


Health Sector Transition and Recovery Programme

COMMUNITY BASED REHABILITATION
Home Visit
Follow Up Report

August 2016

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

NHSSP

UKaid
from the British people

Acronyms

CBR	Community Based Rehabilitation
CIC	Clean Intermittent Bladder Catheterisation
DFID	Department for International Development
DoHS	Department of Health Services
HI	Handicap International
MoH	Ministry of Health
NHSSP	Nepal Health Sector Support Programme
SCI	Spinal Cord Injury
SIRC	the Spinal Cord Rehabilitation Centre
TA	Technical Assistance
UTI	Urinary Tract Infection
WHO	World Health Organization

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1. Background

The 7.8 magnitude earthquake that hit Nepal on the 25th April, 2015, and the multiple after-shocks that followed claimed more than 9,000 lives, left more than 23,000 people injured, and destroyed over half a million homes. Fourteen districts have been identified as those most severely affected.

The Department for International Development (DFID) funded Nepal Health Sector Support Programme (NHSSP) has been providing Technical Assistance (TA) to the Ministry of Health (MoH) and Department of Health Services (DoHS) since 2010 to help implement the second National Health Sector Programme (2010-15). In the aftermath of the quakes, DFID contracted Options to build on its existing programme of TA support and provide further TA support a Health Sector Recovery and Transition Programme. This programme runs until September 2016 and aims to restore essential health services, including obstetric care, family planning, and physical care with a particular focus on Ramechhap, Dolakha, and Sindhupalchowk districts.

2. Specific Background

The devastation caused by the earthquakes led to around 1500-2000 people sustaining serious physical injuries requiring long term rehabilitation support. A further 300-400 people are estimated to be suffering from spinal injuries.

A Spinal Cord Injury (SCI) often leads to permanent disability. People with SCIs are prone to physical and psychological complications and require long term health maintenance support. Specialised follow-up is extremely important for the ongoing provision of health education, psychological support, sign posting to other services, referral for physiotherapy, and rehabilitation etc. Without these services, complications and readmission to district hospitals and specialised centres are more common, putting increased pressure on the health system.

Through this deliverable, The Spinal Cord Rehabilitation Centre (SIRC) is committed to provide 200 ex-patients follow-up support in 14 earthquake affected districts.

3. Rationale

- To get updated on the post rehabilitation situation of the ex-patients
- To get informed about the patient's situation back in the community
- To provide necessary aids supplies and other assistance if required

4. Purpose and Objectives of the Assignment

The main purpose of this assignment is to provide follow-up home visit support services to 200 ex-patients living in 14 affected districts. Specific objectives are:

- To provide patients with basic therapy and self-care techniques

- To provide a referral and sign-posting service for patients requiring more intensive care and rehabilitation. This may include referral to district and national hospitals, Handicap International (HI) out-patient/social work services, and, where required, referral to SIRC

- To liaise and work with representatives of local government and community, NGOs and the private sector to help ensure the successful resettlement of those injured in the earthquake.

5. Tasks

- Five community out-reach workers (Community Based Rehabilitation - CBR) for the project were based in the 14 affected regions.

- Home visits were conducted to provide specialised training and education. The provision of essentials such as urinary catheters and consumables was also ensured.

- Referrals were organized and people with SCIs were be sign-posted to other relevant services.

- SIRC's home visits were complemented by telephone follow-up, advice, and an information service.

- The CBR workers' comprehensive evaluation assessment capturing information on the physical, emotional, and social wellbeing of ex patients including economic/ vocational assessments was completed.

- Lessons learned were documented for CBR workers in order to arrive at an evidenced based model of CBR services provided by SIRC.

6. Methodology

The completion and submission of the first CBR report on 217 ex-patients in May 2016 has informed the presentation of the findings for a second phase of follow up with an additional 200 ex-patients from SIRC. Given the use of the same data collection survey tool, the same format of reporting has been used to enable read-across between both reports. As with the previous follow up activity, a single data collection tool was used by the visiting CBRs when conducting a follow up assessment with patients who have been discharged by SIRC. This form is extensive and takes account of the holistic needs of individuals with SCIs which includes the health, social, vocational, economic, and sexual status at the time of the follow up meeting. By paying attention to the various aspects of a person's life, a full picture of their health can be drawn to identify gaps either in singular or multiple form which could be supported by the CBR worker connected to SIRC support systems. A copy of the form can be found in Annex I.

Each CBR worker followed the same protocol in completing the follow up form on a one to one basis with the individual, asking the same set of questions throughout the interview. The information obtained was then returned to a central point of contact within the Social Department at SIRC where all data was entered into a secure and confidential database. By the end of June 2016, follow up visits with corresponding assessments using this form had been completed for 187 patients. Within this group, the CBR workers were informed by family members that ten ex-patients had since died and could not provide further details beyond the initial pages in the assessment tool. The remaining sections of the assessment tool were available for analysis of 177 individuals. Combining both CBR follow up activities, results from 404 ex-patients were available. Home visit follow up services have been instrumental in referring patients for follow up or back to rehab at SIRC based on the needs and complications of the patients.

7. Findings

A detailed and exhaustive analysis of the information in the dataset for 177 ex-patients was carried out by the evaluation consultant. To aid the presentation of findings, the sub components of the assessment tool served as natural dividers for the presentation results. Data analysis is broken down into the following sections:

7.1 Demographics of Patients

The patients who were analysed include the patients admitted to SIRC from 2002 to 2015. The largest group in the database is from 2015 (n=82). The discharge year of patients ranged from 2002-2016. The average duration for rehabilitation was three months.

This data set included 44% female and 56% male whose ages range from 26 to 90 years of age. 73% of patients were married, 23% single, 1% divorced, and 2% widowed. It was found out that 26% were employed and the remaining were either housewives or stayed at home.

7.2 Accommodation

Seventy seven percent of patients were located in the hills of Nepal while sixteen percent were from the Kathmandu valley.

The areas from which home visit 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	43
Sindhuli	4
Kavre	9
Nuwakot	17
Gorkha	4
Lalitpur	4
Ramechhap	1
Dhading	16
Okhaldhunga	9
Dolakha	13
Siindhu Palchowk	38
Makwanpur	17
Bhaktapur	12
Total	**187**

The findings revealed that 37% of patients are in temporary accommodation such as tents while 61% are living in their own homes. Fifty five percent have had to move communities but it is unclear if this was due to earthquake or as a result of their injury, or both. When asked if home modifications were needed to their house, 35% stated these were still required in order to have access to all parts of their homes. The areas identified most frequently as needing to be modified to improve or gain access were toilet and water tap access (31%). On average, 76% of ex-patients were likely to have modifications within their home to suit their needs.

7.3 History of the Injury

Forty six percent of injuries in patients included in the database were a direct result of the April and May 2015 earthquakes while 36% were due to falls. Eighty two percent of patients were admitted to a hospital within 24 hours of the injury while 13% were taken to hospital between one to three days from the time of the accident. When asked about the number of hospitals they were moved from before being admitted to SIRC for rehabilitation, 67% had been in more than one hospital prior to arriving at SIRC.

7.4 Medical Status Following the Injury

Forty three percent of patients obtained an injury in the lumbar region of the spine, followed by 39% of patients with thoracic specific injuries. A smaller number were classified as cervical (14%) or combined (4%) and 87% of patients were classified as paraplegic and 13% as quadriplegic.

7.5 Interventions

Sixty one percent of patients stated that they had surgery as a result of their injury while 96% of these patients had a procedure to insert an internal fixation which serves to immobilise the spine while the bony bridge heals across the two vertebrae. Metal fixation of the spine is considered a temporary splint to the spine to hold it while it fuses[1]. For 41% of patients, they stated that their surgery occurred within days of being admitted to hospital while 31% reported their surgery took place within weeks of obtaining the injury. For the remainder (28%), the time period ranged from one month to one year.

7.6 Rehabilitation Care (Physical and Mental Health)

The findings showed that 44% of patients have ongoing bladder problems and 37% have at least one Urinary Tract Infection (UTI) per year. Twenty four percent use a catheter with 95% of this group getting a new catheter every month. It was revealed that patients clearly knew how to care for their bladder and catheters with demonstrated knowledge about what to use, when to clean, and where to store catheters. This showed that the patients have received bladder education from SIRC regarding the need for cleanliness to be maintained and use of Clean Intermittent Bladder Catheterisation (CIC) to reduce bladder complications. However, the patients who had bladder problems were using Foleys catheter instead of CIC due to laziness and as a result they were more prone to UTIs. Some patients were using same catheters for a long period of time and using glycerine instead of xylocaine jelly due to the unavailability of catheters in their location. Some were not using anything leading to leakages. The reason for this was they were not able to afford catheters. In order to solve these issues, CBR workers distributed catheters and xylocaine jelly to all the patients visited and SIRC has been distributing catheters and xylocaine jelly to all the patients upon discharge.

The findings further showed that 37% have bowel problems. Patients carried out a number of actions to maintain and improve bowel motions such as eating healthy foods (71%) and drinking fluids regularly. Patients also practiced abdominal massage and used manual evacuation where necessary. Seventy two percent of toilet care is conducted in a toilet or near their home with an additional 10% using a commode chair.

92% reported pain as an issue, although it is important to note that this pain was predominantly experienced ‘sometimes’ rather than ‘often’. It is expected to have some pain after spinal cord injury. There was a predominance of pain in the back and legs. 82% stated this pain did not interfere with daily functioning.

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

Eighty percent of patients had knowledge about autonomic dysreflexia and knew what to do if it occurred. Therefore, the patients were able to manage this problem well.

7.7 Pressure Ulcers

Thirty eight percent of ex-patients stated they had experienced a pressure ulcer and 28% of these patients had received surgery as a treatment option as these patients have higher level complications. The remaining 10% of this group experiencing pressure sores had lesser complications and all had received treatment from SIRC. The primary location of the pressure sores were buttocks (85%) or sacrum (15%).

7.8 Mental Health and Wellbeing

Based on an analysis of the standardised depression anxiety stress score (DASS), 30% of individuals reached the designated cut off criteria for treatment for anxiety and or depression. Ninety three percent of patients got flashbacks as a result of the injury and 98% still experience these now. This could be because of the sudden changes in the situation post-earthquake and changes in their daily lifestyles. It was reported that 77% of patients who required counselling support have seen a counsellor or psychologist for support and 100% reported that this was helpful.

7.9 Mobility Status

Seventy seven percent of patients who use wheelchairs stated that they are in good condition with the remainder having some concerns about repairs required. Fifty five percent of wheelchair users knew where to go to get repairs or a new cushion, which included contacting SIRC. A large range of assistive devices and supports had been provided by SIRC including toilet chairs, mattresses, wheelchairs, and walkers.

7.10 Follow Up

Thirty two percent of patients had received follow up home visits from someone within the last three years while many were receiving telephone follow up. When asked at the end of the survey which areas needed the most attention it was divided between issues relating to pain, then depression, and bowel and bladder issues.

7.11 Family Life and Recreation

Under the family life and recreations section, patients were asked about their familial relationships and community life. Seventy one percent stated that their self-care needs were being met, 68% spent their days doing something purposeful, and the same percentage took part in some kind of recreational activity. Sixty nine percent of patients believed they are able to assume their role within the family and 68% are comfortable with their personal relationships at the moment.

The findings showed that 58% had taken trips out of their community for recreational purposes while 74% had ongoing contact with other individuals with an SCI. These findings revealed that the ex-patients are staying active and involving themselves in the community. The analysis further showed that 96% felt included within community life which is a greater achievement. However, 3% had been abandoned by their main caregiver after they acquired their injury.

7.12 Sexual Health

This was the section most likely to have missing data or references from the CBR workers to say the patient did not want to discuss or feel comfortable talking about this with other family members present and neighbours present.

Of those who did provide responses, there was a clear finding that the information they had about sexual health following their injury came from SIRC and they have the education regarding sexual health after spinal cord injury.

7.13 Vocational Information

Ninety percent of the patients knew the government had a disability policy and 44% have a disability card. Nineteen percent of ex-patients were in receipt of a disability allowance.

For vocational training at SIRC, 54% had received vocational training following their accident, mainly following admission due to the earthquakes. 19% of this cohort stated they are in employment and supporting themselves financially. Their major occupations included farming, business and working in shops. In terms of future intentions, most patients who expressed a desire to work wanted to explore options in retail by opening their own shop or working in a shop for someone else.

7.14 Future Actions Requested by Patients

As an open ended question, participants were free to make any suggestions for what they would like SIRC to provide support for. The most frequently cited issues were firstly, pain (43%) and secondly, depression (18%) and wheelchair issues (27%) and thirdly, bowel and bladder problems (16%).

7.15 Telephonic Follow Up

A dual communication system was in operation at SIRC to ensure all discharged patients received follow up visits or calls. This meant either home based (CBR visits) or telephone check-ins by a trained member of the SIRC follow up team. During the DFID project, 180 calls were made in addition to home visits in which the health, psychological, social, and vocational status of patients was examined.

Using a structured survey and following a strict protocol which detailed to telephonic follow up procedure, a series of questions was asked, similar to the home visits in which issues arising were discussed and needs identified. Interestingly, a very similar pattern of findings emerged from

analysis of telephone responses during this period. The primary difficulties reported by ex-patients were:

- Pressure wounds
- Depression
- Inaccessibility
- Bowel and bladder problems

When further discussions with patients took place they suggested that, both singularly and cumulatively, these issues had a serious impact on daily functioning and adjustment. Quality of life was affected with patients often commenting on the interlinking and compounding nature of these problems. Telephone follow up questions discussed support required by patients in order to reduce further complications. Analysis of this feedback pointed to the need for revisiting information and training to improve retention of knowledge and skills obtained at SIRC. Practicing preventative actions such as skin, bowel, and bladder management would reduce further complications and checking in to assist with knowledge and skill retention was viewed as helpful by patients.

Information gathered during telephonic follow up was a valuable information gathering activity which offered SIRC insight into post discharge patients' experiences and could directly inform CBR planning when making home visits. By understanding the living conditions and challenges faced by SCI individuals within communities, evidence informed plans to strengthen community supports and referral systems could be directive and focused given the information resources available through SIRC telephone follow up approach.

8. Discussion

8.1 Systems to Support and Respond to Patient Needs

The same system of out-reach was implemented by five CBR workers appointed by SIRC who facilitated the identification, meeting, and gathering of information about the needs of SCI individuals who had been discharged from SIRC following rehabilitation. In this period of home visits, deliberate and intentional focus was placed on visiting individuals who had acquired an injury from the 2015 earthquakes and who had received rehabilitation at SIRC.

Applying the same standardised protocol and comprehensive follow up evaluation tool, each CBR worker determined the needs of the patient across a number of key areas such as medical, social, economic, demographic, psychological, vocational, accessibility, and community integration.

A detailed process map was developed between the CBR workers and the evaluation consultant to ensure standardised application of information gathering across the 187 patients. A two-step process was involved in the follow up procedure undertaken by all CBR workers. This began with each worker contacting the patient they were responsible for following up. Where possible a telephone conversation about the forthcoming visit would take place. Questions were asked which would identify pressing issues that the CBR worker could address while on the visit. This would specify equipment or materials that could be brought to the patient initially until the larger follow up assessment was conducted and a more detailed action plan developed. Examples have included: catheters, dressings, Foleys, medications, and xylocaine jelly, etc. The CBR workers also carried mobile phones with them and distributed them to the needy patients so that follow up communication could be continued with them over the telephone. Upon their home visits, if the CBR workers identified major complications in the patient that required treatment at specialised services, then they immediately contacted and coordinated with “Telephone follow up in charge” of SIRC and sent the patient to SIRC for further treatment and prevention of complications.

Following their visit and assessment of patient needs based on responses to the survey and observation of patient health and wellbeing, CBR made referrals, where necessary, to both SIRC and other partners involved in the formal referral system established during this project.

8.2 Issues Arising from Follow Up Assessments

Detailed inspection of the information provided by patients during this cycle of home visits offered comprehensive insights into the health, social, vocational, and community issues being experienced by SCI patients living in the 14 earthquake affected districts receiving community follow up services. This served multiple purposes, ranging from individual needs, to organisational and sectoral learning about community reintegration and daily living with an SCI in Nepal. Most importantly the information directed referrals or supports to the patients to maintain or improve rehabilitation while preventing SCI complications. The available data provides sectoral organisations and government agencies with a strong knowledge base from which informed policy and operational decisions may be taken.

9. Lessons Learned

There are definite changes in the findings with substantially fewer issues being reported with regard to bladder and bowel complications, pressure sores, and psycho social issues. However, it should be noted that this will be influenced by the shorter duration of community integration by patients compared to the previous CBR report. In the first CBR report for this project, patients were more likely to have been living with their condition for longer than this cohort of patients. There is also the potential influence of the range and dosage of activities associated with DFID funded project from which patients in this cohort would have benefited, including: equipment, vocational training, peer and caregiver formalised education programmes. The consistent skew of positive outcomes across all sections of the survey compared to the previous report suggests a higher level of reintegration into the community life with greater levels of self-efficacy among patients and their families.

These findings were in contrast to the previous cohort of patients in the CBR follow up report (May 2016) in which a large volume of diverse needs emerged from patient responses. This group comprised of fewer recently discharged patients with more patients acquiring their injuries before 2014. The findings pointed to the reality of returning to communities following discharge with the goal of family and community integration. A significant number of issues spanning physical, psychological, social and vocational aspects of daily life were highlighted in the findings of CBR follow up assessment. Consideration of these at a singular and cumulative level requires focused commitment to improving outcomes for individuals with SCIs living in districts across Nepal through formal structures of clinical and social supports that patients can access through self or agency referral.

The data generated from 404 SCI individuals living in 14 districts offers a comprehensive evidence base of needs from which operational and strategic decisions relating to CBR systems should be based.

Together these reports call for a series of actions that should be maintained, strengthened, or initiated to improve the active rehabilitation and integration of SCI individuals following their discharge from SIRC. This suggests CBR activities cannot focus solely on addressing clinical outcomes through medical intervention but must embed the components World Health Organization (WHO) matrix that identifies health, education, livelihood, social, and empowerment as the driving components around which CBR activities should be based. The findings of these reports mirror the dimensions of this matrix and affirm the nature of rehabilitation around which all planning and response should be based.

10. Way Forward

The continuation of CBR activities that are rooted in needs driven decision making will be critical to SIRC's system strengthening approach to rehabilitation in the communities of Nepal. Assessment of 404 ex-patients through this project in 2016 has been based on visits to 14 districts only, which

represents relatively low coverage compared with Nepal's total country wide districts. The identification of challenges that affect the physical, psychological, social, and vocational lives of individuals with SCIs through follow up assessments conducted by SIRC CBR workers points to the necessity for focused responses by SIRC, sectoral partners and the Government. By providing robust and reliable information on patient needs as they attempt to integrate into family and community life, decisions are evidence based and subsequently more likely to be in direct response to issues presented by SCI individuals across districts in Nepal. This means SIRC maintaining their commitment to continuous checks with ex-patients through telephonic and in person follow up using formalised assessment tools and measurement scales that rate rehabilitative functioning, adjustment, and needs.

While SIRC has developed through this project a detailed process map of CBR evidence gathering and referral, it is imperative that moving forward, additions are made to this structure that facilitates deeper exploration of issues arising in order to understand their origin and respond with appropriate actions. For example, where pressure ulcers are reoccurring and have led to serious health problems or even death, it is vitally important to understand what precipitated this and led to the demise of a patient. Therefore, evidence gathering should move beyond identification of need to exploration of cause so actions can be put in place to reduce complications through preventative planning and response.

The key to maintaining links between the centre and community based provision is a structured communication system such as the referral system that has been further strengthened during this project. Closing potential gaps in care pathways between discharge and community integration through a referral systems such as this one at SIRC and with partner organisations, should be fully utilised and subject to interval checks to ensure operational processes are meeting the intended objective of the system. This means close links between the CBR team and MDT at SIRC through monthly meetings where review of processes, tools and communication methods can take place. Findings related to retention of patient knowledge and skills regarding preventative actions to reduce complications were challenging after discharge, further emphasized the need for interval checks with patients whether through telephonic follow up or home visits to decrease the likelihood of knowledge and practice attrition. Supporting both patients and families to retain information and skills acquired at SIRC and checking fidelity to these practices could play a significant part in improving functionality and quality of life of SCI individuals.

Appendix 1

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 Admission:

Date of Discharge: **Contact No:**

Married/single/divorced **Job:**

Original location: **Current location:**

Address: **Postal Address:**

E-mail address: **Livestock**:

Demise: **Cause of demise:**

Explain they don't have to answer this question but would be helpful for main income provider

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 contact 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 thatapply):	Heel(s): R/L/both
	Tailbone (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
	Tailbone (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 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	
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/Quadraplegic 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, goose bumps)?	Yes/no
(For T6 and above interviewees) Do you get autonomic dysreflexia symptoms (sudden intense headache, sudden sweating, vision changes, flushing, 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/counselor/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 counselor/support group/home visit(s)/other:
Do you still receive this?	Yes/no/don't know
Accomodation	
Do you and/or your family own or rent your current home?	Own/rent
What type of accommodation do you have?	Private house/Privateapartment
	Own room in house
	Tent
	Temporaryshelterprovided by NGO
	Other
Home Modifications	
Did you have home modifications carried out prior to the earthquake?	Yes/No
Home modifications carried out by SIRC CBR worker	Yes/No/Don't know
Home modifications carried out by your family	Yes/No/Don't know

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
Did you get a wheelchair from SIRC ?	Yes/no/Don't know
What other materials did you get from SIRC ?	
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 caregiver 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:
Sexual Health (Please explain the next section contains a sensitive set of questions which they can answer if they want or leave blank if they would prefer not to answer)	
Were you sexually active before your injury?	Yes/No/Don't know
Do you take part in any physical activity at the moment? (for example, hugging, kissing, touching – not just sexual health)	Yes/No/Don't know
Men: Do you experience ejaculation?	Yes/No/Don't know
Men: Do you use aids to achieve ejaculation?	Yes/No/Don't know

	List aids
Women: Is your menstrual cycle regular?	Yes/No/Don't know
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)

Assessment summary:

Problems **Suggestion/Action plan**

Remarks:

Examiner Name/Signature:

Date/Time:

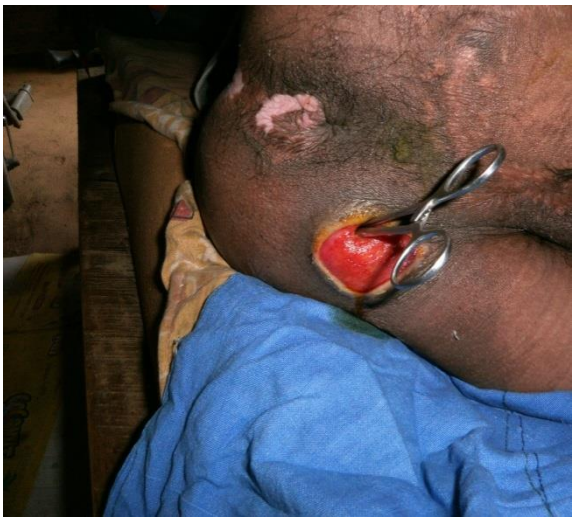
Appendix 2: Success stories of patients visited by CBR workers

1. Ram Bahadur Tamang

Mode of injury: Coal mine injury (Compression by rock)
Address: Ramechhap
Diagnosis: # T11-12
AIS: "A"

Mr. Ram Bahadur Tamang was a labourer (worker) at a coal mine in India. Life was going well for him and his family until a rolling rock hit him on his back while he was working and he sustained a spinal cord injury. Mr. Tamang was carried to one of the hospitals in India and was conservatively managed and was then sent to Nepal for treatment. He was taken to Bir Hospital from where he was referred to the Spinal Cord Rehabilitation Centre (SIRC) for comprehensive rehabilitation. He stayed at SIRC for six months and received comprehensive rehabilitation before he returned home.

Mr Tamang was successfully living his life with a hotel business in his community. However, the disastrous earthquake of 25th April 2015 destroyed his hotel and house. He was forced to stay in a temporary shelter after his house had collapsed. Due to the lack of mobility space inside the shelter he was staying in, he was bed ridden for a couple of months. As a result of this, he developed a pressure ulcer at the sacrum.



Mr. Ram Bahadur Tamang in the community and his Pressure sore

Mr Tamang's case was followed up by community based rehabilitation staff and he was referred back to SIRC for further management of his pressure ulcer. Through a telephone dialogue follow up by focal persons from SIRC and making the necessary transportation arrangements, he was able to come to SIRC. After admission at SIRC and initial wound management with daily dressing and positioning, he was referred to PHECT NEPAL, Kirtipur, for the surgical management of his pressure wound.

Mr. Tamang with CBR worker

After surgical management he was brought back to SIRC. He actively participated in comprehensive top up rehabilitation sessions which helped him to strengthen his upper body and kept him active.

Currently, Mr. Tamang is back in his home and running his hotel business which keeps him busy all of the time. He took a new WM3 wheelchair with him which he can easily traverse the rough roads of Ramechhap. He also took a mattress and toilet chair with him which is noticeably improving his bowel habits and protecting him from for further complications.

Mr. Ram Bahadur Tamang with WM 3 wheeler wheelchair, mattress, and toilet chair at the time of discharge

2. Sumitra Thami

Mode of injury: Fall injury (fall from height)
Address: Dolakha
Diagnosis: #L1
AIS: A

Ms. Sumitra Thami was a farmer as well as a housewife. She was living her life happily until she had a serious accident. She fell from a great height while she was attending a marriage ceremony at her village and sustained a spinal cord injury. She was carried to a nearby health post from where she was referred to Tribhuvan University Teaching Hospital (TUTH). She was surgically managed with internal fixation at TUTH and was then referred to SIRC for comprehensive rehabilitation. She stayed at SIRC for three months receiving rehabilitation with a vocational training of tailoring and went back home.

Ms. Sumitra in front of her temporary shelter (left) and with CBR workers (right)

She was earning and doing well using her vocational training skills in her community until the disastrous earthquake of 25th April 2015 which caused her house to collapse and buried her sewing machine. She was forced to stay in a temporary shelter alone without any work as her sewing machine was buried and these circumstances began to lead her towards depression.

She was followed up by community based rehabilitation (CBR) staff and referred back to SIRC for the further management of her depression and for providing her with further vocational training and a vocational package. With continuous communications from the "Telephonic follow up in charge" from SIRC for arrangements of transportation, she managed to come to SIRC. After her admission, she actively participated in vocational training sessions for sewing. She was given a sewing machine package at her time of discharge.

Currently, Ms Sumitra is back in her home. She is carrying out her regular business of tailoring and is managing to earn a living. She also took a mattress and toilet chair with her upon discharge from SIRC which is helping her bowel and bladder habits and keeping her safe from complications.

Appendix 3: SIRC Home Visits Coverage Map – 187 Ex-Patients