The data set development for the National Spinal Cord Injury Registry of Iran (NSCIR-IR): progress toward improving the quality of care

Zahra Azadmanjir, Seyed Behzad Jazayeri, Roya Habibi Arejan, Zahra Ghodsi, Mahdi Sharif-Alhoseini, Ghazaleh Kheiri, Kazem Zendehdel, Mahdi Safdarian, Farideh Sadeghian, Zahra Khazaeipour, Khatereh Naghdi, Jali Arab Kheradmand, Soheil Saadat, Habibollah Pirnejad, Mohammad Reza Fazel, Esmail Fakharian, Mahdi Mohammadmazdeh, Mohsen Sadeghi-Naini, Houshang Saberi, Pegah Derakhshan, Hadis Sabour, Edward C. Benzel, Gerard Oreilly, Vanessa Noonan, Alexander R. Vaccaro, Seyed Hassan Emami-Razavi, Vafa Rahimi-Movaghar

Abstract

Study design Descriptive study.

Objectives The aim of this manuscript is to describe the development process of the data set for the National Spinal Cord Injury Registry of Iran (NSCIR-IR).

Setting SCI community in Iran.

Methods The NSCIR-IR data set was developed in 8 months, from March 2015 to October 2015. An expert panel of 14 members was formed. After a review of data sets of similar registries in developed countries, the selection and modification of the basic framework were performed over 16 meetings, based on the objectives and feasibility of the registry.

Results The final version of the data set was composed of 376 data elements including sociodemographic, hospital admission, injury incidence, prehospital procedures, emergency department visit, medical history, vertebral injury, spinal cord injury details, interventions, complications, and discharge data. It also includes 163 components of the International Standards for the Neurologic Classification of Spinal Cord Injury (ISNCSCI) and 65 data elements related to quality of life, pressure ulcers, pain, and spasticity.

Conclusion The NSCIR-IR data set was developed in order to meet the quality improvement objectives of the registry. The process was centered around choosing the data elements assessing care provided to individuals in the acute and chronic phases of SCI in hospital settings. The International Spinal Cord Injury Data Set was selected as a basic framework, helped by comparison with data from other countries. Expert panel modifications facilitated the implementation of the registry process with the current clinical workflow in hospitals.

Introduction

Different incidences of traumatic spine fractures (TSF) with or without spinal cord injury (SCI) have been reported in different geographic regions [1–5]. The incidence of traumatic SCI (TSCI) varies between 3.6 and 195.4 per one million around the world; in developing countries, an incidence of 25.5 SCI per million has been reported [6, 7]. In Iran, Heidari et al. reported TSF in 3.8% (619 out of 16,321) of trauma admissions between 1999 and 2004 using the National Trauma Registry (NTR) data [8]; 5.8% (36 out of 619) of people with TSF admitted to a hospital had an associated SCI. In another study, the incidence of TSF in Tehran was estimated to be about 16.35 per 100,000 and less than half of these patients had a simultaneous SCI [9]. The incidence of TSCI in Iran was estimated as 9 per 100,000 persons by another study [10].
When the spinal cord is damaged, long-term disability often ensues [10]. TSCI is a condition with multiple comorbidities and considerable health, social, and economic impacts. The burden of these impacts can be managed by improving quality of care. The lack of a reliable source of information about spine trauma with or without SCI is a significant barrier in evaluation and planning of systems of prevention, control, and care [11]. Until now, there was no spine-specific trauma database or registry system in Iran. The National SCI Registry of Iran (NSCIR-IR) is a project supported by the Ministry of Health and Medical Education to collect and provide TSF and SCI data to evaluate and improve the quality of care of persons with SCI [12].

The development of a data set is an essential phase of designing a registry system [13]. According to Kowal et al., a data set is a common set of data elements used to collect and report data in the registry [14]. Many studies have emphasized the importance of a data set to create national databases and support information sharing on diseases, injuries, and other health-related problems [14–16]. One of the most important and effective tasks for the success or failure of a registry system is the selection of appropriate data items [17]. Data set development is a critical step for nonepidemiologic registries on traumatic conditions that can lead to long-term disabilities such as TSF/SCI. The objectives for a SCI registry are focused on care and outcome measurements, requiring various data inputs from different independent and distinct resources. This study focuses on the development process of the data set for the NSCIR-IR and delineates our experiences, which might be useful for future registries, specifically in developing countries with limited budgets, resources, and information technology infrastructures.

First, a simple review was performed on the data sets of three SCI registries of Australia (Australian Spinal Cord Register), Canada (Rick Hansen SCI Registry (RHSCIR)), and Europe (European Multicenter Study about SCI).

Later, the RHSCIR data set was selected as our basic framework to develop an initial draft data set. The selections were made based on the similarity of RHSCIR to our registry in registry type (Spinal column and SCI (TSF/SCI)) inclusion criteria. Sixteen sessions of the expert panel were held between March and October 2015. We translated the RHSCIR data set dictionary into Farsi and then our expert panel independently reviewed the translation. The accessibility of the data elements of the RHSCIR was examined by experts who were aware of the clinical documentation status and the general content of medical records in hospitals of Iran. It was noted that several variables are not recorded in patients’ hospital charts; therefore, patient medical records were considered as the secondary data source of the registry. Comparability of our registry data with other countries was another issue that was discussed by the expert panel. International data standards are recommended by the World Health Organization (WHO), therefore, the International SCI Data Sets (ISCIDS) were also reviewed. At the third step, the expert panel made changes to Iranian data set of NSCIR-IR in order to accommodate our major data elements and concerns of quality of care. For example, our data set registers different time points from injury time to the time of arrival of ambulance to the trauma scene, time of arrival to hospital, or to a referral center, and time of the surgical stabilization with or without spinal cord decompression. With this design, it will be possible to identify major time delay points in our care providing system.

**Methods**

The development of NSCIR-IR has been one of the main priorities of the National Iranian SCI Research Network since 2012. The data set of NSCIR-IR was developed between March and October 2015. An expert panel with three neurosurgeons, one physiatrist, one general practitioner, one nurse, one community medicine physician, one emergency physician, two epidemiologists, and one health information management specialist was formed. We followed a stepwise approach in the development of the data set. The steps included (i) review of the data sets in similar SCI registries, (ii) selection of a data set as the base framework of the NSCIR-IR data set by the expert panel, and (iii) modification of the basic framework according to data needs, registry objectives, and feasibility of data collection.

Table 1 compares the RHSCIR data set with the two other registries [18, 19]. The RHSCIR data set includes more than 307 variables that cover quality of care [18, 20]. The RHSCIR data set has two types of minimal and extended data elements in which the minimal data set includes 200 mandatory data elements that must be recorded for all patients including those who do not consent to be part of the registry. These minimal data set includes name, family name, age, time, place and mechanism of injury, and questions which are essential for patients’ treatment by care providers. The extended data elements (107 elements) are recorded only for patients who consent to be part of the registry [21]. Our expert panel reviewed the RHSCIR data elements. Some of the RHSCIR data elements were not accessible through primary data sources of the registry e.g., patient-reported or clinician-reported data, observation and measurement by the registry members. Medical records...
Table 1 Compression of data set in three SCI similar registries [19, 20, 35–37].

| Registry abbreviation name | ASCIR | RHSCIR | EMSCI |
|----------------------------|-------|--------|-------|
| Extension name             | Australian Spinal Cord Injury Register | Rick Hansen Spinal Cord Injury Registry | European Multicenter Study about Spinal Cord Injury |
| Start year                 | 1995  | 2004   | 2011  |
| Quality registry           | No, epidemiologic | Yes | Yes |
| Traumatic SCI              | Yes | Yes | Yes |
| Spinal column and spinal cord injury (TSF/SCI<sup>a</sup>) | No | Yes | No |
| Eligibility criteria       | - Inclusion criteria | Acute, traumatic lesion of neural elements in the spinal canal (spinal cord and cauda equina), resulting in temporary or permanent sensory or motor deficit, or bladder/bowel dysfunction | - Individuals sustaining an acute traumatic spinal cord injury - And are currently an inpatient at a participating center |
|                           | - Exclusion criteria | - Nontraumatic SCI | - Nontraumatic SCI |
| Data elements              | Socio-demographic | Yes | Yes | Yes |
| Person identifier          | Yes | Yes | Yes |
| Sex                        | Yes | Yes | Yes |
| Date of birth              | Yes | Yes | Yes |
| Income source              | No  | Yes | No  |
| Marital status             | Yes | No  | No  |
| Education level            | Yes | Yes | No  |
| Occupation                 | Yes | Yes | No  |
| Living setting and arrangement | No  | Yes | No  |
| Address and telephone      | Yes | Yes | Yes |
| Admission                  | Yes | Yes | No  |
| Date/time                  | Yes | Yes | No  |
| Referring institution      | No  | Yes | No  |
| Medical history            | Yes | Yes | Yes |
| Height and weight          | No  | Yes | Yes |
| Comorbidities              | Yes | Yes | Yes |
| Family history             | No  | No  | No  |
| Allergies                  | No  | No  | No  |
| Smoking history            | No  | Yes | No  |
| Drug use                   | No  | Yes | Yes |
| Injury data items          | Yes | Yes | Yes |
| Etiology and mechanism of injury | Yes | Yes | Yes |
| External cause             | Yes | No  | No  |
| Motor vehicle event data   | Yes | No  | No  |
| Safety devices used        | Yes | No  | No  |
| Registry abbreviation name | ASCIR | RHSCIR | EMSCI |
|---------------------------|-------|--------|-------|
| Date/time of injury       | Yes   | Yes    | No    |
| Place of injury occurrence| Yes   | No     | No    |
| Activity when injured     | Yes   | No     | No    |
| Penetrating/blunt injury   | Yes   | No     | No    |
| Brain injury              | No    | No     | No    |
| Glasgow Coma Scale        | Yes   | Yes    | No    |
| Prehospital               |       |        |       |
| Method of transport       | No    | Yes    | No    |
| EMS/transport date/time   | Yes   | No     | No    |
| Prehospital procedures    | No    | No     | No    |
| Vital signs               |       |        |       |
| Pulse                     | Yes   | No     | No    |
| Blood pressure            | Yes   | Yes    | No    |
| Respiratory rate          | Yes   | Yes    | No    |
| Oxygen saturation         | Yes   | No     | No    |
| Injury diagnosis          |       |        |       |
| Neurological level        | Yes   | No     | Yes   |
| SCI type                  | Yes   | No     | Yes   |
| Injury assessments        |       |        |       |
| ASIA impairment Scale     | Yes   | Yes    | Yes   |
| ISS score                 | No    | Yes    | No    |
| Complications             |       |        |       |
| Respiratory problems and assessment | No | Yes | No |
| Mobility problems and assessment | No | Yes | No |
| Endocrine, fertility problems | No | Yes | No |
| Bladder problems          | No    | Yes    | Yes   |
| Bowel problems            | No    | Yes    | No    |
| Pain assessment data      | Yes   | Yes    | Yes   |
| Pressure ulcer            | No    | Yes    | No    |
| Spasticity                | No    | Yes    | No    |
| Urinary tract infection   | No    | Yes    | No    |
| Intraoperative adverse events | No | Yes | Yes |
| Interventions             |       |        |       |
| Surgery date/time         | Yes   | Yes    | Yes   |
| Surgical approach         | No    | Yes    | No    |
| Decompression date/time   | No    | Yes    | No    |
| Ventilator assistance data| No    | Yes    | No    |
| Skeletal traction data    | No    | Yes    | No    |
| Methylprednisolone/ Corticosteroids | No | Yes | No |
were considered as the secondary data source of the registry, however, several variables in the RHSCIR data set were also not recorded in the patient medical records. Table 2 shows the data items and variables, which we did not include in our registry (Table 2).

According to the review of WHO and ISCIDS [22–24], our strategic committee had considerations regarding comparability of the designed data set with international data. WHO recommends the use of standardized coding systems such as the international classification of diseases (ICD), International Standards for Neurological Classification of SCI and ISCIDS for data collection to facilitate comparison between different patients, centers, and countries [22]. The RHSCIR data set and other data sets (Appendix 1) were different from the ISCIDS. Therefore, the expert panel decided was not convinced to use the RHSCIR data set due to concerns of accessibility and comparability of data in our registry with the RHSCIR data set. The expert panel decided to use ISCIDS as the basic framework of NSCIR-IR data set. ISCIDS includes a core data set and several specialized data sets. The core data set includes 24 variables that are the minimal data required for collection for all people with SCI in acute inpatient settings [25]. There are 12 more data sets which are focused on different aspects of SCI and SCI consequences [24]. According to the registry objectives and registration process, the expert panel selected 174 data items from ISCIDS. Data selections were based on accessibility of data and usefulness in quality of care assessment in the acute settings. Selected data items were organized into five sections based on the logical sequence in the process of care (Table 3).

After translation of data items into Farsi, case report forms were designed. Panel members evaluated designed forms and applied the required methods. Major and minor modifications were made to overcome the mentioned challenges in Box 1 (Table 4). The final version of the NSCIR-IR data set was developed with 350 data elements. It includes one data set for acute and one data set for chronic phase of injury (rehabilitation data). Our data items are two of types: mandatory and conditional. Conditional data items are data items that are considered as mandatory based on the clinical situation of the patient. If a data item is not applicable for a patient, it is not necessary to be completed for that patient. For example, if the accident was not a traffic accident, then it is not necessary to record the accident data. Table 5 shows the components of the final version of NSCIR-IR data set. The items were organized into seven case report forms for the acute phase and four case report forms for the chronic phase. All were used in the pilot phase of registry implementation (Table 5). After 8 months of implementation of the pilot phase in three trauma hospitals, changes were

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Table 1 (continued)

| Registry abbreviation name | ASCIR | RHSCIR | EMSCI |
|---------------------------|-------|--------|-------|
| Discharge                 |       |        |       |
| Length of stay in hospital| No    | Yes    | No    |
| Length of stay in ICU     | Yes   | No     | No    |
| Discharge date/time       | Yes   | Yes    | No    |
| Mode of separation        | Yes   | Yes    | No    |
| Cause of death            | No    | Yes    | No    |
| Outcomes                  |       |        |       |
| Glasgow Outcome Score     | Yes   | No     | No    |
| Dependency assessment     | FIM, SCIM | FIM, SCIM | SCIM |
| Quality of life           | EuroQol-5 dimension | LISAT-11, SF36 | EuroQol EQ-5D |

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*aTraumatic spine fracture/spinal cord injury.
*bInternational Standards for Neurological Classification of Spinal Cord Injury.
*cThe Injury Severity Score.
*dFunctional Independence Measure.
*eSpinal Cord Independence Measure.
*fEuroQol-5 dimension is an instrument to evaluate the generic quality of life and is developed in Europe.
*gLife Satisfaction Questionnaire (version 11).
*hThe Short Form [39] Health Survey is a 36-item patient-reported survey of patient health.
made to the data set that are (i) details on the types of respiratory, cardiovascular, and other comorbidities were added into admission form, (ii) procedures in the first hospital in cases with inter-hospital patient transfer were added into admission form, (iii) injury type of Atlas and Axis cervical vertebra (C1-C2), were separated from the other vertebrae and were added as a question into the injury form, (iv) one item was added into the intervention form for the vertebra or vertebrae on which surgery was performed, and (v) one item was added into the discharge form for the type of external fixation device, which patient uses at the time of hospital discharge.

**Discussion**

Our study presents an overview of the data set development process for the NSCIR-IR. Our evidence-based approach along with interdisciplinary expert panel review helped us to develop a comprehensive, yet applicable, data set. Some groups have used review of current evidence and formation of working groups to select the registry data elements [26, 27]. Others have conducted either a survey or Delphi method on an initial version of the data set [28–30]. Svensson-Ranallo et al. [31] performed a comprehensive review for methodologies of data set development in health
should be practical based on routine process [32]. For
emphasized the number of data elements collected that
current clinical practice increases the cost. Tee et al.
routine clinical practice was effective to reduce registration
ISCIDS.
comparability of our registry led us toward using the
items and the necessity of an international framework for
research and care evaluation, the unavailability of most data
which meets all present and future data requirements for
wanted to have a comprehensive and detailed data set,
practicality of the registry [32]. Although, at
a registry lead to a balance between comprehensiveness and
registry. Tee et al. stated that correct data selection items of
literature review and expert committee to form the data sets.
are the use of experts and stakeholders, but the authors
suggested a combined approach with literature review, chart
review, expert committee, and organized data for develop-
ing the minimum data set [31]. In our study, we used the
literature review and expert committee to form the data sets.
It is important to choose the right data elements for a
registry. Tee et al. stated that correct data selection items of
a registry lead to a balance between comprehensiveness and
practicality of the registry [32]. Although, at first, we
wanted to have a comprehensive and detailed data set,
which meets all present and future data requirements for
research and care evaluation, the unavailability of most data
items and the necessity of an international framework for
comparability of our registry led us toward using the
ISCIDS.
Compliance evaluation of determined data elements with
routine clinical practice was effective to reduce registration
workload. Imposition of required uncommon practice in
current clinical practice increases the cost. Tee et al.
emphasized the number of data elements collected that
should be practical based on routine process [32]. For
example, when we chose the RHSCIR data set as our
framework, we found that some of the data were not accessible
at all through primary data sources of the registry. For
care. The results of this review showed that there are dif-
fferent methods such as survey, systematic review, chart
review, and Delphi technique. The most common methods
are the use of experts and stakeholders, but the authors
suggested a combined approach with literature review, chart
review, expert committee, and organized data for develop-
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Compliance evaluation of determined data elements with
routine clinical practice was effective to reduce registration
workload. Imposition of required uncommon practice in
current clinical practice increases the cost. Tee et al.
emphasized the number of data elements collected that
should be practical based on routine process [32]. For
example, when we chose the RHSCIR data set as our
framework, we found that some of the data were not accessible
at all through primary data sources of the registry. For
example, we found the hesitancy of our patients in pro-
viding data related to their income, work status, drinking,
and some other measures as a big barrier for data collection.
In other words, assessing income is very difficult in Iran
especially in people who are self-employed. Most self-
employed Iranians do not express their real income for
cultural reasons. Usually, government employees have
specific income data.
In addition, assessments and interventions for patients in
clinical practice differ between Iran and Canada. For
instance, height and weight of patients are not taken on
arrival to the hospital. Also, some clinical assessments such
as mobility or pain assessment with specialized tools (e.g.,
Berg Balance Scale, Leeds Assessment of Neuropathic
Symptoms and Signs, Douleur Neuropathique 4) are not
part of the routine assessments in Iran. Also, rehabilitation
and assistive devices are not provided in a specialized
manner to the patients in the acute phase. Instead, rehabi-
litation and support services are available at the level of
long-term care. Although, there is connection between the
acute care system and long-term care system; there is a lack
of communication and information sharing between care
providers working in the two levels of Iran health care
system. Patients normally work as messengers, carrying
information between the two levels. In contrast, Canada has
a robust information technology infrastructure. There are
multiple database and reporting systems at all of the health
care services levels. These include the Hospital Morbidity
Database and Discharge Abstract Database for ambulatory
and hospital care, National Rehabilitation Reporting System
for rehabilitation care, NTR for trauma care, Continuing
Care Reporting System, and Home Care Reporting System
for continuing and long-term care [33–38]. Using primary
data sources is not practical in Iran due to limited human
resources for registration and funds allocated according to
the large scale of data that led to a time-consuming and
tedious registration process. Therefore, it was predicted that
using the Canadian SCI registry as the backbone of data set
in NSCIR-IR is impractical.
The NSCIR-IR data set contains spine trauma data such
as the injury morphology and injury type according to the
AOSPINE injury classification system. The classification is
used only in the RHSCIR and not used by other TSF/SCI
registries. Therefore, it is a strong point of the NSCIR-IR
data set. In relation to patient outcome, the data set includes
the Glasgow Outcome Scale that is a physician-reported
outcome; however, it does not include any patient-reported
outcome data, specifically about patient functional inde-
pendence. Other SCI registries use standard measures for
patient-reported outcome such as the Short Form 12 or 36
Health Survey, the Spinal Cord Independence Measure, or
the Functional Independence Measure [21, 39, 40]. This is a
weak point of the NSCIR-IR data set.
Table 4 Lists of major and minor modifications on initial National Spinal Cord Injury Registry of Iran (NSCIR-IR) data set.

| Type                      | Modifications                                                                 | Reason for the modification                                                                 |
|---------------------------|-------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------|
| Major modification        | Removing the musculoskeletal assessment data elements.                         | They are not common in clinical practice in Iranian hospitals.                               |
|                           | Removing some data items from groups of metabolic and endocrine function tests,| They are not the part of routine clinical practice in acute phase of spinal trauma care.     |
|                           | urinary and bowel function tests, entire groups of endocrine system and fasting |                                                                             |
|                           | serum lipid profile.                                                          |                                                                             |
|                           | Adding some required data elements which were not included in                   | They were considered essential to assess the quality of care.                            |
|                           | International Spinal Cord Injury Data Set (e.g., more information for         |                                                                             |
|                           | contact with patient, the entity of associated injuries, mode of              |                                                                             |
|                           | transport to hospital, prehospital procedures, and Glasgow Coma Scale         |                                                                             |
|                           | (GCS)).                                                                       |                                                                             |
|                           | Adding AOSPINE injury classification system as clinical standards.             |                                                                             |
|                           | Adding the full data elements of International Standards for                  | It is beneficial for reporting of spine fracture types and researches on them.            |
|                           | Neurological Classification of Spinal Cord Injury (ASIA).                      |                                                                             |
|                           | Replacing of the validated Persian version of World Health Organization       | It is important to assess the severity of the injury.                                      |
|                           | Quality of Life measure (WHOQOL-BREF) [53] instead of the three items of     | WHO Quality of Life-BREF scale (WHOQOL-BREF) provides better understanding on patient    |
|                           | of the quality of life basic data set.                                        | outcome according to registry objectives.                                                  |
|                           | Transferring detailed pain assessment from data set of acute care phase       | The most common pain in the acute phase of injury is fracture pain and injury site.       |
|                           | to the conditional data items of chronic phase.                               | Assessment of pain due to trauma to other areas of the body was not an objective for our   |
|                           |                                                                               | registry in the acute phase.                                                              |
|                           | Adding the 12 data items including the Modified Ashworth Scale.               | It was necessary for our registry in rehospitalization of patient due to spasticity as    |
| Minor                     | Changing the data element titles.                                             | conditional data items of chronic phase.                                                  |
| modification               | Regrouping some data in designed forms according to logical and time sequence | For better understanding.                                                                 |
|                           | of care process.                                                              | To integrate with the clinical workflow of hospitals.                                     |

Table 5 Components of National Spinal Cord Injury Registry of Iran (NSCIR-IR) data set.

| Category                                                   | Total Pilot phase | After pilot phase, current version | Mandatory Pilot phase | After pilot phase, current version | Conditional Pilot phase | After pilot phase, current version |
|------------------------------------------------------------|-------------------|-----------------------------------|-----------------------|-----------------------------------|------------------------|-----------------------------------|
| Acute phase case report forms                              | 285               | 311                               | 235                   | 235                               | 50                     | 76                                |
| Demographic form                                           | 22                | 22                                | 21                    | 21                                | 1                      | 1                                 |
| Stable (e.g., identifiers, date of birth and etc.)          | 7                 | 7                                 | 7                     | 7                                 | 0                      | 0                                 |
| Unstable (e.g., address, telephone and etc.)               | 15                | 15                                | 14                    | 14                                | 1                      | 1                                 |
| Admission form                                             | 57                | 80                                | 34                    | 32                                | 23                     | 48                                |
| Admission                                                  | 5                 | 5                                 | 5                     | 5                                 | 0                      | 0                                 |
| Injury incidence                                           | 17                | 18                                | 9                     | 10                                | 8                      | 8                                 |
| Prehospital procedures                                     | 15                | 16                                | 5                     | 2                                 | 10                     | 14                                |
| Emergency department                                       | 11                | 11                                | 11                    | 11                                | 0                      | 0                                 |
| Comorbidities and medical history                          | 9                 | 30                                | 4                     | 4                                 | 5                      | 26                                |
| Injury form                                                | 10                | 11                                | 3                     | 3                                 | 7                      | 8                                 |
| Vertebral injury                                           | 6                 | 7                                 | 1                     | 1                                 | 5                      | 6                                 |
| Co-existing injuries                                       | 2                 | 2                                 | 1                     | 1                                 | 1                      | 1                                 |
| Spinal cord injury                                         | 2                 | 2                                 | 1                     | 1                                 | 1                      | 1                                 |
| Intervention form                                          | 15                | 16                                | 3                     | 3                                 | 12                     | 13                                |
| Nonsurgical/surgical Interventions and medications         | 15                | 16                                | 3                     | 3                                 | 12                     | 13                                |
| Complications form                                         | 13                | 13                                | 8                     | 9                                 | 5                      | 4                                 |
| Discharge form                                             | 5                 | 6                                 | 3                     | 4                                 | 2                      | 2                                 |
| International Standards for Neurological Classification of  | 163               | 163                               | 163                   | 163                               | 0                      | 0                                 |
| Spinal Cord Injury                                         |                                                               |                      |                                     |                                     |                                     |
Using the ISCIDS as the basic framework of the NSCIR-IR data set facilitates international comparisons on the quality of provided care to TSF/SCI patients. One of the limitations of our study was that we chose variables based on the expert’s opinion on the availability of data in current medical records. However, due to lack of electronic health records and national or regional standards in medical records documentations, expert opinion was the best resource that we could rely on.

In summary, the NSCIR-IR data set was developed to meet the quality objectives of the registry. It focuses on data representing quality of care provided to patients with TSCI in the acute and chronic phases of their injury. The selected basic framework of the data set for the ISCIDS can help to compare national data with data from other countries. Expert panel modifications facilitate the integration of the registration process with the current clinical workflow within the hospitals.

Data availability

Anonymous data of NSCIR-IR may be accessible for research use, upon written request and approval from the steering committee.

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Author contributions

ZA wrote the draft of the paper, designed and implemented the NSCIR-IR project from idea to deployment, and also has a major role in data set and case report forms development. ZA made major revisions to the paper and its appendix. VR-M designed and implemented the NSCIR-IR project from idea to deployment including data set development and also made major revisions to the paper. SBJ contributed to the design of NSCIR-IR project and also made major revisions to the paper. RHA contributed to the design of NSCIR-IR project and also made major revisions to the paper. KN contributed to the NSCIR-IR project as registrar. GK prepared the appendix. ZK, HS, KZ, JAK, SS, and FS were members of the expert panel and contributed to the paper’s revision. RHA refined the paper according to final comments and modifications.

Compliance with ethical standards

Conflict of interest

The authors declare that they have no conflict of interest.

Ethical approval

This study was approved by Research Ethics Committee of Tehran University of Medical Sciences as a part of National Spinal Cord Injury Registry study.

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Affiliations

Zahra Azadmanjir1,2 · Seyed Behzad Jazayeri1,3 · Roya Habibi Arejan1 · Zahra Ghodsi1 · Mahdi Sharif-Alhoseini1 · Ghazaleh Kheiri1,5 · Kazem Zendehdel6 · Mahdi Safdarian1 · Farideh Sadeghian1,7 · Zahra Khazaipour8 · Khatereh Naghdi1 · Jalil Arab Kheradmand9 · Soheil Saadat1 · Habibollah Pirnejad10 · Mohammad Reza Fazel11 · Esmail Fakharian11 · Mahdi Mohammadzadeh11 · Mohsen Sadeghi-Naini1,12 · Houshang Saberi8,13 · Pegah Derakhshan14 · Hadis Sabour8 · Edward C. Benzel15 · Gerard Oreilly16 · Vanessa Noonan17 · Alexander R. Vaccaro18 · Seyed Hassan Emami-Razavi8 · Vafa Rahimi-Movaghar1,8,19

1 Sina Trauma and Surgery Research Center, Tehran University of Medical Sciences, Tehran, Iran
2 Department of Health Information Management, School of Allied Medical Sciences, Tehran University of Medical Sciences, Tehran, Iran
3 Department of Urology, University of Florida, Jacksonville, FL, USA
4 School of Medicine, Tehran University of Medical Sciences, Tehran, Iran
5 Student’s Scientific Research Center (SSRC), Tehran University of Medical Sciences, Tehran, Iran
6 Cancer Research Center, Cancer Institute, Tehran University of Medical Sciences, Tehran, Iran
7 Center for Health Related Social and Behavioral Science Research, Shahroud University of Medical Sciences, Shahroud, Iran
8 Brain and Spinal Cord Injury Research Center, Neuroscience Institute, Tehran University of Medical Sciences, Tehran, Iran
9 Ahya Neuroscience Research Center, Tehran, Iran
10 Health Information Technology Department, Urmia University of Medical Sciences, Urmia, Iran
11 Trauma Research Center, Kashan University of Medical Sciences, Kashan, Iran
12 Shahid Beheshti University of Medical Science, Tehran, Iran
13 Department of Neurosurgery Imam Khomeini Hospital, Tehran University of Medical Sciences, Tehran, Iran
14 Student Research Committee, School of Medicine, Iran University of Medical Sciences, Tehran, Iran
15 Department of Neurosurgery, Cleveland Clinic Foundation, Cleveland, OH, USA
16 Department of Epidemiology and Preventive Medicine, School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia
17 Rick Hansen Institute, University of British Columbia, Vancouver, BC, Canada
18 Department of Orthopedic Surgery, Rothman Institute, Thomas Jefferson University, Philadelphia, PA, USA
19 Department of Neurosurgery, Shariati Hospital, Tehran University of Medical Sciences, Tehran, Iran