counsellor/doctor/religious leader/support group/other
Did this help?	Yes/no/don't know
Did you have 'flashbacks' about your injury? (Sudden intense images of your experience from the injury that causes physical symptoms and stops you from doing something because you are reliving the experience as though it was real.)	Yes/no/don't know
Do you still have flashbacks?	Yes/no
Do you have sleeping problems?	Yes/no
Do you experience depression (sad mood)?	Yes/no
Do you experience anxiety (nervous mood)?	Yes/no
Do you take medication for depression or anxiety?	Yes/no
If yes, what is the name of the medication?	Name :
	Don't know
Outpatient Rehabilitation Specific "Follow up"	

Have you received any specific follow up for your spinal cord injury within the last 3 years (not inpatient)?	Yes/No/Don't know
If so, what kind of follow up? (Circle all that apply.)	Doctor/nurse/physiotherapist/occupational therapist/peer counsellor/support group/home visit(s)/other:
Do you still receive this?	Yes/no/don't know
Accommodation	
Do you and/or your family own or rent your current home?	Own/rent
What type of accommodation do you have?	Private house/Private apartment
	Own room in house
	Tent
	Temporary shelter provided by NGO
	Other

Reintegration to Normal Living Index	
1. I move around my house/yard as I feel necessary.	Agree/disagree/neutral
2. I move around my community as I feel necessary.	Agree/disagree/neutral
3. I am able to take trips out of town as I feel are necessary.	Agree/disagree/neutral
4. I am comfortable with how my self-care needs (dressing, feeding, toileting, bathing) are met.	Agree/disagree/neutral
5. I spend most of my days occupied in work activity that is necessary or important to me.	Agree/disagree/neutral
6. I am able to participate in recreational activities (hobbies, crafts, sports, reading, television, games computers, etc.) as I want to.	Agree/disagree/neutral

7. I participate in social activities with family, friends and/or business acquaintances as is necessary or desirable to me.	Agree/disagree/neutral
8. I assume a role in my family which meets my needs and those of other family members.	Agree/disagree/neutral
9. In general, I am comfortable with my personal relationships.	Agree/disagree/neutral
10. In general I am comfortable with myself when I am in the company of others.	Agree/disagree/neutral
11. I feel that I can deal with life events as they happen.	Agree/disagree/neutral
Mobility	
Do you use a wheelchair?	Yes/no
If yes, is your wheelchair in good condition?	Yes/no
What is the main problem/concern you have with your wheelchair?	Flat tire/other:
If you needed a new wheelchair, do you know where to get one?	Yes/no

Do you have a cushion for the wheelchair?	Yes/no
If you needed a new cushion, do you know where to get one?	Yes/no
Family/ Main Caregiver Assistance	
Do you have a family/caregiver with you at home?	Yes/no
Have you had different caregivers since the injury?	Yes/no
Have you been abandoned by your main caregiver?	Yes/no
Inclusion in Society	
Do you feel included/involved in your community?	Yes/no/don't know
Do you feel stigmatized/disconnected/badly treated by people because of your disability?	Yes/no/don't know
If yes, why?	
Does the Government have a Policy for the Disabled	Yes/no/don't know
Knowledge of other persons with spinal cord injury	
Do you keep in contact with other people with a similar injury?	Yes/no
Do you know anyone who has died after getting a SCI?	Yes/No/Don't know Name:
The Future	
The future – what does this mean to you?	
Would you like to add anything or tell us anything about your experience/concerns?	

Physiological Assessment: Anxiety and Depression scoring

Anxiety/ Depression	Questionnaire	Yes, Definitely	Yes, some time	No, not much	No, not at all
D	I wake early and then sleep badly for the rest of the night.	3	2	1	0
A	I get very frightened or have panic feelings for apparently no reason at all	3	2	1	0
D	I feel miserable and sad	3	2	1	0
A	I feel anxious when I go out of the house on my own	3	2	1	0
D	I have lost interest in things	3	2	1	0
A	I get palpitations, or sensations of 'butterflies' in my stomach or chest	3	2	1	0
D	I have a good appetite	0	1	2	3
A	I feel scared or frightened	3	2	1	0
D	I feel life is not worth living	3	2	1	0
D	I still enjoy the things I used to	0	1	2	3
A	I am restless and can't keep still	3	2	1	0
A	I am more irritable than usual	3	2	1	0
D	I feel as if I have slowed down	3	2	1	0
A	Worrying thoughts constantly go through my mind	3	2	1	0
Total Anxiety score					

Total Depression score	
Grand total score	

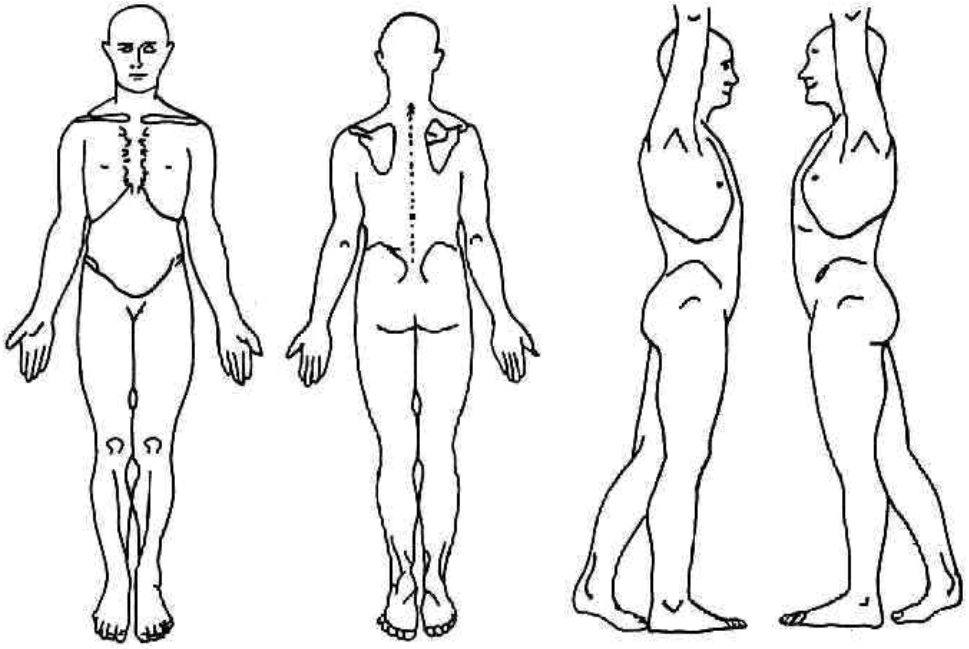
Grading: 0 - 7 = Non-case

Grading: 8 – 10 = Borderline case

Grading: 11+ = Case

Mapping: (Entrance, bedroom, Kitchen, toilet, washing area, and the outside area)

Physical Observation: (Skin, bowel, bladder, pain and contracture)



1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

SCIM Score for bowel, bladder and mobility:

1. Sphincter Management - Bladder

☐

0. Indwelling catheter

3. Residual urine volume (RUV) > 100cc; no regular catheterisation or assisted intermittent catheterisation

6. RUV < 100cc or intermittent self-catheterisation; needs assistance for applying drainage instrument

9. Intermittent self-catheterisation; uses external drainage instrument; does not need assistance for applying

11. Intermittent self-catheterisation; continent between catheterisations; does not use external drainage instrument

13. RUV <100cc; needs only external urine drainage; no assistance is required for drainage

15. RUV <100cc; continent; does not use external drainage instrument

2. Sphincter Management - Bowel

☐

0. Irregular timing or very low frequency (less than once in 3 days) of bowel movements

5. Regular timing, but requires assistance (e.g., for applying suppository); rare accidents (less than twice a month)

8. Regular bowel movements, without assistance; rare accidents (less than twice a month)

10. Regular bowel movements, without assistance; no accidents

Mobility (room and toilet)

☐

3. Mobility in Bed and Action to Prevent Pressure Sores

0. Needs assistance in all activities: turning upper body in bed, turning lower body in bed, sitting up in bed, doing push-ups in wheelchair, with or without adaptive devices, but not with electric aids

2. Performs one of the activities without assistance

4. Performs two or three of the activities without assistance

6. Performs all the bed mobility and pressure release activities independently

4. Transfers: bed-wheelchair

(locking wheelchair, lifting footrests, removing and adjusting arm rests, transferring, lifting feet).

0. Requires total assistance

1. Needs partial assistance and/or supervision, and/or adaptive devices (e.g., sliding board)

2. Independent (or does not require wheelchair)

5. Transfers: wheelchair-toilet-tub

(if uses toilet wheelchair: transfers to and from; if uses regular wheelchair: locking wheelchair, lifting footrests, removing and adjusting armrests, transferring, lifting feet)

0. Requires total assistance

1. Needs partial assistance and/or supervision, and/or adaptive devices (e.g., grab-bars)

2. Independent (or does not require wheelchair)

<u>Mobility (indoors and outdoors, on even surface)</u>

6. Mobility Indoors

0. Requires total assistance

1. Needs electric wheelchair or partial assistance to operate manual wheelchair

2. Moves independently in manual wheelchair

3. Requires supervision while walking (with or without devices)

4. Walks with a walking frame or crutches (swing)

5. Walks with crutches or two canes (reciprocal walking)

6. Walks with one cane

7. Needs leg orthosis only

8. Walks without walking aids

7. Mobility for Moderate Distances (10-100 meters)

0. Requires total assistance

1. Needs electric wheelchair or partial assistance to operate manual wheelchair

2. Moves independently in manual wheelchair

3. Requires supervision while walking (with or without devices)

4. Walks with a walking frame or crutches (swing)

5. Walks with crutches or two canes (reciprocal walking)

6. Walks with one cane

7. Needs leg orthosis only

8. Walks without walking aids

8. Mobility Outdoors (more than 100 meters)

0. Requires total assistance

1. Needs electric wheelchair or partial assistance to operate manual wheelchair

2. Moves independently in manual wheelchair

3. Requires supervision while walking (with or without devices)

4. Walks with a walking frame or crutches (swing)

5. Walks with crutches or two canes (reciprocal waking)

6. Walks with one cane

7. Needs leg orthosis only

8. Walks without walking aids

Mobility Assessment:

Mode of mobility:

Wheelchair used or not:

Condition of wheelchair and cushion:

Repair and spare parts:

Other (like mattress, air mattress etc.):

Accessibility/ Home Modification:

Entrance: Tap:

Porch: Bed:

Bed room: Kitchen:

Toilet area (Door, Room, Commode):

Vocational Training assessment:

Are you making regular the training you have learned at SIRC? .....

If yes:

- What skill…… Is that useful? ……..
- Monthly income……
- How far is the market from your residence? ……..

If no:

- Why is it not regular…….
- What are you doing these days? .....
- What sort of vocational skill do you think is more practical in your society? ……..

Social aspect assessment:

- How often do you visit your local community? ……
- How does your community perceive you? ……..
- Is there any other person in your community with SCI? ……

- Do you have your disability identity card? ……..
- Do you receive your disability allowance? ……..
- Are there any social organizations (health post, NGOs/INGOs) nearby? .....
- Do you find yourself as an integral part of your family? ……
- Does your family support you in your daily activities?

  .....
- Does your family take responsibility for your daily living? ……..
- Are you involved in any SHG (Self- help Group) or DPO (Disable People Organization)? .....

Sexuality / fertility and experience:

- What kinds of problem/issues do you have regarding sexual life and marriage? .....
- Are you satisfied with your sexual life?

  .....
- How is your experience regarding sexual relationship after SCI? .....
- Do you have penile erection?

  .....
- What do you do if you have no erection?

  .....
- Have you used any aids for the erection? If yes what.....
- Is your husband/wife happy with you? Yes/no

  (reasons) ……
- Do you talk about your problems with your partner, friends, and family? .....

Assessment summary:

Problems	**Suggestion/Action plan**

Remarks:

Examiner Name/Signature:

Date/Time: