

THE MODEL SPINAL CORD INJURY SYSTEMS'

DATA COLLECTION SYLLABUS

FOR THE

NATIONAL SPINAL CORD INJURY DATABASE

2000-2005 PROJECT PERIOD

This is a publication of the National Spinal Cord Injury Statistical Center, Birmingham, Alabama, which is funded under cooperative agreement number H133A011201 from the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. The opinions contained in this publication are those of the grantee and do not necessarily reflect those of the U.S. Department of Education.

TABLE OF CONTENTS

| | Page |
|---|-------------|
| Introduction..... | 1 |
| Database History..... | 1 |
| Purpose of the National SCI Database..... | 2 |
| Summary of Changes for the 2000-2005 Project Period..... | 2 |
| The NSCISC’s Personal Computer Data Management Software..... | 5 |
| Changes In Funded Systems for the 2000-2005 Project Period | 6 |
| The National Spinal Cord Injury Statistical Center (NSCISC) Staff | 7 |
| Model Spinal Cord Injury Care Systems’ Staff..... | 8 |
| The Data Collection Syllabus | 12 |
| The National Spinal Cord Injury Database | 13 |
| The Data Collection Mechanism | 13 |
| Reporting Procedures and Guidelines | 14 |
| Definitions for Data Collection Periods | 15 |
| Eligibility Criteria..... | 18 |
| Consent Forms | 19 |
| Reporting on a Patient Who Dies | 19 |
| THE DATA ENTRY PROCESS | 20 |
| Quality Control | 20 |
| Personal Data..... | 20 |
| THE DATA SUBMISSION PROCESS | 20 |
| New Records..... | 20 |
| Update Records..... | 21 |
| When to Submit a New Form I..... | 21 |
| Submission of Data to the NSCISC..... | 21 |
| Form IIs Due List..... | 21 |
| Record Dumps | 22 |
| GUIDELINES FOR CODING PRIMARY CAUSE OF DEATH..... | 23 |
| COPIES OF THE NATIONAL SCI DATABASE..... | 26 |
| To currently funded Model Systems..... | 26 |
| To anyone not affiliated with a currently funded Model System | 27 |

TABLE OF CONTENTS

| | Page |
|--|-----------------|
| List of All Variables in the Current Version of the National SCI Database | 28 |
| Personal Data | 28 |
| Registry | 29 |
| Form I | 30 |
| Form II | 40 |
| Variable Pages..... | 46 - 320 |
| | |
| Appendix A - Interview Materials | |
| The FIM Decision Tree | A1-A41 |
| | |
| Appendix B - Forms | |
| Personal Data Data Collection Form | B1 |
| Registry Data Collection Form | B2 |
| Form I Data Collection Form | B3 |
| Form II Data Collection Form | B10 |
| Interview Form (English) | B17 |
| Interview Form (Spanish) | B34 |
| Appendix C – 1999 Occupational Classification System..... | C1-C9 |
| | |
| Appendix D – Tips for Tracking Patients..... | D1-D18 |
| | |
| Appendix E - Quality Control Documentation | E1-E30 |

INTRODUCTION

A major priority of the National Spinal Cord Injury Statistical Center (NSCISC) is continual refinement and improvement of the National SCI Database. Recommendations for revisions are made not only by the NSCISC staff but also by the national data collectors, project directors and members of the Database Committee (established by the Project Directors in 1989).

Database History

The National Spinal Cord Injury Database began in Phoenix Arizona in 1975. Data were collected retrospectively back to 1973 and prospectively since 1975. With some exceptions, data have been collected on all persons receiving initial inpatient rehabilitation at a Model Spinal Cord Injury System within one year of spinal cord injury. Only patients who were injured in and usually resided in the geographic catchment area of the Model System and whose injuries occurred due to trauma have been allowed in the database. The database is not population based since patients who are not treated at Model SCI Systems are not included. It has been estimated that between 10 and 15% of all new spinal cord injuries each year are included in the database. Two sets of data have been collected. Form I includes demographic data and information on acute care and rehabilitation experiences and treatment outcomes and is collected once on all persons. From 1986 to September 2000, Form I was collected on persons admitted to a Model System within 60 days of injury. The Registry database was created for patients admitted between post-injury day 61 and 365. The Registry database included only very limited demographic data and no patient follow-up data. Beginning October 2000 the Form I data submission criteria reverted back to the pre-1986 rule (i.e., Form I data are collected on all patients admitted to a system within one year of injury). Since 1995, the Form I for persons admitted to the Model System within 24 hours of injury is more detailed than the Form I for remaining patients.

Other changes to the Form I eligibility criteria were made in 2000: (1) *subjects must receive treatment/care in all components of the system* was changed to *persons must receive acute care and/or rehab in the System*; (2) the stipulation that, prior to system admission, subjects cannot have been discharged from a hospital for a period longer than that normally accepted as therapeutic leave of absence was deleted; (3) *subjects shall usually reside in and must have been injured in the System's catchment area* was changed to *persons must reside in the catchment area and may be injured outside the catchment area*. During their December 2004 meeting the Directors changed *persons must receive acute care and/or rehab in the System* to *must receive acute inpatient rehab in the System (unless they expire, recover or have minimal deficit during System acute care); may receive System inpatient subacute rehab*. Also, these pre-2000 rules were restored: (A) Must be discharged from the SCI care system as (1) normal neurologically or minimal deficit, (2) expired, or (3) having completed inpatient rehabilitation. (B) The patient is not eligible for Form I if he leaves against medical advice or transfers out of System prior to completion of the initial inpatient rehabilitation process. And (C) If there will be no follow-up (for reasons other than their becoming normal neuro, minimal neuro or deceased) then, the patient should be entered into the Registry (not Form I). The remaining Form I eligibility criteria have not changed since the start of the database: (1) persons must have neurologic deficit at the time of admission; (2) a signed informed consent is required; and (3) subjects must be discharged as recovered (or with minimal deficit); expired or having completed rehab.

Form II includes data collected annually to reflect both occurrences during the year and current status at the time of the annual evaluation. Beginning in 1996 a sampling process was implemented to reduce workload at systems with large patient populations since grant-funding levels were equalized across all systems beginning in 1995. Through September 2000, Form II was collected in post-injury years 1, 2, 5, 10 and every 5 years thereafter except for a sample of 125 patients from each Model System who continued to have a reduced set of Form II data

collected every year. To further reduce the workload during the 2000-2005 project period, Form II data collection was no longer required at year 2 and the sample of 125 patients per Model System on whom data are collected each follow-up year was terminated.

Changes in the exact variables included in both Form I and Form II have occurred every two or three years as variables with poor reliability or diminished utility are deleted and new items of importance and interest are added. A detailed description of the history of the database can be found in the November 1999 issue of the Archives of Physical Medicine and Rehabilitation (pages 1365-1371) and lists of all changes have been published in the NSCISC statistical reports.

At the beginning of each new five-year funding period, the NSCISC removes variables deleted during the previous project period from the data collection forms and syllabus. All current variables are consecutively numbered and every attempt is made to group related variables. A complete list of Form I and Form II variables (with their "1995-2000" and "2000-2005" project period variable numbers) may be found beginning on page 26.

Whenever changes occur in the National Spinal Cord Injury Database records currently in the database are all converted to the new format. All previous versions of the National Spinal Cord Injury Database are stored at the NSCISC.

PURPOSE OF THE NATIONAL SCI DATABASE

Within the scope of the Model SCI System program, the purpose of the National SCI Database is as follows:

1. To study the longitudinal course of traumatic spinal cord injury and factors that affect that course.
2. To identify and evaluate trends over time in etiology, demographic, and injury severity characteristics of persons who incur a spinal cord injury.
3. To identify and evaluate trends over time in health services delivery and treatment outcomes for persons with spinal cord injury.
4. To establish expected rehabilitation treatment outcomes for persons with spinal cord injury.
5. To facilitate other research such as the identification of potential persons for enrollment in appropriate spinal cord injury clinical trials and research projects or as a springboard to population-based studies.

The National SCI Database is not intended to study the effectiveness of Model System care compared to other systems of health care delivery. It is also not by itself intended to gather and maintain population-based data on spinal cord injuries.

SUMMARY OF CHANGES FOR THE 2000-2005 PROJECT PERIOD

At the December, 1999 Project Directors' meeting, a decision was made to appoint an ad-hoc committee to develop recommendations for the revision of the national database that would be implemented at the beginning of the new grant cycle in October, 2000. The ad-hoc committee consisted of 5 Model System researchers and they began the database review process by soliciting suggestions from Archives special issue paper authors and the standing committees of the Project Directors. Representatives from NIDRR, CDC, PVA and NHTSA joined the ad-hoc committee in its deliberations. That committee presented its plan for approval to the Project Directors at their June 2000 meeting and the following changes were approved:

- The eligibility criteria for Form I would be expanded in such a way that most current registry patients and even some patients who may not be eligible currently for the registry would be eligible for Form I and subsequent follow-up on Form II. Since this would greatly increase the workload at some Model Systems, sampling may be implemented at those model systems depending on NIDRR funding decisions. A Registry data file will be used for cases excluded from Form I. As in the past, only traumatic SCI cases would be allowed into the database, and only from Model System patients. The database would remain without a population basis.
- A reduced version of the Form III data collection protocol previously field-tested at 5 model systems has been incorporated into Form I. This requires the reporting of all dates of admission and discharge from each inpatient and organized formal outpatient rehab phase of treatment wherever it occurred (within or outside the system) until ultimate completion of rehabilitation or the first anniversary of injury. For those phases that took place within the model system, additional information on billed charges and units of service provided are to be reported.
- To reduce workload, the sample of 125 patients on whom data are collected each follow-up year has been terminated.
- To reduce workload, Form II data collection is no longer required at year 2. Form II data collection will occur only at years 1, 5, 10, and every 5 years thereafter.
- A few variables that are particularly useful for linking data to other databases or comparing Model System data with other data were added:
 - ICD 10 codes requested by CDC
 - Zip code of residence requested by CDC
 - Work-relatedness of injury requested by NHTSA
 - Veteran status and use of VA health care services requested by PVA
- Each rehospitalization will be documented separately to include length of stay and cause (selected from a simple prespecified list).
- To reduce workload, the following variables were deleted:
 - marital status at discharge
 - Form I and Form II sensory and motor left and right ZPP; all neurologic data after year 1
 - all remaining associated injuries
 - use of mechanical ventilation during system was replaced by mechanical ventilation at rehab admission (use at discharge was retained)
 - dates of all secondary medical complications and surgical procedures
 - Form I secondary medical complications of autonomic dysreflexia, cardiopulmonary arrest, kidney stones, renal function, and gastrointestinal hemorrhage
 - Form II secondary medical complications of autonomic dysreflexia, renal function, and long bone fractures
 - Form II surgical procedures of syring surgery, surgical ablation or pump placement for pain or spasticity, and electrical stimulators
 - interview quality indicators of who provided the answers and the interviewer's assessment of accuracy
- The psychosocial interview portion of Form II data collection would include the following changes that would on balance result in a very slight increase in workload based on total number of items:
 - Deletion of the SF-12 except for item 1 (overall health) and item 8 (pain)

- Use of the CHART Short Form (19 items, 6 dimensions and the total) rather than the full CHART
- Addition of the CHIEF Short Form on access to the environment (12 items, 5 subscales and the total)
- Addition of the Brief Patient Health Questionnaire for Depression (10 items plus the major depression syndrome item and the severity of depression score)
- Addition of 1 drug use item, the CAGE (4 items and the total score) and four other single alcohol items
- Addition of the severity of pain variable
- Addition of the identity of patients has been approved for inclusion in a separate data file at the NSCISC. Procedures to maintain confidentiality will be developed and IRB approval will need to be obtained for this to occur. Separate permission may need to be obtained from each patient to allow this information to be exported from the local System databases to the NSCISC.

At their December 2004 meeting, the Project Directors voted to

- revert back to some of the pre-2000 Eligibility Criteria and
- data collection for outpatient treatment phases and hours of treatment for all treatment phases were discontinued.

THE NSCISC'S PERSONAL COMPUTER DATA MANAGEMENT SOFTWARE

The NSCISC's Personal Computer Data Management Software was first released in December 1990. This PC software changed the data submission process (from hard-copy forms sent by systems to the NSCISC for data entry) to data entry at the system level with an Export function that prepares computerized data for submission to the NSCISC. At first all data files were shipped to the NSCISC on floppy disks. Now systems have the options of uploading the export file to the NSCISC's server via the Internet [using the File Transfer Protocol (FTP) software], attaching the file to an Email message, or shipping the file on a CD.

The software is a self-contained system that provides all functions the systems need to enter their data locally and export it to the NSCISC. These functions include the ability to enter new records; edit, delete or copy current records; view individual records as well as a list of records available for a particular patient. The Export function selects (for shipment to the NSCISC) all the system's Personal Data, Registry, Form I and Form II records. This function also queries the System's Personal Data records and copies only those personal data items (i.e., name, social security number, etc.) that the patient has agreed may be sent to the NSCISC. All other data in the Personal Data file are replaced by "X's". This export file is then encrypted.

Additional software functions include

- Dataset building functions that allow systems to build custom datasets (using either their local data and/or the national database). In addition to using the data from each record type (i.e., Personal Data, Registry, Form I or Form II), the user may select from combinations of Form I and Form II or Form I and Registry records. Several dataset conditions are available (such as using only the records for the day-1 admissions; excluding the records of the deceased patients; selecting only records entered after a certain date, etc.)
- The Form IIs Due function produces a list of patients for whom follow-up forms are due within a user-defined range of dates. The user may restrict the list to only "lost" patients, Form IIs that have not yet been entered and/or Form IIs due for the required data submission years. A list of all patients coded "lost" on their last Form II is also available through this function. This function may be used to generate a list of Form IIs due in the future and, this list may be used to help schedule patients for interviews and/or clinic visits.
- The List Patients function selects patients based on user-defined criteria. Data from all variables selected by the user are included on this list. This function may be used, for example, to obtain a list of database patients who may meet the criteria for another study.
- The Patient Notes function allows the user to enter any other information not collected in the database. Systems also have the ability to change the Password into the software as often as needed. Multiple users of the software are each assigned unique User IDs and passwords.
- The software Users' Manual is designed and written for basic users.

Software features to improve the quality of data include checking for valid codes as the data are entered; the computation of the number of days between dates as well as totals for other variables (such as the Total FIM score) and the computation of the Motor Level.

Other software features to improve efficiency include (1) the ability to advance through a list of records searching for patients by patient number, alternate ID or name; (2) no need to enter leading zeros; (3) skipping variables that are required only of day-1 admissions when working in a record for a non-day-1 admission; (4) a GoTo key to advance to a particular variable during data entry. Tool Tips displaying the valid codes or referring the user to the syllabus page that contains this information are available for every variable. The Exam Dates function produces a table with the acceptable range of dates for obtaining the interview data, the annual exam data and the data to be collected during the annual year for each year of follow-up. This is a time-saving feature since there are different range of dates for each of these types of data.

For the 2000-2005 project period the software was rewritten from the Clipper programming language to Visual Basic language. The software is now totally Windows compatible providing point-and-click capabilities for the user. The format of the data files also changed (from Dbase to ACCESS format). ACCESS format allows systems to more easily utilize copies of the national database.

The Quality Control (QC) Program

The NSCISC's PC software includes a stand-alone Quality Control program that performs more than 500 checks on the database. Each variable is checked for "legal codes" during the data entry process and cross-variable and cross-record checking are performed using the QC software. See Appendix E of this syllabus for complete documentation of all the checks in this software.

CHANGES IN FUNDED SYSTEMS FOR THE 2000-2005 PROJECT PERIOD

- NIDRR has funded 16 systems for the 2000-2005-project period. One previously funded system (Miami, Florida) has returned and one new system (Pittsburgh, Pennsylvania) has been added. Funding was not continued for the systems in Chicago, Cleveland, Detroit and Milwaukee.

**THE NATIONAL SPINAL CORD INJURY STATISTICAL CENTER
(NSCISC)**

| <u>Name</u> | <u>Title</u> | <u>Email</u> | <u>SRC* Room</u> | <u>Phone (205)</u> |
|-----------------------------|--|------------------|------------------|--------------------|
| Michael J. DeVivo, Dr.P.H. | Director, NSCISC | devivo@uab.edu | 515 | 934-3320 |
| Amie B. Jackson, M.D. | Co-director, NSCISC | jacksona@uab.edu | 190 | 934-3330 |
| J. Scott Richards, Ph.D. | Director of Research | richards@uab.edu | 530 | 934-3454 |
| LaQuette Hunter, MPH | Manager of Data Collection and Analysis | lthunter@uab.edu | 515 | 934-5048 |
| Jimmie Loats, B.S. | Database Analyst | jloats@uab.edu | 515 | 934-3348 |
| Daniel R. Vaughan, B.S.E.E. | Manager, Computer Services | vaughand@uab.edu | 543 | 934-3321 |
| Vicki Farris, B.S. | Information Systems Specialist | farris@uab.edu | 515 | 934-5049 |
| Yuying Chen, M.D., Ph.D. | Statistical Analyst | yychen@uab.edu | 506 | 934-3329 |
| Glenda Marsh | Office Service Specialist | gmarsh@uab.edu | 515 | 934-3320 |

UAB SPINAL CORD INJURY CARE SYSTEM

| <u>Name</u> | <u>Title</u> | <u>Email</u> | <u>SRC* Room</u> | <u>Phone (205)</u> |
|--------------------------|---------------------|------------------|------------------|--------------------|
| Amie B. Jackson, M.D. | Project Director | jacksona@uab.edu | 190 | 934-3330 |
| J. Scott Richards, Ph.D. | Co-project Director | richards@uab.edu | 530 | 934-3454 |
| Kay Canupp, M.S. | Data Collector | canupp@uab.edu | 556 | 934-0355 |
| Victoria Allen, B.S. | Research Specialist | mkitso@uab.edu | 515 | 934-5048 |

* Spain Rehabilitation Center

| |
|-----------------------------------|
| NSCISC FAX Number: (205) 934-2709 |
|-----------------------------------|

Mailing Address

| |
|---|
| <p>National Spinal Cord Injury Statistical Center 1717 6th Avenue South, Room 515 Birmingham, AL 35233-7330</p> |
|---|

MODEL SPINAL CORD INJURY SYSTEMS

2000-2005 Project Period

| PROJECT DIRECTOR | PRIMARY DATA COLLECTOR |
|------------------|------------------------|
|------------------|------------------------|

| University of Alabama at Birmingham SCI Care System | |
|---|---|
| Amie B. Jackson, M.D. 1717 6th Avenue South, Room 190 Birmingham, AL 35233-7330 (205) 934-3330 (V), 975-9754 (F) jacksona@uab.edu | Victoria "Tori" Allen 1717 6th Avenue South, Room 515 Birmingham, AL 35233-7330 (205) 934-5048 (V), 934-2709 (F) mkitso@uab.edu |

| Regional SCI Care System of Southern California | |
|---|---|
| Robert L. Waters, M.D. Rancho Los Amigos National Rehab Center, HB 117 7601 East Imperial Highway Downey, CA 90242 (562) 401-7161 (V), 803-5623 (F) rwaters@dhs.co.la.ca.us | Ulises Perez-Flores Rancho Los Amigos National Rehab Center HB-206 7601 East Imperial Highway Downey, CA 90242 (562) 401-7048 (V), 803-5623 (F) dragases@appleisp.net |

| Northern California SCI System | |
|---|--|
| Kazuko Shem, M.D. Santa Clara Valley Medical Center 751 South Bascom Avenue San Jose, CA 95128 (408) 885-2000 (V), 885-2028 (F) kazuko.shem@hhs.co.santa-clara.ca.us | Kathy Miller Santa Clara Valley Medical Center 751 S. Bascom Ave. San Jose, CA 95128 (408) 793 – 6426 (V), (408) 793-6434 (F) Kathy.Miller@hhs.co.santa-clara.ca.us |

| Rocky Mountain Regional SCI System | |
|---|--|
| Daniel Lammertse, M.D. Craig Hospital 3425 South Clarkson Street Englewood, CO 80113-9839 (303) 789-8220 (V), 789-8470 (F) dlammertse@craig-hospital.org | Susan Solnick Craig Hospital SCI Research Department 3425 South Clarkson Street Englewood, CO 80113-9839 (303) 789-8203 (V), 789-8567 (F) ssolnick@craig-hospital.org |

| South Florida Model SCI System | |
|--|---|
| Marca L. Sipski, M.D. Department of Rehabilitation Medicine University of Miami School of Medicine PO Box 016960 (D-461) Miami, FL 33101 (305) 585-1339 (V); 585-1340 (F) m.sipski@miami.edu | Neyton Baltodano L105 Rehabilitation Center Jackson Memorial Hospital 1611 NW 12 th Avenue Miami, FL 33136 (305)585-1339 (V), 585-1340 (F) nbaltoda@.med.miami.edu |

MODEL SPINAL CORD INJURY SYSTEMS

2000-2005 Project Period

| PROJECT DIRECTOR | PRIMARY DATA COLLECTOR |
|------------------|------------------------|
|------------------|------------------------|

| Georgia Regional SCI System | |
|--|--|
| David F. Apple, Jr., M.D. Shepherd Center 2020 Peachtree Road, NW Atlanta, GA 30309 (404) 350-7353 (V), 355-1826 (F) david_apple@shepherd.org | Pat Duncan Shepherd Center 2020 Peachtree Road, NW Atlanta, GA 30309 (404) 350-7591 (V), 355-1826 (F) pat_duncan@shepherd.org |

| New England Regional SCI Center | |
|---|--|
| Steve Williams, M.D. Preston F511 732 Harrison Ave Boston, MA 02118-2393 (617) 638-7911 (V); 638-7313 (F) steve.williams@bmc.org | Bethlyn Houlihan 374 Congress St., Suite 502 Boston MA 02118 (617) 426-4447, Ext. 20 (V), 426-4547 (F) bvergo@bu.edu |

| University of Michigan Model SCI System | |
|---|--|
| Denise Tate, Ph.D. D4100 Medical Professional Building University of Michigan Hospitals 1500 E. Medical Center Dr. Ann Arbor, MI 48109-0718 (734) 936-7052 (V); 936-7048 (F) dgtate@umich.edu | Jane Walters 300 North Ingalls, N12A09 Ann Arbor, MI 48109-0491 (734) 763-0971 (V), 936-5492 (F) janewal@umich.edu |

| Missouri Model Spinal Cord Injury System | |
|--|---|
| Laura Schopp, Ph.D. Dept. of Health Psychology One Hospital Drive, DC046.46 Columbia, MO 65212 (573) 882-8847 (V); 884-4540 (F) schoppl@health.missouri.edu | Lisa Williams Dept. of Health Psychology One Hospital Drive, DC046.46 Columbia, MO 65212 (573) 884-8094 (V); 884-2902 (F) Williamslm@health.missouri.edu |

MODEL SPINAL CORD INJURY SYSTEMS

2000-2005 Project Period

| PROJECT DIRECTOR | PRIMARY DATA COLLECTOR |
|------------------|------------------------|
|------------------|------------------------|

| | |
|--------------------------------|--|
| Northern New Jersey SCI System | |
|--------------------------------|--|

| | |
|---|---|
| <p>Steven Kirshblum, M.D. Kessler Institute for Rehabilitation 1199 Pleasant Valley Way West Orange, NJ 07052 (973) 731-3600 x2258 (V); 243-6861 (F) skirshblum@kessler-rehab.com</p> | <p>Kate Francis Kessler Med. Rehab. Research & Education Corp. 1199 Pleasant Valley Way West Orange, NJ 07052 (973)324-3538 (V), 243-6869 (F) kfrancis@kmrrec.org</p> |
|---|---|

| | |
|------------------------------|--|
| Mount Sinai SCI Model System | |
|------------------------------|--|

| | |
|---|---|
| <p>Kristjan T. Ragnarsson, M.D. Mount Sinai School of Medicine 1425 Madison Ave., Room 4-25 New York, NY 10029-6574 (212) 659-9340 (V); 348-5901 (F) kristjan.ragnarsson@mssm.edu</p> | <p>Vishali Saldi 1425 Madison Ave. Box 1240 New York, NY 10029 (212) 659-9356 (V); 348-5901 (F) Vishali.Saldi@msnyuhealth.org</p> |
|---|---|

| | |
|--|--|
| Regional SCI System of Delaware Valley | |
|--|--|

| | |
|--|---|
| <p>John F. Ditunno, M.D. Thomas Jefferson University Hospital 132 South 10th Street, 375 Main Bldg. Philadelphia, PA 19107 (215) 955-5580 (V); 955-5152 (F) john.ditunno@jefferson.edu</p> | <p>Mary Patrick Thomas Jefferson University Hospital 132 South 10th Street, 375 Main Bldg. Philadelphia, PA 19107 (215) 955-6579 (V), 955-5152 (F) Mary.Patrick@jefferson.edu</p> |
|--|---|

| | |
|---|--|
| University of Pittsburgh Model System on SCI (UPMC-SCI) | |
|---|--|

| | |
|---|--|
| <p>Michael Boninger, M.D. University of Pittsburgh 3471 Fifth Avenue, Suite 201 Pittsburgh, PA 15213 (412) 648-6954 (V); 692-4410 (F) mlboning@pitt.edu</p> | <p>Ryan Phillips University of Pittsburgh 3471 Fifth Avenue, Suite 202 Pittsburgh, PA 15213 (412) 648-6982 (V), 692-4354 (F) phillipsrl@upmc.edu</p> |
|---|--|

MODEL SPINAL CORD INJURY SYSTEMS

2000-2005 Project Period

| | |
|------------------|------------------------|
| PROJECT DIRECTOR | PRIMARY DATA COLLECTOR |
|------------------|------------------------|

| TEXAS REGIONAL SCI SYSTEM | |
|--|---|
| William H. Donovan, M.D. The Institute for Rehabilitation & Research 1333 Moursund Street Houston, TX 77030 (713) 797-5991/5916 (V); 797-5904 (F) donovw@tirr.tmc.edu | Glen Baker TIRR 1333 Moursund Street Houston, TX 77030 (713) 797-5972 (V); 799-7017 (F) bakergl@tirr.tmc.edu |

| Virginia Commonwealth Regional Spinal Cord Injury System | |
|---|---|
| William McKinley, M.D. Medical College of Virginia, Box 980661 Richmond, VA 23298-0661 (804) 828-4233 (V); 828-5074 (F) wmckinley@hsc.vcu.edu | Karen L. Brooke Medical College of Virginia, Box 980542 Richmond, VA 23298-0542 (804) 828-3705 (V); 828-2378 (F) klbrooke@vcu.edu |

| Northwest Regional SCI System | |
|--|--|
| Diana D. Cardenas, M.D. Department of Rehab Medicine University of Washington, Box 356490 Seattle, WA 98195-6490 (206) 543 8171 (V); 685-3244 (F) dianamac@u.washington.edu | Debra Glazer Department of Rehab Med, Box 356490 1959 N.E. Pacific Street Seattle, WA 98195-6490 (206) 685-3880 (V); 685-3244 (F) dglaze@u.washington.edu |

NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH

Theresa B. SanAgustin, M.D.; Program Officer, NIDRR

(202) 245-7516 (V); 245-7323 (F)

Email: Theresa.SanAgustin@ed.gov

For FEDEX use: Potomac Center Plaza
 550 12th Street, SW, Room 6072
 Washington, D.C. 20204

For U.S. postal mail use: 400 Maryland Avenue,
 SW, PCP#6072
 Washington, DC 20202-2700

Phillip Beatty, M.A., Project Officer

(202) 245-7267 (V); (202) 245-7323 (F)

Email phillip.beatty@ed.gov

Address: Potomac Center Plaza
 550 12th Street, SW, Room 6073
 Washington, DC 20204

THE DATA COLLECTION SYLLABUS

Optimum accuracy and data comparability in the National SCI Database can be achieved only if all data are collected prospectively according to the specifications in this data collection syllabus. This document contains extensive information on the National SCI Database including reporting procedures and guidelines, eligibility criteria, definitions of data collection periods, complete descriptions of all variables, record formats for analysts, samples of data collection forms and other data-submission forms and a listing of all quality control checks performed on the database. This syllabus also contains other useful information such as the names and addresses of the Project Directors and Primary Data Collectors for all the currently participating Model SCI Care Systems and the same information for the National Spinal Cord Injury Statistical Center (NSCISC) staff members.

There is a syllabus page for each variable in the National SCI Database. For the most part, if a variable is in more than 1 dataset (i.e., Personal Data, Registry, Form I and Form II) only 1 syllabus page is provided. Use the List of Variables beginning on page 26 to locate the syllabus page for each variable. The list is in numerical order by the current variable number. This list also contains the "old variable number" (i.e., that variable's number in the 1995-2000 version of the database).

Whenever applicable each syllabus page contains the following sections:

| | |
|------------------------|--|
| Variable Number | The number assigned to that variable in the database. |
| Variable Name | The name assigned to that variable in the database. |
| Description | Descriptive information on that variable including the data collection time(s) |
| Character | The number of characters for each coding position in the variable |
| Codes | A list of all valid codes for that variable As much as possible, the following "Universal codes" have been assigned: 0 or all 0's = "No" 8 or all 8's = "Not Applicable" "Not Tested" or "Yes, Number (or Grade) Unknown" 9 or all 9's = "Unknown" |
| Comments | Other information regarding the variable |
| Source | Sources of information pertaining to a variable. |
| QC | Comments on the quality control checks performed on that variable |
| Software | Instructions/clarification regarding how the software processes the variable. |
| Revisions | Dates and historical information on changes in the variable |
| Conversion | Information on how data in the variable were converted whenever there were coding and/or reporting criteria revisions. |
| Example(s) | Hypothetical situations and the appropriate code(s) |

The NATIONAL SPINAL CORD INJURY DATABASE

THE DATA COLLECTION MECHANISM

In order to obtain accurate and complete data, a system must establish an effective data collection mechanism. The personnel required and the mechanism for retrieving data will depend, of course, on the system's resources.

Minimally, a system must have a Project Director and a Primary Data Collector. Together they should assess what data are routinely being collected and documented at their system and develop a mechanism to collect and document the data for all other required variables.

The Project Director assigns data collection activities to staff members and must be familiar with the data collection syllabus and study objectives.

This person provides support for the Primary Data Collector and is a source of information regarding syllabus questions.

The Primary Data Collector - assumes the responsibility of compiling all data required in the data collection syllabus. Most often this person needs the cooperation of several other staff members in order to obtain all required data. For example, the Social Services department might be responsible for variables such as Level of Education, Marital Status, etc. The primary data collector may also wish to attend rounds as another means of gathering data.

Often the Primary Data Collector must furnish "in-house" data collection forms on which all variables to be collected by a particular department are listed. Such a form provides a checklist of all required data items. Staff members completing "in-house" forms must also have copies of the syllabus pages for all variables they document.

The Primary Data Collector may also have the responsibility of scheduling patients for follow-up visits since this person may use the database software to generate lists of patients who will be due for follow-up in the future. If this person schedules patient visits, he/she will know when to distribute the "in-house" forms to collect follow-up data.

This person is designated to receive all NSCISC mail outs to data collectors.

A Liaison Nurse is helpful for obtaining acute care data.

Since data for the majority of the follow-up variables may be obtained by phone, an Interviewer may also be needed. An interviewer who speaks languages other than English is also very useful for systems that have high percentages of non-English speaking patients.

A Data Entry Clerk may be needed if the Primary Data Collector does not have sufficient time to collect and enter data. Often this clerical level person may do other tasks such as record filing, contacting patients to schedule visits, confirming appointments, etc.

An Analyst may be needed if a system wishes to utilize statistical software (such as SAS, SPSS, BMDP) to analyze its data and/or the national database. Although the NSCISC's PC software provides the capabilities for simple data analyses (frequencies and percentages) other analyses require the use of specific statistical analyses software.

REPORTING PROCEDURES AND GUIDELINES

Variables in the National Spinal Cord Injury Database are divided into 4 data files:

- 1) **Personal Data - for all patients.**
- 2) **Registry – limited data for patients who are not eligible for Form I.**
- 3) **Form I – for all patients who are eligible. Additional data are collected for patients who enter the system within 24 hours.**
- 4) **Form II – for all Form I patients. Data collection is done in follow-up years 1, 5, 10, 15, 20, 25 and 30. Additional data are collected in year 1.**

PERSONAL DATA

Personal Data information may be collected on all patients. Some Personal Data items may be exported to the NSCISC (with the patient's consent) and other Personal Data items reside only in the System's data files and are never exported to the NSCISC. The data collection form for the Personal Data file contains only those variables that are available for export to the NSCISC for inclusion in the National Database. Personal Data items (to be exported) are **numbered 100 through 105 plus the EXStat variable**. Personal Data are exported based on the selections made during data entry. (see [page 295](#) for details). See [page 28](#) for a complete listing of the Personal Data variables. This list also contains the corresponding syllabus page number where you will find complete details on each variable.

REGISTRY

Registry data are selected Form I variables for patients who are not eligible for Form I data collection. **Registry variables are numbered 100, 101, 106, 107, 109A, 110, 111, 112, 113, 114, 116, 131D, 132D, 136D, 138D and 145**. A list of all Registry variables may be found on [page 29](#). This list also contains the corresponding syllabus page number where you will find complete details on each variable.

FORM I

Form I variables provide extensive data on the patient's status at the time of SCI and document events occurring during the initial hospitalization period and death data.

Beginning in November 1995 Form I consists of Core and Extended variables. **Core** items are collected on all patients who meet the Form I eligibility criteria. The **Extended data** are additional variables that are collected only on those who enter the system within 24 hours of injury. **Form I variables are numbered 100 to 165**. A list of all Form I variables begins on [page 30](#). This list also contains the corresponding syllabus page number where you will find complete details on each variable.

FORM II

Form II – follow-up data – are required on all patients who are eligible for follow-up in year 1 and in every 5th post-injury year (i.e., years 1, 5, 10, 15, 20, 25 and 30). For patients who are still in the initial hospitalization/rehabilitation process on their first anniversary of injury, a year 02 replaces the year 01 Form II. Form IIs are allowed to be submitted for other (non-required) years. See [page 199](#) for rules on patients who recover. Additional variables are collected on all patients on the **Year 1 (or year 2) Form II. Form II variables are numbered 100, 101, and 200 through 267. Form II, Year 1 (or year 2) variables are numbered 240 through 243**. Form II data submission is required of all patients who have a Form I [except for patients who die during the initial System hospitalization period or who recover (or have minimal deficit) by the end of the initial rehabilitation period]. A complete list of all Form II variables begins on [page 40](#). This list also contains the corresponding syllabus page number where you will find complete details on each variable.

Any patient having Form II data must have a Form I record also.

DATA MANAGEMENT VARIABLES

Data management variables (QC Status, Batch Number, Indate and Update) are included in all datasets. The Sample variable is present only in the Form I data file. Data management variables are generated by the NSCISC's software and cannot be modified by the user. Additional data management variables (Patient Status, Twos and Last) are present in the Personal Data file – only in the local data file at each System.

DEFINITIONS FOR DATA COLLECTION PERIODS

REGISTRY AND FORM I –

All Registry and Form I data collection periods occur during the “Initial System Hospitalization Period” (i.e., from the time of spinal cord injury until definitive discharge from the System). The initial System hospitalization period is an individually planned program of acute medical/surgical and/or rehabilitation services following spinal cord injury.

First System Admission (System Admit) - The first admission to the System. This may be an admission to the System's acute medical/surgical, subacute medical/surgical, acute rehab or subacute rehab unit.

During Acute Medical/Surgical Care –

Inpatient hospitalization, in the System, following spinal cord injury until the beginning of the initial rehabilitation program (or the patient's death, whichever comes earlier) that takes place for medical or surgical care or the treatment of a secondary medical complication.

Acute Medical/Surgical Care includes all medical surgical care provided in the intensive care unit (ICU), non-ICU beds, SCI specialty unit beds and subacute medical care units.

During Inpatient Rehabilitation - the period of time between admission to and discharge from the System's inpatient (acute and/or subacute) rehab unit.

Rehabilitation includes some combination of physical therapy, occupational therapy, speech therapy, recreational therapy, patient and family education, and rehabilitation psychology, medicine and nursing care.

Initial Rehab - The initial individually planned program of rehabilitation services following spinal cord injury.

Admission Date to Inpatient Rehabilitation (Admit to System Inpatient Rehab, at Inpatient Rehab Admit) - For all systems, the beginning of the inpatient rehabilitation phase is marked by admission to the System's inpatient rehabilitation hospital; transfer to the System's inpatient acute or subacute rehabilitation unit; or commencement of the inpatient rehabilitation program in a System's multipurpose unit.

Inpatient Rehab Discharge – discharge from the System's inpatient (acute or subacute) rehab unit.

Discharge – discharge from initial System hospitalization to a definitive living situation.

For those patients requiring both acute and inpatient rehabilitation care, discharge from the inpatient rehabilitation unit is the discharge.

Discharge from the acute care unit is acceptable for those patients who complete inpatient rehabilitation in the acute care unit; achieve complete recovery or minimal deficit status prior to rehab admission; or, who expire during acute care.

During System – The period of time between the initial admission to and discharge from the System for the initial individually planned program of acute medical/surgical and/or rehabilitation services following spinal cord injury.

Outpatient Rehabilitation – Data collection for this period of time was discontinued for all patients admitted to the System as of January 1, 2005.

FORM II

Post-injury (anniversary) year - the first post-injury year begins the day after the discharge from the initial hospitalization period and ends the day before the first anniversary of injury. Submission of a year 01 Form II is required. When a patient is still in the initial acute/rehab process past his first anniversary, a year 01 Form II is not submitted but a year 02 Form II is required.

Subsequent post-injury years begin the day of the anniversary date and end the day before the next anniversary date and, the date of injury is always used to calculate post-injury (anniversary) years. See the example for “Exam and Interview dates” (page 17).

Window variables – For the year 01 (or the “substituted” year 02) Form II, data may be collected from 182 days before the anniversary date to 182 days after the anniversary date. For all subsequent follow-up years, data may be collected from 182 days prior to the anniversary to 365 days after the anniversary date. “Window” variables are V211 to V213, 223 to 239 and 244 to 267. Window variables are marked with an ! on the Form II data collection form. See the example for “Exam and Interview dates” (page 17).

The NSCISC’s software contains functions to calculate (1) the correct post-injury year for an exam (or interview) date; (2) the range of dates for an anniversary year; and (3) the range of dates for the “window” variables. See the Software Users’ Manual for complete instructions.

During the annual examination - during the patient's annual physical examination. These are variables V211 to V213 and V244 to V249. Annual exam data may be collected from 182 days before the anniversary date. However, unlike the interview variables, the cut-off for obtaining annual exam data is always up to 182 days after the anniversary date. See the example for “Exam and Interview dates” (page 17).

During the anniversary year being reported - occurring between the beginning and the end of a particular anniversary (post-injury) year. These are variables 214 to 222D and 250A to 267.. See the example for “Exam and Interview dates” (page 17).

On the anniversary of injury - the patient's status as it was on the anniversary date for the post-injury year being reported. These are variables 203 to 208. See the example for “Exam and Interview dates” (page 17).

| Anniversary Year Number (V200) | Anniversary Date | Windows Of Time For Variables Collected | | | | | |
|--------------------------------|------------------|---|------------|------------------------|------------|----------------------|------------|
| | | during the anniversary year | | during the annual exam | | during the interview | |
| | | Beginning | End | Beginning | End | Beginning | End |
| 1 | 05/19/1974 | 10/23/1973 | 05/18/1974 | 11/18/1973 | 11/17/1974 | 11/18/1973 | 11/17/1974 |
| 5 | 05/19/1978 | 05/19/1977 | 05/18/1978 | 11/18/1977 | 11/17/1978 | 11/18/1977 | 05/18/1979 |
| 10 | 05/19/1983 | 05/19/1982 | 05/18/1983 | 11/18/1982 | 11/17/1983 | 11/18/1982 | 05/18/1984 |
| 15 | 05/19/1988 | 05/19/1987 | 05/18/1988 | 11/18/1987 | 11/17/1988 | 11/18/1987 | 05/18/1989 |
| 20 | 05/19/1993 | 05/19/1992 | 05/18/1993 | 11/18/1992 | 11/17/1993 | 11/18/1992 | 05/18/1994 |
| 25 | 05/19/1998 | 05/19/1997 | 05/18/1998 | 11/18/1997 | 11/17/1998 | 11/18/1997 | 05/18/1999 |
| 30 | 05/19/2003 | 05/19/2002 | 05/18/2003 | 11/18/2002 | 11/17/2003 | 11/18/2002 | 05/18/2004 |
| 35 | 05/19/2008 | 05/19/2007 | 05/18/2008 | 11/18/2007 | 11/17/2008 | 11/18/2007 | 05/18/2009 |

Since the Last Form II Record – change in status between the current Form II and the last Form II with known data in the variable being documented. When coding the year 1 Form II, document the change in status between the year 1 Form II and the Form I. These are variables 209 and 210.

Rehospitalization - Inpatient hospitalizations for acute medical or surgical care that occur after the initial rehabilitation program is completed.

OTHER DATA COLLECTION INFORMATION:

Rules for rounding fractions of an hour:

- For any fraction of the first hour
 - round up to 1 hour.
- After the first hour:
 - if the time is less than ½ hour, round down
 - if the time is ½ hour or more, round up.

Examples:

| <u>Total Time</u> | |
|-----------------------|-----------|
| 10 minutes | = 1 hour |
| 20 minutes (1/3 hour) | = 1 hour |
| 30 minutes (1/2 hour) | = 1 hour |
| 1 1/3 hours | = 1 hour |
| 1 1/2 hours | = 2 hours |
| 3 hours, 45 minutes | = 4 hours |
| 4 hours, 15 minutes | = 4 hours |

ELIGIBILITY CRITERIA

The following criteria affect those patients who are admitted into the Model System on or after 1 January 2005.

1. All persons must receive System inpatient acute rehabilitation. Persons who expire or achieve complete recovery or minimal deficit status at the time of discharge from System inpatient acute care are also eligible.

Those who complete an organized rehab program prior to System admission are totally excluded from this database.

2. All persons must be treated at a Model System within 1 year of injury.
3. All persons must have a clinically discernible degree of neurologic (spinal cord) impairment following a traumatic event. Persons with spinal cord dysfunction not resulting from a traumatic event are specifically excluded from enrollment in the database.

Persons with minimal neurologic impairment on admission into the system who complete inpatient rehab in the system's acute (or subacute) medical/surgical care unit may continue to be included in the database if they are hospitalized in the system more than 1 week. In such cases, their data will be analyzed as a separate category.

4. All persons must not have been previously treated at a Model System post-injury. This criterion is to ensure that no patient is enrolled into the database by more than one Model System.
5. A. A signed Informed Consent and HIPAA Authorization (may be the same or different documents depending on IRB requirements) must be obtained from all persons before enrollment in the database. See page 19A for more details.
B. If a person dies during the initial acute System stay, a signed Informed Consent is not required (if the System's IRB exempts data obtained purely from chart reviews). Only Registry data may be submitted on persons with no signed Informed Consent (provided the person also meets eligibility criteria 1, 2, 3 and 4). HIPAA Authorization is not required for research on deceased persons.

6. All persons must reside in the geographic catchment area of the Model System at the time of the injury. Subjects may be injured outside the catchment area.
7. Must be a citizen of the United States.

The reason for this limitation is a practical one. If a patient will return to their country of citizenship after injury, then follow-up will not be practical. However, if the patient is expected to remain in the catchment area, and the patient meets all other eligibility criteria, they may be included in the Form I database.

8. All persons must be discharged from the System as (1) normal neurologically or minimal deficit (2) expired or (3) having completed inpatient rehabilitation.

A Form I patient must meet all eligibility criteria. A registry patient must meet (at least) eligibility criteria 1, 2, 3 and 4. A person who does not meet eligibility criteria 1, 2, 3 and 4 is not eligible for the National SCI Database at all.

The NSCISC PC software includes an ELIGIBILITY function that determines if a patient is eligible for inclusion in the National SCI Database and, if so, whether the patient's data should be entered as a Registry or Form I record. Complete instructions for this function may be found in the NSCISC's PC Data Management Software Users' Manual.

| Changes in Eligibility Criteria | |
|---|---|
| 1995-2000 | 2000-2005 |
| Shall have incurred trauma to the spinal cord within 60 days of admission to the system. | Must be admitted to a system within 365 days of injury |
| Shall usually reside in the catchment area | Must reside in the catchment area |
| Must have been injured in the system's catchment area | May be injured outside the catchment area. |
| Will receive treatment and care in all components of the system | Must receive acute inpatient rehab in the system (unless the patient expires, recovers or has minimal deficit during System acute medical care). May also receive system inpatient subacute rehab (effective for patients admitted to the system as of January 1, 2005) |
| Must be discharged from the SCI care system as (1) normal neurologically or minimal deficit, (2) expired, or (3) having completed inpatient rehabilitation. | Effective for patients admitted to the system as of January 1, 2005. Patients who do not meet this criterion are eligible for the Registry provided they meet Criteria 1, 2, 3 and 4. |
| ...leave against medical advice or transfer out of System prior to completion of the initial inpatient rehabilitation process = not eligible for Form I | Effective for patients admitted to the system as of January 1, 2005. These patients are eligible for the Registry if they meet Criteria 1, 2, 3 and 4. |
| No follow-up (for reasons other than their becoming normal neuro, minimal neuro or deceased) = Registry patient | Effective for patients admitted to the system as of January 1, 2005) |
| A signed Informed Consent is not required for Registry patients. | Same (provided the System's IRB allows use of data that's available in the medical records without a signed informed consent). |
| | Signed Informed Consent is required for export of Personal Data to the NSCISC. |
| | Signed HIPAA Authorization is required for all Form I and Registry patients enrolled on or after April 14, 2003 except those patients who die prior to discharge. |
| Patients who complete an organized rehabilitation program prior to system admission are totally excluded from the database | Same |
| Patients whose follow-up data are obtained exclusively by mail and/or phone interview are eligible for Form I. | Same |
| ...included in the database if they are hospitalized in the System more than 1 week. | There is no minimal stay in the System to qualify for inclusion in the database (Registry or Form I) except for those who are admitted with minimal deficit. These patients must be hospitalized in the system for more than 1 week. |

CONSENT FORMS

Each patient whose information will be included in the Form I and Form II data files must sign a Consent Form. Often a family member must give this consent. A member of the Social Services staff or the Liaison Nurse could be used to obtain this document. Separate permission may be needed to permit the System to export Personal Data (i.e., Patient Name, Social Security Number, Date of Birth and Zip Codes for Residences) from the System database to the NSCISC. A person may decline to participate in the Personal Data submission but may agree to participate in Form I/Form II data collection. See additional information on page 19A.

REPORTING ON A PATIENT WHO DIES

The Date of Death, Cause of Death and Autopsy variables are present on Form I (variables 145, 146 and 147). The NSCISC's PC software inserts default codes for "Alive" in these variables whenever a new Form Is created. If the patient dies during follow-up, these Form I variables (variables 145, 146 and 147) must be updated with the appropriate information; however (as of November 1995) a Form II is NOT REQUIRED to be submitted for the post-injury year in which the patient died.

NSCISC POLICY ON INFORMED CONSENT

Informed consent should be obtained on all new patients enrolled in the NSCISC Form I database using a consent form that includes the request for personal identifiers and the certificate of confidentiality language as approved by both the local model system IRB and NIH. A copy of the consent form in current use should be on file at NIH.

Informed consent should also be obtained on all previously enrolled patients (Form II) who have not been consented using a consent form that includes the request for personal identifiers and the certificate of confidentiality language as approved by both the local model system IRB and NIH. Verbal consent over the telephone may be used with permission of the local model system IRB. Consent can be obtained at the time of the next scheduled data collection interview or earlier if a convenient opportunity presents itself.

Once informed consent has been obtained using a consent form that includes the request for personal identifiers and the certificate of confidentiality language as approved by both the local model system IRB and NIH, subsequent re-consent at the next annual evaluation is not required by the NSCISC but may be required by the local model system IRB.

An attempt should be made to obtain informed consent for new patients enrolled in the NSCISC Registry database using a consent form that includes the request for personal identifiers and the certificate of confidentiality language as approved by both the local model system IRB and NIH. Although the NSCISC does not require informed consent from patients enrolled in the registry, the local model system IRB may make this requirement or may require that an informed consent waiver be obtained from the IRB.

Model systems are required to adhere to local IRB informed consent requirements whenever they are more stringent than the requirements of the NSCISC.

Personal identifiers cannot be sent to the NSCISC database without the patient's signed informed consent granting permission to do so.

NSCISC POLICY ON HIPAA AUTHORIZATION

A signed HIPAA authorization is required by the NSCISC for all new patients enrolled in the NSCISC Registry or Form I database after April 14, 2003. The form of the HIPAA authorization will be dictated by the local model system IRB and may either be a separate document or may be included in the informed consent document.

Each model system is required to check with its local IRB concerning the necessity of acquiring HIPAA authorization to continue to collect data (Form II) on previously enrolled patients who have never given HIPAA authorization. The NSCISC has been advised by the UAB IRB that a signed HIPAA authorization is also required to continue collecting new data on these patients, but is not required to use or disclose data from previously enrolled patients for whom no further data are collected. Once previously obtained, new HIPAA authorization is only required when data collection will continue past the expiration date of the current HIPAA authorization.

If the local model system IRB either decides that HIPAA authorization is not required from patients enrolled in the database prior to April 14, 2003 in order to continue collecting follow-up data or grants a waiver of HIPAA authorization for patients enrolled before April 14, 2003, then the model system should follow its local IRB guidance on this issue.

THE DATA ENTRY PROCESS

The PROCESS function in the Main Menu of the NSCISC PC software allows the user to input records into any of the databases. Data may be entered into the System's computer separately (as each form is completed) or after several forms are ready. Detailed instructions for data entry may be found in the software's Users' Manual. A Session Log is created each time a user enters the software and this session log may be used to check that all data forms have actually been entered. No blanks are allowed in any variable in the database - unless a variable has multiple coding positions (such as variable 143B – Spinal Decompression). For such variables, once a "non-yes code" (e.g., no, not applicable or unknown) is entered, the user must leave the remaining coding positions blank. In fact, the software will not allow the user to enter any data in the remaining positions - it will automatically advance the user to the next variable.

QUALITY CONTROL (QC)

The NSCISC's PC software includes stand-alone Quality Control software that performs more than 500 checks on the database. Each variable is checked for "legal codes" during the data entry process and cross-variable and cross-record checking are performed using the QC software. See Appendix E of this syllabus for complete documentation of all the checks in this software. See the Users' Manual for instructions on running QC.

PERSONAL DATA

The System ID and Patient Number are the only patient identifiers in the Registry, Form I and Form II national database files. The "system version" of the NSCISC's PC software allows systems to add Patient Name, Address, Telephone Number, an Alternate ID (such as the Medical Records number), Social Security Number, Date of Birth and Zip Codes for Residences.

With proper IRB approval and consent from each patient, some of these personal data items (i.e., Patient Name, Social Security Number, Date of Birth and Zip Codes) will be exported to the NSCISC. These data will be stored in the Personal Data file at the NSCISC and access is restricted only to the Director of NSCISC and the NSCISC's Manager of Computer Services.

The Personal Data will be used by the Director of NSCISC to link data from the National SCI Database with data from other sources and to avoid duplicate entry into the National SCI Database. The information is also used to help systems identify study patients after there has been a gap in funding. None of the Personal Data will be released to anyone and none of the Personal Data will be used in any other study. Only the System ID and Patient Number will be retained as links to other data files.

THE DATA SUBMISSION PROCESS

NEW RECORDS

Records submitted to the NSCISC are counted as either New Entries or Updates. A new entry record is a computerized record entered on a patient for the first time. A new entry may be a Personal Data, Form I or Registry record. A new Form II entry creates a computerized record for a particular anniversary year. Each Form II being entered for the first time is considered a new entry. For example, if forms are completed for anniversary years 1 and 5 for a particular patient these will be considered two new entry Form II's. The Indate variable is the date on which each record is newly created. This is a computer-generated data management variable that cannot be modified by the user.

Blank Page

UPDATE RECORDS

An update is submitted to modify an existing Personal Data, Registry, Form I or Form II record. For Form II, each year updated is counted separately. For example, if Variable 208 is corrected on annuals 1 and 5, these forms will be counted as two Form II updates.

Updates are usually completed to: (1) revise variables previously coded as unknown; (2) correct discrepancies identified by the system coordinator or by the NSCISC's quality control checking programs; or (3) complete a variable left blank on the original, new entry form.

NOTE: data collectors are encouraged to update records whenever new data are obtained.

WHEN TO SUBMIT A NEW FORM I

A new Form I (to enter a new patient into the database) should be submitted to the NSCISC as soon as 80% or more of the Form I information is available. A Form I update can be done at a later time to provide information that may be obtained on a delayed basis (e.g., hospitalization charges).

SUBMISSION OF DATA TO THE NSCISC

The EXPORT function in the Main Menu of the NSCISC's Data Management Software copies all Personal Data, Registry, Form I and Form II records for shipment to the NSCISC. Complete instructions for this function may be found in the NSCISC's PC Data Management Software Users' Manual.

There are 2 data submission deadlines each calendar year (for the Semi-annual and Annual statistical reports). All systems are notified of these deadlines. The Annual Report is distributed prior to the summer Directors meeting and the Semi-annual report is distributed prior to the winter Directors meeting.

Session Logs are generated by the software and list all forms entered or updated during a software session. This list should be used by the data entry person to assure that all forms have actually been entered. See details in the Users' Manual.

FORM IIS DUE LIST

The Form IIs Due list contains required Form II's that are due for submission between the dates specified by the user. If the range of dates is in the future, the list may be used to help schedule patients for their annual examinations (or interviews). Instructions for the Form IIs Due function begin on page 69 of the Software Users' Manual.

The Form IIs Due list (based on the conditions selected by the user) may contain (1) only those Form IIs that are due and have not yet been entered; (2) Form IIs due for patients whose last Form II was coded "lost"; (3) Form IIs due for all years; and (4) address information. Form II data are required of patients who are discharged from the initial hospitalization alive and not discharged with "normal" or "minimal deficit" neurologic status.

A patient remains eligible for continued follow-up until he/she (1) dies or (2) recovers from the injury (i.e., normal neuro or minimal deficit). Form II data submission in post-injury years 1 (or 2), 5, 10, 15, 20, 25 and 30 is required of all Form I patients. When a patient is transferred to another System, the original System continues to be responsible for follow-up data submission.

If a Form II is submitted declaring the patient "lost to system" (i.e., V201 = code 5), the patient still remains eligible for future follow-up but future Form IIs should not be submitted unless the

patient's Category of Follow-up Care changes from "lost" (i.e., consecutive "lost" Form IIs should not be submitted).

If more than one Form II for a particular patient is due, each record is included on the list. This listing includes patient numbers (V101); the Patient Name (if that information has been entered in the patient's Personal Data record); the year for the Form II that is due (V200); a "Y" in the Form II Entered column if the Form II has been entered into the database; the QC status for that entered record; the Anniversary Date (i.e., the date the Form II was due for submission); the earliest and latest dates the Annual Exam data may be obtained; the earliest and latest dates the interview data may be obtained; the Overdue Marker; the last Form II entered for that patient; and, the category of follow-up care (V201) on the that last Form II.

The Overdue Marker indicates the number of days between the anniversary date and the report date: no mark = less than 365 days; * = 365 to 729 days (1-2 years): ** = more than 729 days (more than 2 years). Since systems are allowed up to 1 year after the anniversary date to obtain interview data (for year 01 it's only 6 months), priority should first be given to those forms marked by ** and next to those marked *.

For each Form II on the list that is more than 1 year past the window of time to collect data, a new Form II (coding the patient "lost" in the Category of Care variable) should IMMEDIATELY be submitted. If this is not done, the form will be counted as "missing" in the Tracking Report that is distributed with the NSCISC's Semi-annual and Annual statistical reports. This analysis is a System performance indicator. If data are obtained at a later date, this Form II record can always be updated.

Systems should generate a Form IIs due list at least twice a year (using the Semi-annual and Annual Statistical Report submission deadline dates as the cut-off dates for the lists). These lists may be generated as often as needed (because, forms will drop off the list as new Form IIs are entered).

For those systems that have a Form II data collector (in addition to a Primary data collector), it should be the Primary data collector's responsibility to generate the Form IIs Due list. The Primary data collector is the person responsible for doing whatever it takes to get the Form IIs submitted on time and, the other Form II data collector should organize data collection efforts based on the Form IIs Due list. Both data collectors should work together to avoid having a Form II more than 1 year overdue.

RECORD DUMPS

A record dump is a computer printout of a Personal Data, Registry, Form I or Form II record, as it exists in the computer files. Dumps are generated using the FILE/Dumps function in the PC software. Record dumps are formatted to fit on a standard 8 1/2" X 11" sheet of paper, in landscape orientation.

It is extremely important to "dump" a record before it is deleted - in the event it must be re-entered. If a record has been in existence through several database conversions the user cannot simply re-enter the record using the original data collection form since chances are, the data collection form is an out-dated version.

Instructions for the Record Dump function begin on page 15 of the Software Users' Manual.

GUIDELINES FOR CODING PRIMARY CAUSE OF DEATH

- A. In general, death certificates will have a line that documents the immediate cause of death followed by two or three lines under the heading "due to or as a consequence of." There will also be a line to document "other significant conditions."

As a general rule, the primary cause of death will be the cause entered alone on the lowest line of the "due to or as a consequence of" sequence unless it is unlikely that this condition gave rise to all the other conditions listed above it. An "Other significant condition" would be coded as a secondary cause of death unless it can be specifically linked to the causes listed above it, in which case it might be included in a combined primary cause of death. **Any mention of spinal cord injury, paraplegia, etc. (including late effects of SCI) should be ignored.** If no other information is available (no autopsy report, no death certificate, no summary information from a rehospitalization, etc.) code the cause of death unknown.

For example, consider the following cases:

1. Immediate cause: Cardiac arrest 427.50
 Due to or as a consequence of:
 Due to or as a consequence of:
 Unless additional information can be acquired, **select cardiac arrest (427.50)** because, unfortunately, it is the only option available.
2. Immediate cause: Cardiorespiratory arrest 427.50
 Due to or as a consequence of: Pneumonia 486.00
 Due to or as a consequence of:
Select pneumonia (486.00) since it led to the cardiorespiratory arrest.
3. Immediate cause: Cardiorespiratory arrest 427.50
 Due to or as a consequence of: Septicemia 038.90
 Due to or as a consequence of: Pneumonia 486.00
Select pneumonia (486.00) because it led to the other conditions. List septicemia as a secondary cause.
4. Immediate cause: Cardiac arrest 427.50
 Due to or as a consequence of: Arteriosclerosis 440.90
 Due to or as a consequence of: Brown-Sequard syndrome 344.80
Select arteriosclerosis (440.90) and ignore the reference to SCI.
5. Immediate cause: Cardiorespiratory arrest 427.50
 Due to or as a consequence of: Septicemia 038.90
 Due to or as a consequence of: Renal failure 586.00
Select septicemia (038.90) because renal failure (which would ordinarily have been chosen) cannot cause septicemia. List renal failure as a secondary cause.
6. Immediate cause: Arteriosclerosis 440.90
 Due to or as a consequence of: Pneumonia 486.00
 Due to or as a consequence of:
Select arteriosclerosis (440.90) because pneumonia (which would ordinarily have been chosen) cannot cause arteriosclerosis. List pneumonia as a secondary cause.

| | | |
|--------------------------------|----------------|--------|
| 7. Immediate cause: | Cardiac arrest | 427.50 |
| Due to or as a consequence of: | Hemorrhage | 459.00 |
| Due to or as a consequence of: | | |
| Other significant conditions: | Peptic ulcer | 533.40 |

Unless there is specific evidence indicating the hemorrhage was not associated with the peptic ulcer, **select peptic ulcer with hemorrhage (533.40)** because hemorrhage (which would ordinarily have been chosen) can be linked with peptic ulcer to identify a more specific condition. The important question is whether this death is better classified as resulting from a disease of the digestive system or a disease of veins and lymphatics. Certainly, the former seems more appropriate given the available information.

| | | |
|--------------------------------|---------------------|--------|
| 8. Immediate cause: | Pernicious anemia | 281.00 |
| Due to or as a consequence of: | Cerebral hemorrhage | 431.00 |
| Due to or as a consequence of: | Arteriosclerosis | 440.90 |

Select pernicious anemia (281.00). Although arteriosclerosis can cause a cerebral hemorrhage, it cannot cause pernicious anemia. Cerebral hemorrhage also cannot cause pernicious anemia. Therefore, with no apparent causal sequence leading directly to the immediate cause of death, the immediate cause is selected as the primary cause of death. The others should be listed as secondary causes.

B. In general, ill-defined conditions should not be selected as the primary cause of death unless no alternative exists.

For example:

| | | |
|--------------------------------|-----------------------|--------|
| 1. Immediate cause: | Myocardial infarction | 410.90 |
| Due to or as a consequence of: | Tachycardia | 785.00 |
| Due to or as a consequence of: | | |

Select myocardial infarction (410.90) because tachycardia (which would ordinarily have been chosen) is considered a "symptom or ill-defined condition." Tachycardia can be listed as a secondary cause of death.

C. In general, trivial conditions should be ignored. If death is the result of an adverse reaction to treatment for a trivial condition (such as renal failure resulting from taking aspirin for recurrent migraines), then code the adverse reaction as the primary cause of death. If the trivial condition is not reported as the cause of a more serious complication and a more serious unrelated condition is reported, then code the more serious condition as the primary cause of death.

For example:

| | | |
|--------------------------------|---------------------------|--------|
| 1. Immediate cause: | Congenital anomaly of eye | 743.90 |
| Due to or as a consequence of: | Congenital heart disease | 746.90 |
| Due to or as a consequence of: | | |

Select congenital heart disease (746.90) even though it cannot cause a congenital anomaly of the eye because the latter is considered a trivial condition unlikely by itself to cause death.

D. When the normal selection process results in choosing a condition which is described only in general terms and a related cause is also reported which provides more precise information about the system or nature of the chosen condition, reselect the more informative cause as the primary cause of death.

For example:

- | | | |
|--------------------------------|--------------------------|--------|
| 1. Immediate cause: | Cerebral thrombosis | 434.00 |
| Due to or as a consequence of: | Cerebrovascular accident | 436.00 |
| Due to or as a consequence of: | | |

Select cerebral thrombosis (434.00) because it is more informative and precise than cerebrovascular accident (which would ordinarily have been chosen). Cerebrovascular accident can be listed as a secondary cause.

- | | | |
|--------------------------------|----------------|--------|
| 2. Immediate cause: | Pyelonephritis | 590.80 |
| Due to or as a consequence of: | Kidney stone | 592.00 |
| Due to or as a consequence of: | Renal disease | 593.90 |

Select kidney stone (592.00). Both kidney stone and pyelonephritis are more specific than renal disease, but kidney stone would have been selected if renal disease had not been listed on the certificate. Therefore, it is preferred over pyelonephritis, which can be listed as a secondary cause of death along with renal disease.

- E. It is important to consider the interval between onset and death for each condition specified on the death certificate. Acute conditions that occurred a protracted time prior to death probably will not be the primary cause of death.

For example:

- | | | |
|--------------------------------|-------------------------------------|--------|
| Immediate cause: | Congestive heart failure (3 months) | 428.00 |
| Due to or as a consequence of: | Pneumonia (1 year) | 486.00 |
| Due to or as a consequence of: | | |

Select congestive heart failure (428.00) because the episode of pneumonia occurred a long time before the patient died as well as long before the symptomatic heart disease began.

- F. The use of E codes is very important because it is the only way to distinguish accidents, suicides and homicides from each other as well as from natural causes of death. However, E codes should only be used to reflect injuries that occur after the original SCI producing event. Therefore, with rare exceptions, E codes should not be used for a patient who dies during the initial hospitalization period.

If an E code is appropriate, it will always be the primary cause of death.

The distinction between accident, suicide and homicide can be found in a separate box on the death certificate below the list of causes.

- G. When the death certificate does not provide adequate information (for example when the only cause of death listed is "paraplegia"), other sources of information (such as a discharge summary if the patient was hospitalized at the time of death, or an autopsy report if one is available) should be acquired whenever possible. As a last resort, if an appropriate cause of death cannot be determined, the cause of death can be coded as unknown.

- H. Obviously, there will be many instances in which the selection of primary cause of death will be a close judgment call. Unfortunately, the only way to avoid this is to make the guidelines even more burdensome than contained herein. Moreover, it is important to leave enough flexibility in the decision making process to allow the most appropriate cause to be selected in unusual circumstances and in cases where the death certificate makes no sense (a frequent occurrence).

| |
|---|
| Questions regarding the appropriate primary cause of death should be resolved by the Project Director or other system physicians. |
|---|

POLICY FOR OBTAINING A COPY OF THE NATIONAL SPINAL CORD INJURY DATABASE

(for anyone affiliated with a currently funded Model Spinal Cord Injury Care System)

As in the past, any currently participating system may purchase a copy of the entire National SCI Database. For the Personal Data, only the data management fields (e.g., QC Status, etc.) are included in the data file (since these fields are essential if the requestor will be using the Dataset Building function in the NSCISC's software to create datasets). This copy of the entire National SCI Database is available:

(1) on CD; or

(2) may be downloaded from the NSCISC's server using the File Transfer Protocol.

There is a \$100.00 fee for method 1 and no charge for method 2. The file is available in Access format.

The current version of the Model Systems' Data Collection Syllabus (in MS Word and Acrobat format) is provided with the data files to assure the correct version of the syllabus is used with that copy of the national database.

◇ Access or statistical software (such as SPSS or SAS) is needed to analyze this database.

◇ Anyone affiliated with a currently funded Model Spinal Cord Injury Care System may purchase a copy of the entire National SCI Database (with the limited Personal Data fields). Requests must be submitted to the NSCISC in writing, and signed by the Model System's Project Director or Co-director. Systems are requested to inform the NSCISC of their research topic and share the results of database analyses with the Model Systems' group.

◇ During their July 1996 meeting the Project Directors approved a policy that prohibits analyses that compare any or all systems (other than one's own system data against the aggregate). Also, any results that compare a system against the aggregate for marketing purposes are prohibited.

Beginning on April 14, 2003, the requestor must sign a confidentiality agreement with the NSCISC prior to receiving the data as required under HIPAA guidelines for the release of limited data sets for research purposes.

Although the NSCISC staff will provide some assistance with analyses, the system must also have the services of a statistician or data analyst to utilize the database.

Call Bette Go for more information on formats and/or methods of transmission.

NOTE: this policy is subject to change.

POLICY FOR OBTAINING RAW DATA FROM THE NATIONAL SPINAL CORD INJURY DATABASE
(for anyone not affiliated with a currently funded Model Spinal Cord Injury Care System)

All requests for access to the National SCI Database must be forwarded to the National Spinal Cord Injury Statistical Center (NSCISC).

1. Requests should reflect:
 - a. Purpose
 - b. Commercial use and relationship if any
 - c. Confidentiality precautions
 - d. Responsible party
 - e. Data required
2. Requestor must purchase a copy of the data collection syllabus (containing descriptions of all variables).
3. Personal data (name and SSN) will not be released.
4. Only data up to 5 years prior to the request date will be available.
5. Requestor should provide 20 copies of the proposal, to be forwarded by the NSCISC, to the Project Directors and, to the Project Officer from the funding agency (NIDRR).
6. Scientific proposals must include IRB clearance.
7. Graduate students must have their proposal approved by either their department Chair or the Chair of their dissertation or thesis committee.
8. The requestor must return a signed agreement to the NSCISC (limiting the requestor to the terms of the original proposal) and to comply with HIPAA guidelines for the release of limited data sets.
9. A copy of the requestor's manuscript must be sent to the NSCISC for review prior to submission for possible publication and, a copy of any actual publication must be sent to the NSCISC.
10. All publications must acknowledge the NSCISC, Model Systems and NIDRR and include the disclaimer that the opinions expressed are those of the authors and not necessarily those of the NSCISC, Model Systems or NIDRR.
11. Ballots will be conducted by letter/FAX or held until the next biannual meeting of the Project Directors. An affirmative vote is required from each Project Director for release of his/her System's data.
12. The Model Systems may at their discretion appoint a mentor to advise the research team as needed.
13. The NSCISC's fee for this service is contingent on the complexity of the request. An estimate will be provided, upon request, based on the provision of all details from the requestor.

NOTE: this policy is subject to change.

NSCISC POLICY ON DATA SECURITY

Each model system will maintain its own NSCISC data set using software provided by the NSCISC. The raw data files will be in Microsoft Access format and will be protected by a password assigned by the NSCISC. To maintain data safety, integrity and security, any attempt to circumvent password protection to enter the Access data tables that contain the raw data is strictly forbidden.

All data will be encrypted prior to submission to the NSCISC using software provided by the NSCISC.

The NSCISC will provide a copy of any model system's data set to be used for analytic or other data management purposes on request. Each model system will also have the capacity to build data sets in a variety of formats using software provided by the NSCISC so that there will never be a legitimate need to enter the raw data in the Access tables.

The NSCISC will periodically check the database and immediately and without exception notify its NIDRR Project Officer of any apparent violations of this policy that may come to its attention so that appropriate action can be taken. Any additional NSCISC work made necessary by such violations will be billed to the model system at a fee to be determined by the NSCISC.

| Personal Data Variables (Access table name: Personal Data) | | | | | | |
|--|--------------------------|------------------------------|---|------------|------------------|---------------|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 Dat_PatID file | 2000-2005 Personal Data file | | | | |
| 1. | 100 | V100 | System ID | 2 | Text | 46 |
| 2. | 101 | V101 | Patient Number | 6 | Text | 47 |
| 3. | FName | V102F | Patient Name, First | 12 | Text | 49 |
| 4. | MName | V102I | Patient Name, Middle Initial | 1 | Text | 49 |
| 5. | LName | V102L | Patient Name, Last | 23 | Text | 49 |
| 6. | Socsecnum | V103 | Social Security Number | 9 | Text | 50 |
| 7. | Birth | V104 | Date of Birth | 10 | Text | 51 |
| 8. | New | V105I | Zip Code for Residence at Injury | 5 | Text | 57 |
| 9. | New | V105EI | Extended Zip Code for Residence at Injury | 4 | Text | 57 |
| 10. | New | V105_1 | Zip Code, Res., Yr. 01 Anniversary | 5 | Text | 57 |
| 11. | New | V105E_1 | Ext. Zip Code for Res., Yr. 01 Anniv. | 4 | Text | 57 |
| 12. | New | V105_5 | Zip Code, Res., Yr. 05 Anniversary | 5 | Text | 57 |
| 13. | New | V105E_5 | Ext. Zip Code for Res., Yr. 05 Anniv. | 4 | Text | 57 |
| 14. | New | V105_10 | Zip Code, Res., Yr. 10 Anniversary | 5 | Text | 57 |
| 15. | New | V105E_10 | Ext. Zip Code for Res., Yr. 10 Anniv. | 4 | Text | 57 |
| 16. | New | V105_15 | Zip Code, Res., Yr. 15 Anniversary | 5 | Text | 57 |
| 17. | New | V105E_15 | Ext. Zip Code for Res., Yr. 15 Anniv. | 4 | Text | 57 |
| 18. | New | V105_20 | Zip Code, Res., Yr. 20 Anniversary | 5 | Text | 57 |
| 19. | New | V105E_20 | Ext. Zip Code for Res., Yr. 20 Anniv. | 4 | Text | 57 |
| 20. | New | V105_25 | Zip Code, Res., Yr. 25 Anniversary | 5 | Text | 57 |
| 21. | New | V105E_25 | Ext. Zip Code for Res., Yr. 25 Anniv. | 4 | Text | 57 |
| 22. | New | V105_30 | Zip Code, Res., Yr. 30 Anniversary | 5 | Text | 57 |
| 23. | New | V105E_30 | Ext. Zip Code for Res., Yr. 30 Anniv. | 4 | Text | 57 |
| 24. | * | Alt_ID | Alternate ID | 12 | Text | 48 |
| 25. | * | Address1 | Address1 | 30 | Text | 52 |
| 26. | * | Address2 | Address2 | 30 | Text | 52 |
| 27. | * | City | City | 20 | Text | 53 |
| 28. | * | State | State | 2 | Text | 54 |
| 29. | * | Zip | Zip | 5 | Text | 55 |
| 30. | * | New | ZipE | 4 | Text | 55 |
| 31. | * | Phone | Phone | 10 | Text | 56 |
| 32. | * | New | Patient Status | 15 | Text | 59 |
| 33. | * | New | Registry | Byte | Number | 60 |
| 34. | * | New | Form I | Byte | Number | 60 |
| 35. | * | New | Form IIs | Integer | Number | 61 |
| 36. | * | New | Last Form II | 2 | Text | 61 |
| 37. | * | Notes | Notes | - | Memo | 62 |
| 38. | ** | New | EXStat | 4 | Text | 295 |
| 39. | ** | New | QCSTAT | Byte | Number | 297 |
| 40. | ** | New | BATCH | 10 | Text | 298 |
| 41. | ** | New | INDATE | ShortDate | Date | 299 |
| 42. | ** | New | UPDATE | ShortDate | Date | 300 |

| Personal Data Variables (Access table name: Personal Data) | | | | | | | |
|---|--------------------------|------------------------------|----------------------|---------------------------------------|------------------|---------------|-----|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page | |
| | 1995-2000 Dat_PatID file | 2000-2005 Personal Data file | | | | | |
| 43. | * | New | Contact1Name | Name of Contact #1 | 128 | Text | 62A |
| 44. | * | New | Contact1Address1 | Address, Line 1 for Contact #1 | 128 | Text | 62B |
| 45. | * | New | Contact1Address2 | Address, Line 2 for Contact #1 | 128 | Text | 62B |
| 46. | * | New | Contact1City | City for Contact #1 | 50 | Text | 62C |
| 47. | * | New | Contact1State | State for Contact #1 | 2 | Text | 62D |
| 48. | * | New | Contact1Zip | Zip Code for Contact #1 | 5 | Text | 62E |
| 49. | * | New | Contact1ZipE | Extended Zip Code for Contact #1 | 4 | Text | 62E |
| 50. | * | New | Contact1Phone | Telephone Number for Contact #1 | 25 | Text | 62F |
| 51. | * | New | Contact1Last UpDated | Date Info Last Updated for Contact #1 | 10 | Date | 62F |
| 52. | * | New | Contact2Name | Name of Contact #2 | 128 | Text | 62A |
| 53. | * | New | Contact2Address1 | Address, Line 1 for Contact #2 | 128 | Text | 62B |
| 54. | * | New | Contact2Address2 | Address, Line 2 for Contact #2 | 128 | Text | 62B |
| 55. | * | New | Contact2City | City for Contact #2 | 50 | Text | 62C |
| 56. | * | New | Contact2State | State for Contact #2 | 2 | Text | 62D |
| 57. | * | New | Contact2Zip | Zip Code for Contact #2 | 5 | Text | 62E |
| 58. | * | New | Contact2ZipE | Extended Zip Code for Contact #1 | 4 | Text | 62E |
| 59. | * | New | Contact2Phone | Telephone Number for Contact #2 | 25 | Text | 62F |
| 60. | * | New | Contact2Last UpDated | Date Info Last Updated for Contact #2 | 10 | Date | 62F |
| 61. | * | New | Contact3Name | Name of Contact #3 | 128 | Text | 62A |
| 62. | * | New | Contact3Address1 | Address, Line 1 for Contact #3 | 128 | Text | 62B |
| 63. | * | New | Contact3Address2 | Address, Line 2 for Contact #3 | 128 | Text | 62B |
| 64. | * | New | Contact3City | City for Contact #3 | 50 | Text | 62C |
| 65. | * | New | Contact3State | State for Contact #3 | 2 | Text | 62D |
| 66. | * | New | Contact3Zip | Zip Code for Contact #3 | 5 | Text | 62E |
| 67. | * | New | Contact3ZipE | Extended Zip Code for Contact #1 | 4 | Text | 62E |
| 68. | * | New | Contact3Phone | Telephone Number for Contact #3 | 25 | Text | 62F |
| 69. | * | New | Contact3Last UpDated | Date Info Last Updated for Contact #3 | 10 | Date | 62F |

* The data in these variables reside only in each System's data file – these data are never exported to the NSCISC. All other Personal Data are exported to the NSCISC only with the patient's consent.

** Data Management variables that are generated by the software.

| Summary – Personal Data File | | |
|------------------------------|-------------|---------------|
| | System File | NSCISC's file |
| Total Number of Variables | 69 | 28 |

| Registry Variables (Access table name: Registry) | | | | | | |
|---|-----------------|-----------|---|------------|------------------|---------------|
| Variable | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 | 2000-2005 | | | | |
| 1. | 100 | 100 | System ID | 2 | Text | 28 |
| 2. | 101 | 101 | Patient Number | 6 | Text | 47 |
| 3. | 102 | 106 | Date of Injury | ShortDate | Date | 63 |
| 4. | 103 | 107 | Date of First System Admission | 8 | Text | 64 |
| 5. | New | 109A | Number of Days from Injury to First System Admission | 3 | Text | 68 |
| 6. | 105 | 110 | Date of Discharge | 8 | Text | 70 |
| 7. | 110 | 111 | Age at injury | 3 | Text | 73 |
| 8. | 111 | 112 | Sex | 1 | Text | 74 |
| 9. | 112 | 113 | Racial or Ethnic Group | 1 | Text | 75 |
| 10. | 113 | 114 | Hispanic Origin | 1 | Text | 76 |
| 11. | 114 | 116 | Traumatic Etiology | 2 | Text | 78 |
| 12. | 125D | 131D | Category of Neurologic Impairment at Discharge | 1 | Text | 100 |
| 13. | New | 132D | ASIA Impairment Scale at Discharge | 1 | Text | 102 |
| 14. | 126DL | 136DL | Level of Preserved Neuro Function at Discharge, Left | 3 | Text | 110 |
| 15. | 126DR | 136DR | Level of Preserved Neuro Function at Discharge, Right | 3 | Text | 110 |
| 16. | New | 138D | Utilization of Mechanical Ventilation at Discharge | 1 | Text | 114 |
| 17. | 147 | 145 | Date of Death | 8 | Text | 169 |
| 18. | * QCSTAT | QCSTAT | Quality Control Status | Byte | Number | 297 |
| 19. | * BATCH | BATCH | Batch Number | 10 | Text | 298 |
| 20. | * INDATE | INDATE | Date Record Originally Entered | ShortDate | Date | 299 |
| 21. | * UPDATE | UPDATE | Last Date Record Updated | ShortDate | Date | 300 |

| Summary – Registry File | |
|---------------------------|----|
| Total Number of Variables | 21 |

* Data Management variables that are generated by the software.

Form I Variables (Access Table Name: Form I S1)

| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
|----------------|-----------------|-----------|--|------------|------------------|---------------|
| | 1995-2000 | 2000-2005 | | | | |
| 1. | 100 | 100 | System ID | 2 | Text | 28 |
| 2. | 101 | 101 | Patient Number | 6 | Text | 47 |
| 3. | 102 | 106 | Date of Injury | ShortDate | Date | 63 |
| 4. | 103 | 107 | Date of First System Admission | 8 | Text | 64 |
| 5. | 104 | 108 | Date of First System Inpatient Rehab Admission | 8 | Text | 66 |
| 6. | 108A | 109A | Number of Days from Injury First System Admission | 3 | Text | 68 |
| 7. | 108B | 109R | Number of Days from Injury to First System Inpatient Rehab Admission | 3 | Text | 69 |
| 8. | 105 | 110 | Date of Discharge | 8 | Text | 70 |
| 9. | 110 | 111 | Age at injury | 3 | Text | 73 |
| 10. | 111 | 112 | Sex | 1 | Text | 74 |
| 11. | 112 | 113 | Racial or Ethnic Group | 1 | Text | 75 |
| 12. | 113 | 114 | Hispanic Origin | 1 | Text | 76 |
| 13. | 234 | 115 | Is English the patient's primary language? | 1 | Text | 77 |
| 14. | 114 | 116 | Traumatic Etiology | 2 | Text | 78 |
| 15. | | | Unused | 5 | Text | |
| 16. | | | Unused | 5 | Text | |
| 17. | New | 118_1 | External Cause of Injury | 7 | Text | 81 |
| 18. | New | 118_2 | SCI Nature of Injury | 7 | Text | 82 |
| 19. | New | 119 | Work Relatedness | 1 | Text | 83 |
| 20. | 115O | 120I | Place of Residence at Injury | 2 | Text | 85 |
| 21. | 115D | 120D | Place of Residence at Discharge | 2 | Text | 85 |
| 22. | 116O | 121 | Marital Status at Injury | 1 | Text | 87 |
| 23. | 117 | 122 | Highest Formal Educational Level Completed at Injury | 1 | Text | 88 |
| 24. | 118 | 123 | Primary Occupational, Educational or Training Status - at Injury | 1 | Text | 89 |
| 25. | New | 124 | Job Census Code | 2 | Text | 90 |
| 26. | New | 125 | Are you a veteran of the U.S. military forces? | 1 | Text | 91 |
| 27. | New | 126_1 | VA Healthcare System Services Used During System (1) | 1 | Text | 92 |
| 28. | New | 126_2 | VA Healthcare System Services Used (2) | 1 | Text | 92 |
| 29. | New | 126_3 | VA Healthcare System Services Used (3) | 1 | Text | 92 |
| 30. | New | 126_4 | VA Healthcare System Services Used (4) | 1 | Text | 92 |
| 31. | New | 126_5 | VA Healthcare System Services Used (5) | 1 | Text | 92 |
| 32. | 120_1 | 127_1 | Sponsors of SCI Care and Services During System_1 | 2 | Text | 94 |
| 33. | 120_2 | 127_2 | Sponsors of SCI Care and Services During System_2 | 2 | Text | 94 |
| 34. | 120_3 | 127_3 | Sponsors of SCI Care and Services During System_3 | 2 | Text | 94 |
| 35. | 120_4 | 127_4 | Sponsors of SCI Care and Services During System_4 | 2 | Text | 94 |
| 36. | 120_5 | 127_5 | Sponsors of SCI Care and Services During System_5 | 2 | Text | 94 |
| 37. | 121_1 | 128_1 | Type of Reimbursement During System_1 | 1 | Text | 96 |
| 38. | 121_2 | 128_2 | Type of Reimbursement During System_2 | 1 | Text | 96 |
| 39. | 121_3 | 128_3 | Type of Reimbursement During System_3 | 1 | Text | 96 |
| 40. | 121_4 | 128_4 | Type of Reimbursement During System_4 | 1 | Text | 96 |
| 41. | 121_5 | 128_5 | Type of Reimbursement During System_5 | 1 | Text | 96 |
| 42. | 122 | 129 | Medical Case Manager During System | 1 | Text | 97 |
| 43. | 124A | 130A | Date of the Neurologic Examination at Initial System Exam | 8 | Text | 98 |
| 44. | 125A | 131A | Category of Neurologic Impairment at Initial System Exam | 1 | Text | 100 |
| 45. | 131A | 132A | ASIA Impairment Scale at Initial System Exam | 1 | Text | 102 |
| 46. | 132AAL | 133AAL | ASIA Motor Index Score, C5, Initial Exam, Left | 1 | Text | 104 |
| 47. | 132ABL | 133ABL | ASIA Motor Index Score, C6, Initial Exam, Left | 1 | Text | 104 |

Form I Variables (Access Table Name: Form I S1)

| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
|----------------|-----------------|-----------|---|------------|------------------|---------------|
| | 1995-2000 | 2000-2005 | | | | |
| 48. | 132ACL | 133ACL | ASIA Motor Index Score, C7, Initial Exam, Left | 1 | Text | 104 |
| 49. | 132ADL | 133ADL | ASIA Motor Index Score, C8, Initial Exam, Left | 1 | Text | 104 |
| 50. | 132AEL | 133AEL | ASIA Motor Index Score, T1, Initial Exam, Left | 1 | Text | 104 |
| 51. | 132AFL | 133AFL | ASIA Motor Index Score, L2, Initial Exam, Left | 1 | Text | 104 |
| 52. | 132AGL | 133AGL | ASIA Motor Index Score, L3, Initial Exam, Left | 1 | Text | 104 |
| 53. | 132AHL | 133AHL | ASIA Motor Index Score, L4, Initial Exam, Left | 1 | Text | 104 |
| 54. | 132AIL | 133AIL | ASIA Motor Index Score, L5, Initial Exam, Left | 1 | Text | 104 |
| 55. | 132AJL | 133AJL | ASIA Motor Index Score, S1, Initial Exam, Left | 1 | Text | 104 |
| 56. | 132AL | 133AL | ASIA Motor Index Score Initial Exam Subtotal L | 2 | Text | 104 |
| 57. | 132AAR | 133AAR | ASIA Motor Index Score, C5, Initial Exam, Right | 1 | Text | 104 |
| 58. | 132ABR | 133ABR | ASIA Motor Index Score, C6, Initial Exam, Right | 1 | Text | 104 |
| 59. | 132ACR | 133ACR | ASIA Motor Index Score, C7, Initial Exam, Right | 1 | Text | 104 |
| 60. | 132ADR | 133ADR | ASIA Motor Index Score, C8, Initial Exam, Right | 1 | Text | 104 |
| 61. | 132AER | 133AER | ASIA Motor Index Score, T1, Initial Exam, Right | 1 | Text | 104 |
| 62. | 132AFR | 133AFR | ASIA Motor Index Score, L2, Initial Exam, Right | 1 | Text | 104 |
| 63. | 132AGR | 133AGR | ASIA Motor Index Score, L3, Initial Exam, Right | 1 | Text | 104 |
| 64. | 132AHR | 133AHR | ASIA Motor Index Score, L4, Initial Exam, Right | 1 | Text | 104 |
| 65. | 132AIR | 133AIR | ASIA Motor Index Score, L5, Initial Exam, Right | 1 | Text | 104 |
| 66. | 132AJR | 133AJR | ASIA Motor Index Score, S1, Initial Exam, Right | 1 | Text | 104 |
| 67. | 132AR | 133AR | ASIA Motor Index Score Initial Exam Subtotal R | 2 | Text | 104 |
| 68. | 132AT | 133AT | ASIA Motor Index Score Initial Exam Total | 3 | Text | 104 |
| 69. | 127AL | 134AL | Sensory Level at Initial System Exam, Left | 3 | Text | 107 |
| 70. | 127AR | 134AR | Sensory Level at Initial System Exam, Right | 3 | Text | 107 |
| 71. | 128AL | 135AL | Motor Level at Initial System Exam, Left | 3 | Text | 108 |
| 72. | 128AR | 135AR | Motor Level at Initial System Exam, Right | 3 | Text | 108 |
| 73. | 126AL | 136AL | Level Preserved Neurologic Function at Initial System Exam, Left | 3 | Text | 110 |
| 74. | 126AR | 136AR | Level Preserved Neurologic Function at Initial System Exam, Right | 3 | Text | 110 |
| 75. | New | 130R | Date of the Neuro Exam at Admit to System Inpatient Rehab | 8 | Text | 98 |
| 76. | New | 131R | Category of Neuro Impairment at Admit to Sys.Inpt. Rehab | 1 | Text | 100 |
| 77. | New | 132R | ASIA Impairment Scale at Admit to System Inpatient Rehab | 1 | Text | 102 |
| 78. | 132RAL | 133RAL | ASIA Motor Index Score, C5, Inpatient Rehab Admit, Left | 1 | Text | 104 |
| 79. | 132RBL | 133RBL | ASIA Motor Index Score, C6, Inpatient Rehab Admit, Left | 1 | Text | 104 |
| 80. | 132RCL | 133RCL | ASIA Motor Index Score, C7, Inpatient Rehab Admit, Left | 1 | Text | 104 |
| 81. | 132RDL | 133RDL | ASIA Motor Index Score, C8, Inpatient Rehab Admit, Left | 1 | Text | 104 |
| 82. | 132REL | 133REL | ASIA Motor Index Score, T1, Inpatient Rehab Admit, Left | 1 | Text | 104 |
| 83. | 132RFL | 133RFL | ASIA Motor Index Score, L2, Inpatient Rehab Admit, Left | 1 | Text | 104 |
| 84. | 132RGL | 133RGL | ASIA Motor Index Score, L3, Inpatient Rehab Admit, Left | 1 | Text | 104 |
| 85. | 132RHL | 133RHL | ASIA Motor Index Score, L4, Inpatient Rehab Admit, Left | 1 | Text | 104 |
| 86. | 132RIL | 133RIL | ASIA Motor Index Score, L5, Inpatient Rehab Admit, Left | 1 | Text | 104 |
| 87. | 132RJL | 133RJL | ASIA Motor Index Score, S1, Inpatient Rehab Admit, Left | 1 | Text | 104 |
| 88. | 132RL | 133RL | ASIA Motor Index Score Inpatient Rehab Admit Subtotal L | 2 | Text | 104 |
| 89. | 132RAR | 133RAR | ASIA Motor Index Score, C5, Inpatient Rehab Admit, Right | 1 | Text | 104 |
| 90. | 132RBR | 133RBR | ASIA Motor Index Score, C6, Inpatient Rehab Admit, Right | 1 | Text | 104 |
| 91. | 132RCR | 133RCR | ASIA Motor Index Score, C7, Inpatient Rehab Admit, Right | 1 | Text | 104 |
| 92. | 132RDR | 133RDR | ASIA Motor Index Score, C8, Inpatient Rehab Admit, Right | 1 | Text | 104 |
| 93. | 132RER | 133RER | ASIA Motor Index Score, T1, Inpatient Rehab Admit, Right | 1 | Text | 104 |
| 94. | 132RFR | 133RFR | ASIA Motor Index Score, L2, Inpatient Rehab Admit, Right | 1 | Text | 104 |
| 95. | 132RGR | 133RGR | ASIA Motor Index Score, L3, Inpatient Rehab Admit, Right | 1 | Text | 104 |
| 96. | 132RHR | 133RHR | ASIA Motor Index Score, L4, Inpatient Rehab Admit, Right | 1 | Text | 104 |

| Form I Variables (Access Table Name: Form I S1) | | | | | | |
|---|-----------------|-----------|---|------------|------------------|---------------|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 | 2000-2005 | | | | |
| 97. | 132RIR | 133RIR | ASIA Motor Index Score, L5, Inpatient Rehab Admit, Right | 1 | Text | 104 |
| 98. | 132RJR | 133RJR | ASIA Motor Index Score, S1, Inpatient Rehab Admit, Right | 1 | Text | 104 |
| 99. | 132RR | 133RR | ASIA Motor Index Score Inpatient Rehab Admit Subtotal Right | 2 | Text | 104 |
| 100. | 132RT | 133RT | ASIA Motor Index Score at Inpatient Rehab Admit, Total | 3 | Text | 104 |
| 101. | New | 134RL | Sensory Level at Admit to System Inpatient Rehab, Left | 3 | Text | 107 |
| 102. | New | 134RR | Sensory Level at Admit to System Inpatient Rehab, Right | 3 | Text | 107 |
| 103. | New | 135RL | Motor Level at Admit to System Inpatient Rehab, Left | 3 | Text | 108 |
| 104. | New | 135RR | Motor Level at Admit to System Inpatient Rehab, Right | 3 | Text | 108 |
| 105. | New | 136RL | Level Preserved Neuro Function at Admit to Sys. Inpt. Rehab, Left | 3 | Text | 110 |
| 106. | New | 136RR | Level Preserved Neuro Function at Admit to Sys. Inpt.Rehab, Right | 3 | Text | 110 |
| o107. | 124D | 130D | Date of the Neurologic Examination at Discharge | 8 | Text | 98 |
| o108. | 125D | 131D | Category of Neurologic Impairment at Discharge | 1 | Text | 100 |
| o109. | 131D | 132D | ASIA Impairment Scale at Discharge | 1 | Text | 102 |
| o110. | 132DAL | 133DAL | ASIA Motor Index Score, C5, Discharge, Left | 1 | Text | 104 |
| o111. | 132DBL | 133DBL | ASIA Motor Index Score, C6, Discharge, Left | 1 | Text | 104 |
| o112. | 132DCL | 133DCL | ASIA Motor Index Score, C7, Discharge, Left | 1 | Text | 104 |
| o113. | 132DDL | 133DDL | ASIA Motor Index Score, C8, Discharge, Left | 1 | Text | 104 |
| o114. | 132DEL | 133DEL | ASIA Motor Index Score, T1, Discharge, Left | 1 | Text | 104 |
| o115. | 132DFL | 133DFL | ASIA Motor Index Score, L2, Discharge, Left | 1 | Text | 104 |
| o116. | 132DGL | 133DGL | ASIA Motor Index Score, L3, Discharge, Left | 1 | Text | 104 |
| o117. | 132DHL | 133DHL | ASIA Motor Index Score, L4, Discharge, Left | 1 | Text | 104 |
| o118. | 132DIL | 133DIL | ASIA Motor Index Score, L5, Discharge, Left | 1 | Text | 104 |
| o119. | 132DJL | 133DJL | ASIA Motor Index Score, S1, Discharge, Left | 1 | Text | 104 |
| o120. | 132DL | 133DL | ASIA Motor Index Score Discharge Subtotal L | 2 | Text | 104 |
| o121. | 132DAR | 133DAR | ASIA Motor Index Score, C5, Discharge, Right | 1 | Text | 104 |
| o122. | 132DBR | 133DBR | ASIA Motor Index Score, C6, Discharge, Right | 1 | Text | 104 |
| o123. | 132DCR | 133DCR | ASIA Motor Index Score, C7, Discharge, Right | 1 | Text | 104 |
| o124. | 132DDR | 133DDR | ASIA Motor Index Score, C8, Discharge, Right | 1 | Text | 104 |
| o125. | 132DER | 133DER | ASIA Motor Index Score, T1, Discharge, Right | 1 | Text | 104 |
| o126. | 132DFR | 133DFR | ASIA Motor Index Score, L2, Discharge, Right | 1 | Text | 104 |
| o127. | 132DGR | 133DGR | ASIA Motor Index Score, L3, Discharge, Right | 1 | Text | 104 |
| o128. | 132DHR | 133DHR | ASIA Motor Index Score, L4, Discharge, Right | 1 | Text | 104 |
| o129. | 132DIR | 133DIR | ASIA Motor Index Score, L5, Discharge, Right | 1 | Text | 104 |
| o130. | 132DJR | 133DJR | ASIA Motor Index Score, S1, Discharge, Right | 1 | Text | 104 |
| o131. | 132DR | 133DR | ASIA Motor Index Score Discharge Subtotal R | 2 | Text | 104 |
| o132. | 132DT | 133DT | ASIA Motor Index Score Discharge Total | 3 | Text | 104 |
| o133. | 127DL | 134DL | Sensory Level at Discharge, Left | 3 | Text | 107 |
| o134. | 127DR | 134DR | Sensory Level at Discharge, Right | 3 | Text | 107 |
| o135. | 128DL | 135DL | Motor Level at Discharge, Left | 3 | Text | 108 |
| o136. | 128DR | 135DR | Motor Level at Discharge, Right | 3 | Text | 108 |
| o137. | 126DL | 136DL | Level of Preserved Neurologic Function at Discharge, Left | 3 | Text | 110 |
| o138. | 126DR | 136DR | Level of Preserved Neurologic Function at Discharge, Right | 3 | Text | 110 |
| o139. | 134D | 137 | Method of Bladder Management at Discharge | 2 | Text | 111 |
| 140. | 135S | 138R | Utilization of Mechanical Ventilation at System Rehab Admit | 1 | Text | 114 |
| o141. | 135D | 138D | Utilization of Mechanical Ventilation at Discharge | 1 | Text | 114 |

Form I Variables (Access Table Name: Form I S2)

| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
|----------------|-----------------|-----------|--|------------|------------------|---------------|
| | 1995-2000 | 2000-2005 | | | | |
| | 100 | 100 | System ID | 2 | Text | 28 |
| | 101 | 101 | Patient Number | 6 | Text | 47 |
| 142. | 136A_1 | 139A_1 | Pressure Ulcers Occiput During Acute | 1 | Text | 115 |
| 143. | 136A_2 | 139A_2 | Pressure Ulcers Scapula Left During Acute | 1 | Text | 115 |
| 144. | 136A_3 | 139A_3 | Pressure Ulcers Scapula Right During Acute | 1 | Text | 115 |
| 145. | 136A_4 | 139A_4 | Pressure Ulcers Elbow Left During Acute | 1 | Text | 115 |
| 146. | 136A_5 | 139A_5 | Pressure Ulcers Elbow Right During Acute it | 1 | Text | 115 |
| 147. | 136A_6 | 139A_6 | Pressure Ulcers Ribs Left During Acute | 1 | Text | 115 |
| 148. | 136A_7 | 139A_7 | Pressure Ulcers Ribs Right During Acute | 1 | Text | 115 |
| 149. | 136A_8 | 139A_8 | Pressure Ulcers Spinous Process During Acute | 1 | Text | 115 |
| 150. | 136A_9 | 139A_9 | Pressure Ulcers Iliac Crest Left During Acute | 1 | Text | 115 |
| 151. | 136A_10 | 139A_10 | Pressure Ulcers Iliac Crest Right During Acute | 1 | Text | 115 |
| 152. | 136A_11 | 139A_11 | Pressure Ulcers Sacral During Acute | 1 | Text | 115 |
| 153. | 136A_12 | 139A_12 | Pressure Ulcers Ischium Left During Acute | 1 | Text | 115 |
| 154. | 136A_13 | 139A_13 | Pressure Ulcers Ischium Right During Acute | 1 | Text | 115 |
| 155. | 136A_14 | 139A_14 | Pressure Ulcers Trochanter Left During Acute | 1 | Text | 115 |
| 156. | 136A_15 | 139A_15 | Pressure Ulcers Trochanter Right During Acute | 1 | Text | 115 |
| 157. | 136A_16 | 139A_16 | Pressure Ulcers Genital During Acute | 1 | Text | 115 |
| 158. | 136A_17 | 139A_17 | Pressure Ulcers Knee Left During Acute | 1 | Text | 115 |
| 159. | 136A_18 | 139A_18 | Pressure Ulcers Knee Right During Acute | 1 | Text | 115 |
| 160. | 136A_19 | 139A_19 | Pressure Ulcers Malleolar Left During Acute | 1 | Text | 115 |
| 161. | 136A_20 | 139A_20 | Pressure Ulcers Malleolar Right During Acute | 1 | Text | 115 |
| 162. | 136A_21 | 139A_21 | Pressure Ulcers Heel Left During Acute | 1 | Text | 115 |
| 163. | 136A_22 | 139A_22 | Pressure Ulcers Heel Right During Acute | 1 | Text | 115 |
| 164. | 136A_23 | 139A_23 | Pressure Ulcers Foot Left During Acute | 1 | Text | 115 |
| 165. | 136A_24 | 139A_24 | Pressure Ulcers Foot Right During Acute | 1 | Text | 115 |
| 166. | 136A_25 | 139A_25 | Pressure Ulcers Unclassified Left During Acute | 1 | Text | 115 |
| 167. | 136A_26 | 139A_26 | Pressure Ulcers Unclassified Center During Acute | 1 | Text | 115 |
| 168. | 136A_27 | 139A_27 | Pressure Ulcers Unclassified Right During Acute | 1 | Text | 115 |
| 169. | 136R_1 | 139R_1 | Pressure Ulcers Occiput During Inpatient Rehab | 1 | Text | 115 |
| 170. | 136R_2 | 139R_2 | Pressure Ulcers Scapula Left During Inpatient Rehab | 1 | Text | 115 |
| 171. | 136R_3 | 139R_3 | Pressure Ulcers Scapula Right During Inpatient Rehab | 1 | Text | 115 |
| 172. | 136R_4 | 139R_4 | Pressure Ulcers Elbow Left During Inpatient Rehab | 1 | Text | 115 |
| 173. | 136R_5 | 139R_5 | Pressure Ulcers Elbow Right During Inpatient Rehab | 1 | Text | 115 |
| 174. | 136R_6 | 139R_6 | Pressure Ulcers Ribs Left During Inpatient Rehab | 1 | Text | 115 |
| 175. | 136R_7 | 139R_7 | Pressure Ulcers Ribs Right During Inpatient Rehab | 1 | Text | 115 |
| 176. | 136R_8 | 139R_8 | Pressure Ulcers Spinous Process During Inpatient Rehab | 1 | Text | 115 |
| 177. | 136R_9 | 139R_9 | Pressure Ulcers Iliac Crest Left During Inpatient Rehab | 1 | Text | 115 |
| 178. | 136R_10 | 139R_10 | Pressure Ulcers Iliac Crest Right During Inpatient Rehab | 1 | Text | 115 |
| 179. | 136R_11 | 139R_11 | Pressure Ulcers Sacral During Inpatient Rehab | 1 | Text | 115 |
| 180. | 136R_12 | 139R_12 | Pressure Ulcers Ischium Left During Inpatient Rehab | 1 | Text | 115 |
| 181. | 136R_13 | 139R_13 | Pressure Ulcers Ischium Right During Inpatient Rehab | 1 | Text | 115 |
| 182. | 136R_14 | 139R_14 | Pressure Ulcers Trochanter Left During Inpatient Rehab | 1 | Text | 115 |
| 183. | 136R_15 | 139R_15 | Pressure Ulcers Trochanter Right During Inpatient Rehab | 1 | Text | 115 |
| 184. | 136R_16 | 139R_16 | Pressure Ulcers Genital During Inpatient Rehab | 1 | Text | 115 |
| 185. | 136R_17 | 139R_17 | Pressure Ulcers Knee Left During Inpatient Rehab | 1 | Text | 115 |
| 186. | 136R_18 | 139R_18 | Pressure Ulcers Knee Right During Inpatient Rehab | 1 | Text | 115 |
| 187. | 136R_19 | 139R_19 | Pressure Ulcers Malleolar Left During Inpatient Rehab | 1 | Text | 115 |
| 188. | 136R_20 | 139R_20 | Pressure Ulcers Malleolar Right During Inpatient Rehab | 1 | Text | 115 |

Form I Variables (Access Table Name: Form I S2)

| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
|----------------|-----------------|-----------|---|------------|------------------|---------------|
| | 1995-2000 | 2000-2005 | | | | |
| 189. | 136R_21 | 139R_21 | Pressure Ulcers Heel Left During Inpatient Rehab | 1 | Text | 115 |
| 190. | 136R_22 | 139R_22 | Pressure Ulcers Heel Right During Inpatient Rehab | 1 | Text | 115 |
| 191. | 136R_23 | 139R_23 | Pressure Ulcers Foot Left During Inpatient Rehab | 1 | Text | 115 |
| 192. | 136R_24 | 139R_24 | Pressure Ulcers Foot Right During Inpatient Rehab | 1 | Text | 115 |
| 193. | 136R_25 | 139R_25 | Pressure Ulcers Unclassified Left During Inpatient Rehab | 1 | Text | 115 |
| 194. | 136R_26 | 139R_26 | Pressure Ulcers Unclassified Center During Inpatient Rehab | 1 | Text | 115 |
| 195. | 136R_27 | 139R_27 | Pressure Ulcers Unclassified Right During Inpatient Rehab | 1 | Text | 115 |
| 196. | 137A | 140A | Number of Pressure Ulcers During Acute | 2 | Text | 120 |
| 197. | 137R | 140R | Number of Pressure Ulcers Developed During System Inpatient Rehab | 2 | Text | 120 |
| 198. | New | 141 | Grade of Worst Pressure Ulcer Present at Sys. Inpatient Rehab. Admit | 1 | Text | 121 |
| 199. | 139AA | 142AA | Post-operative Wound Infection at the Site of the Spinal Surgery Performed During Acute | 1 | Text | 124 |
| 200. | 139AC | 142AB | Number of Episodes of Pneumonia During Acute | 2 | Text | 125 |
| 201. | 139AD | 142AC | Pulmonary Embolism During Acute | 1 | Text | 126 |
| 202. | 139AE_1-139AE_5 | 142AD | Thrombophlebitis, Deep Vein Thrombosis During Acute | 1 | Text | 127 |
| 203. | 139RA | 142RA | Post-operative Wound Infection at the Site of the Spinal Surgery Performed During Rehab | 1 | Text | 124 |
| 204. | 139RC | 142RB | Number of Episodes of Pneumonia During Rehab | 2 | Text | 125 |
| 205. | 139RD | 142RC | Pulmonary Embolism During Rehab | 1 | Text | 126 |
| 206. | 139RE_1-5 | 142RD | Thrombophlebitis, Deep Vein Thrombosis During Rehab | 1 | Text | 127 |
| 207. | 144AA_1 | 143AA | Laminectomy During Acute | 1 | Text | 133 |
| 208. | 144BA_1 | 143AB_1 | Spinal Decompression During Acute (1) | 1 | Text | 134 |
| 209. | 144BA_2 | 143AB_2 | Spinal Decompression During Acute (2) | 1 | Text | 134 |
| 210. | 144BA_3 | 143AB_3 | Spinal Decompression During Acute (3) | 1 | Text | 134 |
| 211. | 144CA_1 | 143AC_1 | Spinal Fusion During Acute (1) | 1 | Text | 135 |
| 212. | 144CA_2 | 143AC_2 | Spinal Fusion During Acute (2) | 1 | Text | 135 |
| 213. | 144CA_3 | 143AC_3 | Spinal Fusion During Acute (3) | 1 | Text | 135 |
| 214. | 144DA_1 | 143AD_1 | Internal Fixation of the Spine During Acute (1) | 1 | Text | 136 |
| 215. | 144DA_2 | 143AD_2 | Internal Fixation of the Spine During Acute (2) | 1 | Text | 136 |
| 216. | 144DA_3 | 143AD_3 | Internal Fixation of the Spine During Acute (3) | 1 | Text | 136 |
| 217. | 144E_1 | 143AE_1 | Surgical Repair of Failed Spinal Fusion During Acute (1) | 1 | Text | 137 |
| 218. | 144E_2 | 143AE_2 | Surgical Repair of Failed Spinal Fusion During Acute (2) | 1 | Text | 137 |
| 219. | 144E_3 | 143AE_3 | Surgical Repair of Failed Spinal Fusion During Acute (3) | 1 | Text | 137 |
| 220. | 144F_1 | 143AF_1 | Surgical Repair, Correction, or Removal of Internal Fixation Device During Acute (1) | 1 | Text | 138 |
| 221. | 144F_2 | 143AF_2 | Surgical Repair, Correction, or Removal of Internal Fixation Device During Acute (2) | 1 | Text | 138 |
| 222. | 144F_3 | 143AF_3 | Surgical Repair, Correction, or Removal of Internal Fixation Device During Acute (3) | 1 | Text | 138 |
| 223. | 144G | 143AG | Number of OR Visits for Spine Surgeries During Acute | 2 | Text | 139 |
| 224. | 144H | 143AH | Laparotomy During Acute | 1 | Text | 140 |
| 225. | 144I | 143AI | Traction During Acute | 1 | Text | 141 |
| 226. | 144J | 143AJ | Halo Vest, Halo Brace,Other Orthosis for Neck During Acute | 1 | Text | 142 |
| 227. | 144K | 143AK | Closure of Decubitus Ulcer(s) During Acute | 1 | Text | 143 |
| 228. | New | 143RA | Laminectomy During Rehab | 1 | Text | 133 |
| 229. | New | 143RB_1 | Spinal Decompression During Rehab (1) | 1 | Text | 134 |
| 230. | New | 143RB_2 | Spinal Decompression During Rehab (2) | 1 | Text | 134 |
| 231. | New | 143RB_3 | Spinal Decompression During Rehab (3) | 1 | Text | 134 |
| 232. | New | 143RC_1 | Spinal Fusion During Rehab (1) | 1 | Text | 135 |
| 233. | New | 143RC_2 | Spinal Fusion During Rehab (2) | 1 | Text | 135 |

Form I Variables (Access Table Name: Form I S2)

| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
|----------------|-----------------|-----------|--|------------|------------------|---------------|
| | 1995-2000 | 2000-2005 | | | | |
| 234. | New | 143RC_3 | Spinal Fusion During Rehab (3) | 1 | Text | 135 |
| 235. | New | 143RD_1 | Internal Fixation of the Spine During Rehab (1) | 1 | Text | 136 |
| 236. | New | 143RD_2 | Internal Fixation of the Spine During Rehab (2) | 1 | Text | 136 |
| 237. | New | 143RD_3 | Internal Fixation of the Spine During Rehab (3) | 1 | Text | 136 |
| 238. | 144E_1 | 143RE_1 | Surgical Repair of Failed Spinal Fusion During Rehab (1) | 1 | Text | 137 |
| 239. | New | 143RE_2 | Surgical Repair of Failed Spinal Fusion During Rehab (2) | 1 | Text | 137 |
| 240. | New | 143RE_3 | Surgical Repair of Failed Spinal Fusion During Rehab (3) | 1 | Text | 137 |
| 241. | 144F_1 | 143RF_1 | Surgical Repair, Correction, or Removal of Internal Fixation Device During Rehab (1) | 1 | Text | 138 |
| 242. | New | 143RF_2 | Surgical Repair, Correction, or Removal of Internal Fixation Device During Rehab (2) | 1 | Text | 138 |
| 243. | New | 143RF_3 | Surgical Repair, Correction, or Removal of Internal Fixation Device During Rehab (3) | 1 | Text | 138 |
| 244. | 144G | 143RG | Number of OR Visits for Spine Surgeries During Rehab | 2 | Text | 139 |
| 245. | 144H | 143RH | Laparotomy During Rehab | 1 | Text | 140 |
| 246. | 144I | 143RI | Traction During Rehab | 1 | Text | 141 |
| 247. | 144J | 143RJ | Halo Vest,Halo Brace,Other Orthosis for Neck During Rehab | 1 | Text | 142 |
| 248. | 144K | 143RK | Closure of Decubitus Ulcer(s) During Rehab | 1 | Text | 143 |
| 249. | 146AA | 144AA | FIM at Admit to Inpatient Rehab - Eating | 1 | Text | 151 |
| 250. | 146AB | 144AB | FIM - Self Care: Grooming | 1 | Text | 152 |
| 251. | 146AC | 144AC | FIM - Self Care: Bathing | 1 | Text | 153 |
| 252. | 146AD | 144AD | FIM - Self Care: Dressing, Upper Body | 1 | Text | 154 |
| 253. | 146AE | 144AE | FIM - Self Care: Dressing, Lower Body | 1 | Text | 155 |
| 254. | 146AF | 144AF | FIM - Self Care: Toileting | 1 | Text | 156 |
| 255. | 146AG | 144AG | FIM - Sphincter Control: Bladder Management | 1 | Text | 157 |
| 256. | 146AH | 144AH | FIM - Sphincter Control: Bowel Management | 1 | Text | 159 |
| 257. | 146AI | 144AI | FIM - Mobility (Transfer): Bed, Chair, Wheelchair | 1 | Text | 161 |
| 258. | 146AJ | 144AJ | FIM - Mobility (Transfer): Toilet | 1 | Text | 162 |
| 259. | 146AK | 144AK | FIM - Mobility (Transfer): Tub, Shower | 1 | Text | 163 |
| 260. | 146AL | 144AL | FIM - Locomotion: Walk or Wheelchair | 1 | Text | 164 |
| 261. | 146ALM | 144ALM | FIM - Locomotion: Mode | 1 | Text | 166 |
| 262. | 146AM | 144AM | FIM - Locomotion: Stairs | 1 | Text | 167 |
| 263. | 146AS | 144AT | FIM - Total Score at Admit to Inpatient Rehab | 2 | Text | 168 |
| 264. | 146DA | 144DA | FIM at Discharge from Inpatient Rehab - Eating | 1 | Text | 151 |
| 265. | 146DB | 144DB | FIM - Self Care: Grooming | 1 | Text | 152 |
| 266. | 146DC | 144DC | FIM - Self Care: Bathing | 1 | Text | 153 |
| 267. | 146DD | 144DD | FIM - Self Care: Dressing, Upper Body | 1 | Text | 154 |
| 268. | 146DE | 144DE | FIM - Self Care: Dressing, Lower Body | 1 | Text | 155 |
| 269. | 146DF | 144DF | FIM - Self Care: Toileting | 1 | Text | 156 |
| 270. | 146DG | 144DG | FIM - Sphincter Control: Bladder Management | 1 | Text | 157 |
| 271. | 146DH | 144DH | FIM - Sphincter Control: Bowel Management | 1 | Text | 159 |
| 272. | 146DI | 144DI | FIM - Mobility (Transfer): Bed, Chair, Wheelchair | 1 | Text | 161 |
| 273. | 146DJ | 144DJ | FIM - Mobility (Transfer): Toilet | 1 | Text | 162 |
| 274. | 146DK | 144DK | FIM - Mobility (Transfer): Tub, Shower | 1 | Text | 163 |
| 275. | 146DL | 144DL | FIM - Locomotion: Walk or Wheelchair | 1 | Text | 164 |
| 276. | 146DLM | 144DLM | FIM - Locomotion: Mode | 1 | Text | 166 |
| 277. | 146DM | 144DM | FIM - Locomotion: Stairs | 1 | Text | 167 |
| 278. | 146DS | 144DT | FIM - Total Score at Discharge from Inpatient Rehab | 2 | Text | 168 |
| 279. | 147 | 145 | Date of Death | 8 | Text | 169 |
| 280. | 148_1 | 146_1 | Cause of Death (Primary) | 7 | Text | 170 |

| Form I Variables (Access Table Name: Form I S2) | | | | | | |
|---|-----------------|-----------|--------------------|------------|------------------|---------------|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 | 2000-2005 | | | | |
| 281. | 148_2 | 146_2 | Cause of Death (2) | 6 | Text | 170 |
| 282. | 148_3 | 146_3 | Cause of Death (3) | 6 | Text | 170 |
| 283. | 148_4 | 146_4 | Cause of Death (4) | 6 | Text | 170 |
| 284. | 148_5 | 146_5 | Cause of Death (5) | 6 | Text | 170 |
| 285. | 149 | 147 | Autopsy | 1 | Text | 171 |

| Form I Variables (Access Table Name: Form I S3) | | | | | | |
|---|-----------------|-----------|--|------------|------------------|---------------|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 | 2000-2005 | | | | |
| | 100 | 100 | System ID | 2 | Text | 28 |
| | 101 | 101 | Patient Number | 6 | Text | 47 |
| 286. | New | 148_1 | Treatment Phase – Phase 1 | 1 | Text | 173 |
| 287. | New | 149_1 | System or Non-system - Phase 1 | 1 | Text | 178 |
| 288. | New | 150_1 | Date of Admission – Phase 1 | 8 | Text | 179 |
| 289. | New | 151_1 | Date of Discharge – Phase 1 | 8 | Text | 180 |
| 290. | New | 152_1 | Number of Short-term Discharge Days - Phase 1 | 3 | Text | 181 |
| 291. | New | 153_1 | Number of Days in Treatment Phase - Phase 1 | 4 | Text | 183 |
| 292. | New | 154_1 | Charges - Phase 1 | 7 | Text | 184 |
| 293. | New | 155_1 | Charges Reliability Code – Phase 1 | 1 | Text | 185 |
| 294. | New | 156_1 | Hours of Physical Therapy – Phase 1 <i>Deleted 12/2004</i> | 3 | Text | 187 |
| 295. | New | 157_1 | Hours of Occupational Therapy - Phase 1 <i>Deleted 12/2004</i> | 3 | Text | 188 |
| 296. | New | 158_1 | Hours of Recreational Therapy - Phase 1 <i>Deleted 12/2004</i> | 3 | Text | 189 |
| 297. | New | 159_1 | Hours of Vocational Rehab – Phase 1 <i>Deleted 12/2004</i> | 3 | Text | 190 |
| 298. | New | 160_1 | Hours of Psychological Counseling - Phase 1 <i>Deleted 12/2004</i> | 3 | Text | 191 |
| 299. | New | 161_1 | Hours of Social Worker – Phase 1 <i>Deleted 12/2004</i> | 3 | Text | 192 |
| 300. | New | 162_1 | Hours of Other Therapy - Phase 1 <i>Deleted 12/2004</i> | 3 | Text | 193 |
| 301. | New | 148_2 | Treatment Phase – Phase 2 | 1 | Text | 173 |
| 302. | New | 149_2 | System or Non-system - Phase 2 | 1 | Text | 178 |
| 303. | New | 150_2 | Date of Admission – Phase 2 | 8 | Text | 179 |
| 304. | New | 151_2 | Date of Discharge – Phase 2 | 8 | Text | 180 |
| 305. | New | 152_2 | Number of Short-term Discharge Days - Phase 2 | 3 | Text | 181 |
| 306. | New | 153_2 | Number of Days in Treatment Phase - Phase 2 | 4 | Text | 183 |
| 307. | New | 154_2 | Charges - Phase 2 | 7 | Text | 184 |
| 308. | New | 155_2 | Charges Reliability Code – Phase 2 | 1 | Text | 185 |
| 309. | New | 156_2 | Hours of Physical Therapy – Phase 2 <i>Deleted 12/2004</i> | 3 | Text | 187 |
| 310. | New | 157_2 | Hours of Occupational Therapy - Phase 2 <i>Deleted 12/2004</i> | 3 | Text | 188 |
| 311. | New | 158_2 | Hours of Recreational Therapy - Phase 2 <i>Deleted 12/2004</i> | 3 | Text | 189 |
| 312. | New | 159_2 | Hours of Vocational Rehab – Phase 2 <i>Deleted 12/2004</i> | 3 | Text | 190 |
| 313. | New | 160_2 | Hours of Psychological Counseling - Phase 2 <i>Deleted 12/2004</i> | 3 | Text | 191 |
| 314. | New | 161_2 | Hours of Social Worker – Phase 2 <i>Deleted 12/2004</i> | 3 | Text | 192 |
| 315. | New | 162_2 | Hours of Other Therapy - Phase 2 <i>Deleted 12/2004</i> | 3 | Text | 193 |
| 316. | New | 148_3 | Treatment Phase – Phase 3 | 1 | Text | 173 |
| 317. | New | 149_3 | System or Non-system - Phase 3 | 1 | Text | 178 |
| 318. | New | 150_3 | Date of Admission – Phase 3 | 8 | Text | 179 |
| 319. | New | 151_3 | Date of Discharge – Phase 3 | 8 | Text | 180 |
| 320. | New | 152_3 | Number of Short-term Discharge Days - Phase 3 | 3 | Text | 181 |
| 321. | New | 153_3 | Number of Days in Treatment Phase - Phase 3 | 4 | Text | 183 |
| 322. | New | 154_3 | Charges - Phase 3 | 7 | Text | 184 |
| 323. | New | 155_3 | Charges Reliability Code – Phase 3 | 1 | Text | 185 |
| 324. | New | 156_3 | Hours of Physical Therapy – Phase 3 <i>Deleted 12/2004</i> | 3 | Text | 187 |
| 325. | New | 157_3 | Hours of Occupational Therapy - Phase 3 <i>Deleted 12/2004</i> | 3 | Text | 188 |
| 326. | New | 158_3 | Hours of Recreational Therapy - Phase 3 <i>Deleted 12/2004</i> | 3 | Text | 189 |
| 327. | New | 159_3 | Hours of Vocational Rehab – Phase 3 <i>Deleted 12/2004</i> | 3 | Text | 190 |

Form I Variables (Access Table Name: Form I S3)

| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
|----------------|-----------------|-----------|--|------------|------------------|---------------|
| | 1995-2000 | 2000-2005 | | | | |
| 328. | New | 160_3 | Hours of Psychological Counseling - Phase 3 <i>Deleted 12/2004</i> | 3 | Text | 191 |
| 329. | New | 161_3 | Hours of Social Worker – Phase 3 <i>Deleted 12/2004</i> | 3 | Text | 192 |
| 330. | New | 162_3 | Hours of Other Therapy - Phase 3 <i>Deleted 12/2004</i> | 3 | Text | 193 |
| 331. | New | 148_4 | Treatment Phase – Phase 4 | 1 | Text | 173 |
| 332. | New | 149_4 | System or Non-system - Phase 4 | 1 | Text | 178 |
| 333. | New | 150_4 | Date of Admission – Phase 4 | 8 | Text | 179 |
| 334. | New | 151_4 | Date of Discharge – Phase 4 | 8 | Text | 180 |
| 335. | New | 152_4 | Number of Short-term Discharge Days - Phase 4 | 3 | Text | 181 |
| 336. | New | 153_4 | Number of Days in Treatment Phase - Phase 4 | 4 | Text | 183 |
| 337. | New | 154_4 | Charges - Phase 4 | 7 | Text | 184 |
| 338. | New | 155_4 | Charges Reliability Code – Phase 4 | 1 | Text | 185 |
| 339. | New | 156_4 | Hours of Physical Therapy – Phase 4 <i>Deleted 12/2004</i> | 3 | Text | 187 |
| 340. | New | 157_4 | Hours of Occupational Therapy - Phase 4 <i>Deleted 12/2004</i> | 3 | Text | 188 |
| 341. | New | 158_4 | Hours of Recreational Therapy - Phase 4 <i>Deleted 12/2004</i> | 3 | Text | 189 |
| 342. | New | 159_4 | Hours of Vocational Rehab – Phase 4 <i>Deleted 12/2004</i> | 3 | Text | 190 |
| 343. | New | 160_4 | Hours of Psychological Counseling - Phase 4 <i>Deleted 12/2004</i> | 3 | Text | 191 |
| 344. | New | 161_4 | Hours of Social Worker – Phase 4 <i>Deleted 12/2004</i> | 3 | Text | 192 |
| 345. | New | 162_4 | Hours of Other Therapy - Phase 4 <i>Deleted 12/2004</i> | 3 | Text | 193 |
| 346. | New | 148_5 | Treatment Phase – Phase 5 | 1 | Text | 173 |
| 347. | New | 149_5 | System or Non-system - Phase 5 | 1 | Text | 178 |
| 348. | New | 150_5 | Date of Admission – Phase 5 | 8 | Text | 179 |
| 349. | New | 151_5 | Date of Discharge – Phase 5 | 8 | Text | 180 |
| 350. | New | 152_5 | Number of Short-term Discharge Days - Phase 5 | 3 | Text | 181 |
| 351. | New | 153_5 | Number of Days in Treatment Phase - Phase 5 | 4 | Text | 183 |
| 352. | New | 154_5 | Charges - Phase 5 | 7 | Text | 184 |
| 353. | New | 155_5 | Charges Reliability Code – Phase 5 | 1 | Text | 185 |
| 354. | New | 156_5 | Hours of Physical Therapy – Phase 5 <i>Deleted 12/2004</i> | 3 | Text | 187 |
| 355. | New | 157_5 | Hours of Occupational Therapy - Phase 5 <i>Deleted 12/2004</i> | 3 | Text | 188 |
| 356. | New | 158_5 | Hours of Recreational Therapy - Phase 5 <i>Deleted 12/2004</i> | 3 | Text | 189 |
| 357. | New | 159_5 | Hours of Vocational Rehab – Phase 5 <i>Deleted 12/2004</i> | 3 | Text | 190 |
| 358. | New | 160_5 | Hours of Psychological Counseling - Phase 5 <i>Deleted 12/2004</i> | 3 | Text | 191 |
| 359. | New | 161_5 | Hours of Social Worker – Phase 5 <i>Deleted 12/2004</i> | 3 | Text | 192 |
| 360. | New | 162_5 | Hours of Other Therapy - Phase 5 <i>Deleted 12/2004</i> | 3 | Text | 193 |
| 361. | New | 148_6 | Treatment Phase – Phase 6 | 1 | Text | 173 |
| 362. | New | 149_6 | System or Non-system - Phase 6 | 1 | Text | 178 |
| 363. | New | 150_6 | Date of Admission – Phase 6 | 8 | Text | 179 |
| 364. | New | 151_6 | Date of Discharge – Phase 6 | 8 | Text | 180 |
| 365. | New | 152_6 | Number of Short-term Discharge Days - Phase 6 | 3 | Text | 181 |
| 366. | New | 153_6 | Number of Days in Treatment Phase - Phase 6 | 4 | Text | 183 |
| 367. | New | 154_6 | Charges - Phase 6 | 7 | Text | 184 |
| 368. | New | 155_6 | Charges Reliability Code – Phase 6 | 1 | Text | 185 |
| 369. | New | 156_6 | Hours of Physical Therapy – Phase 6 <i>Deleted 12/2004</i> | 3 | Text | 187 |
| 370. | New | 157_6 | Hours of Occupational Therapy - Phase 6 <i>Deleted 12/2004</i> | 3 | Text | 188 |
| 371. | New | 158_6 | Hours of Recreational Therapy - Phase 6 <i>Deleted 12/2004</i> | 3 | Text | 189 |
| 372. | New | 159_6 | Hours of Vocational Rehab – Phase 6 <i>Deleted 12/2004</i> | 3 | Text | 190 |
| 373. | New | 160_6 | Hours of Psychological Counseling - Phase 6 <i>Deleted 12/2004</i> | 3 | Text | 191 |
| 374. | New | 161_6 | Hours of Social Worker – Phase 6 <i>Deleted 12/2004</i> | 3 | Text | 192 |
| 375. | New | 162_6 | Hours of Other Therapy - Phase 6 <i>Deleted 12/2004</i> | 3 | Text | 193 |
| 376. | New | 148_7 | Treatment Phase – Phase 7 | 1 | Text | 173 |
| 377. | New | 149_7 | System or Non-system - Phase 7 | 1 | Text | 178 |
| 378. | New | 150_7 | Date of Admission – Phase 7 | 8 | Text | 179 |
| 379. | New | 151_7 | Date of Discharge – Phase 7 | 8 | Text | 180 |
| 380. | New | 152_7 | Number of Short-term Discharge Days - Phase 7 | 3 | Text | 181 |
| 381. | New | 153_7 | Number of Days in Treatment Phase - Phase 7 | 4 | Text | 183 |
| 382. | New | 154_7 | Charges - Phase 7 | 7 | Text | 184 |

Form I Variables (Access Table Name: Form I S3)

| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
|----------------|-----------------|-----------|--|------------|------------------|---------------|
| | 1995-2000 | 2000-2005 | | | | |
| 383. | New | 155_7 | Charges Reliability Code – Phase 7 | 1 | Text | 185 |
| 384. | New | 156_7 | Hours of Physical Therapy – Phase 7 Deleted 12/2004 | 3 | Text | 187 |
| 385. | New | 157_7 | Hours of Occupational Therapy - Phase 7 Deleted 12/2004 | 3 | Text | 188 |
| 386. | New | 158_7 | Hours of Recreational Therapy - Phase 7 Deleted 12/2004 | 3 | Text | 189 |
| 387. | New | 159_7 | Hours of Vocational Rehab – Phase 7 Deleted 12/2004 | 3 | Text | 190 |
| 388. | New | 160_7 | Hours of Psychological Counseling - Phase 7 Deleted 12/2004 | 3 | Text | 191 |
| 389. | New | 161_7 | Hours of Social Worker – Phase 7 Deleted 12/2004 | 3 | Text | 192 |
| 390. | New | 162_7 | Hours of Other Therapy - Phase 7 Deleted 12/2004 | 3 | Text | 193 |
| 391. | New | 148_8 | Treatment Phase – Phase 8 | 1 | Text | 173 |
| 392. | New | 149_8 | System or Non-system - Phase 8 | 1 | Text | 178 |
| 393. | New | 150_8 | Date of Admission – Phase 8 | 8 | Text | 179 |
| 394. | New | 151_8 | Date of Discharge – Phase 8 | 8 | Text | 180 |
| 395. | New | 152_8 | Number of Short-term Discharge Days - Phase 8 | 3 | Text | 181 |
| 396. | New | 153_8 | Number of Days in Treatment Phase - Phase 8 | 4 | Text | 183 |
| 397. | New | 154_8 | Charges - Phase 8 | 7 | Text | 184 |
| 398. | New | 155_8 | Charges Reliability Code – Phase 8 | 1 | Text | 185 |
| 399. | New | 156_8 | Hours of Physical Therapy – Phase 8 Deleted 12/2004 | 3 | Text | 187 |
| 400. | New | 157_8 | Hours of Occupational Therapy - Phase 8 Deleted 12/2004 | 3 | Text | 188 |
| 401. | New | 158_8 | Hours of Recreational Therapy - Phase 8 Deleted 12/2004 | 3 | Text | 189 |
| 402. | New | 159_8 | Hours of Vocational Rehab – Phase 8 Deleted 12/2004 | 3 | Text | 190 |
| 403. | New | 160_8 | Hours of Psychological Counseling - Phase 8 Deleted 12/2004 | 3 | Text | 191 |
| 404. | New | 161_8 | Hours of Social Worker – Phase 8 Deleted 12/2004 | 3 | Text | 192 |
| 405. | New | 162_8 | Hours of Other Therapy - Phase 8 Deleted 12/2004 | 3 | Text | 193 |
| 406. | New | 148_9 | Treatment Phase – Phase 9 | 1 | Text | 173 |
| 407. | New | 149_9 | System or Non-system - Phase 9 | 1 | Text | 178 |
| 408. | New | 150_9 | Date of Admission – Phase 9 | 8 | Text | 179 |
| 409. | New | 151_9 | Date of Discharge – Phase 9 | 8 | Text | 180 |
| 410. | New | 152_9 | Number of Short-term Discharge Days - Phase 9 | 3 | Text | 181 |
| 411. | New | 153_9 | Number of Days in Treatment Phase - Phase 9 | 4 | Text | 183 |
| 412. | New | 154_9 | Charges - Phase 9 | 7 | Text | 184 |
| 413. | New | 155_9 | Charges Reliability Code – Phase 9 | 1 | Text | 185 |
| 414. | New | 156_9 | Hours of Physical Therapy – Phase 9 Deleted 12/2004 | 3 | Text | 187 |
| 415. | New | 157_9 | Hours of Occupational Therapy - Phase 9 Deleted 12/2004 | 3 | Text | 188 |
| 416. | New | 158_9 | Hours of Recreational Therapy - Phase 9 Deleted 12/2004 | 3 | Text | 189 |
| 417. | New | 159_9 | Hours of Vocational Rehab – Phase 9 Deleted 12/2004 | 3 | Text | 190 |
| 418. | New | 160_9 | Hours of Psychological Counseling - Phase 9 Deleted 12/2004 | 3 | Text | 191 |
| 419. | New | 161_9 | Hours of Social Worker – Phase 9 Deleted 12/2004 | 3 | Text | 192 |
| 420. | New | 162_9 | Hours of Other Therapy - Phase 9 Deleted 12/2004 | 3 | Text | 193 |
| 421. | New | 148_10 | Treatment Phase – Phase 10 | 1 | Text | 173 |
| 422. | New | 149_10 | System or Non-system - Phase 10 | 1 | Text | 178 |
| 423. | New | 150_10 | Date of Admission – Phase 10 | 8 | Text | 179 |
| 424. | New | 151_10 | Date of Discharge – Phase 10 | 8 | Text | 180 |
| 425. | New | 152_10 | Number of Short-term Discharge Days - Phase 10 | 3 | Text | 181 |
| 426. | New | 153_10 | Number of Days in Treatment Phase - Phase 10 | 4 | Text | 183 |
| 427. | New | 154_10 | Charges - Phase 10 | 7 | Text | 184 |
| 428. | New | 155_10 | Charges Reliability Code – Phase 10 | 1 | Text | 185 |
| 429. | New | 156_10 | Hours of Physical Therapy – Phase 10 Deleted 12/2004 | 3 | Text | 187 |
| 430. | New | 157_10 | Hours of Occupational Therapy - Phase 10 Deleted 12/2004 | 3 | Text | 188 |
| 431. | New | 158_10 | Hours of Recreational Therapy - Phase 10 Deleted 12/2004 | 3 | Text | 189 |
| 432. | New | 159_10 | Hours of Vocational Rehab – Phase 10 Deleted 12/2004 | 3 | Text | 190 |
| 433. | New | 160_10 | Hours of Psychological Counseling - Phase 10 Deleted 12/2004 | 3 | Text | 191 |
| 434. | New | 161_10 | Hours of Social Worker – Phase 10 Deleted 12/2004 | 3 | Text | 192 |
| 435. | New | 162_10 | Hours of Other Therapy - Phase 10 Deleted 12/2004 | 3 | Text | 193 |
| 436. | New | 148_11 | Treatment Phase – Phase 11 | 1 | Text | 173 |
| 437. | New | 149_11 | System or Non-system - Phase 11 | 1 | Text | 178 |
| 438. | New | 150_11 | Date of Admission – Phase 11 | 8 | Text | 179 |

Form I Variables (Access Table Name: Form I S3)

| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page | |
|----------------|-----------------|-----------|---|--------------------------------|------------------|---------------|-----|
| | 1995-2000 | 2000-2005 | | | | | |
| 439. | New | 151_11 | Date of Discharge – Phase 11 | 8 | Text | 180 | |
| 440. | New | 152_11 | Number of Short-term Discharge Days - Phase 11 | 3 | Text | 181 | |
| 441. | New | 153_11 | Number of Days in Treatment Phase - Phase 11 | 4 | Text | 183 | |
| 442. | New | 154_11 | Charges - Phase 11 | 7 | Text | 184 | |
| 443. | New | 155_11 | Charges Reliability Code – Phase 11 | 1 | Text | 185 | |
| 444. | New | 156_11 | Hours of Physical Therapy – Phase 11 <i>Deleted 12/2004</i> | 3 | Text | 187 | |
| 445. | New | 157_11 | Hours of Occupational Therapy - Phase 11 <i>Deleted 12/2004</i> | 3 | Text | 188 | |
| 446. | New | 158_11 | Hours of Recreational Therapy - Phase 11 <i>Deleted 12/2004</i> | 3 | Text | 189 | |
| 447. | New | 159_11 | Hours of Vocational Rehab – Phase 11 <i>Deleted 12/2004</i> | 3 | Text | 190 | |
| 448. | New | 160_11 | Hours of Psychological Counseling - Phase 11 <i>Deleted 12/2004</i> | 3 | Text | 191 | |
| 449. | New | 161_11 | Hours of Social Worker – Phase 11 <i>Deleted 12/2004</i> | 3 | Text | 192 | |
| 450. | New | 162_11 | Hours of Other Therapy - Phase 11 <i>Deleted 12/2004</i> | 3 | Text | 193 | |
| 451. | New | 148_12 | Treatment Phase – Phase 12 | 1 | Text | 173 | |
| 452. | New | 149_12 | System or Non-system - Phase 12 | 1 | Text | 178 | |
| 453. | New | 150_12 | Date of Admission – Phase 12 | 8 | Text | 179 | |
| 454. | New | 151_12 | Date of Discharge – Phase 12 | 8 | Text | 180 | |
| 455. | New | 152_12 | Number of Short-term Discharge Days - Phase 12 | 3 | Text | 181 | |
| 456. | New | 153_12 | Number of Days in Treatment Phase - Phase 12 | 4 | Text | 183 | |
| 457. | New | 154_12 | Charges - Phase 12 | 7 | Text | 184 | |
| 458. | New | 155_12 | Charges Reliability Code – Phase 12 | 1 | Text | 185 | |
| 459. | New | 156_12 | Hours of Physical Therapy – Phase 12 <i>Deleted 12/2004</i> | 3 | Text | 187 | |
| 460. | New | 157_12 | Hours of Occupational Therapy - Phase 12 <i>Deleted 12/2004</i> | 3 | Text | 188 | |
| 461. | New | 158_12 | Hours of Recreational Therapy – Phase 12 <i>Deleted 12/2004</i> | 3 | Text | 189 | |
| 462. | New | 159_12 | Hours of Vocational Rehab – Phase 12 <i>Deleted 12/2004</i> | 3 | Text | 190 | |
| 463. | New | 160_12 | Hours of Psychological Counseling - Phase 12 <i>Deleted 12/2004</i> | 3 | Text | 191 | |
| 464. | New | 161_12 | Hours of Social Worker – Phase 12 <i>Deleted 12/2004</i> | 3 | Text | 192 | |
| 465. | New | 162_12 | Hours of Other Therapy - Phase 12 <i>Deleted 12/2004</i> | 3 | Text | 193 | |
| 466. | 109A | 163A | Number of Days Hospitalized in System’s Acute Care Unit | 4 | Text | 195 | |
| 467. | 109B | 163R | Number of Days Hospitalized in System’s Inpatient Rehab Unit | 4 | Text | 195 | |
| 468. | 123T | 164 | Total System Hospitalization Charges | 7 | Text | 196 | |
| 469. | 123TR | 165 | Reliability Code for Total System Hospitalization Charges | 1 | Text | 197 | |
| 470. | * | SAMPLE | SAMPLE | Sample Code | 1 | Text | 296 |
| 471. | * | QCSTAT1 | QCSTAT1 | Quality Control Status | Byte | Number | 297 |
| 472. | * | BATCH1 | BATCH1 | Batch Number | 10 | Text | 298 |
| 473. | * | INDATE1 | INDATE1 | Date Record Originally Entered | ShortDate | Date | 299 |
| 474. | * | UPDATE1 | UPDATE1 | Last Date Record Updated | ShortDate | Date | 300 |

| Summary – Form I File | |
|---------------------------|-----|
| Total Number of Variables | 474 |

* Data Management variables that are generated by the software.

| Form II Variables (Access table name: Form II S1) | | | | | | |
|---|-----------------|-----------|---|------------|------------------|---------------|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 | 2000-2005 | | | | |
| 1. | 200 | 100 | System ID | 2 | Text | 28 |
| 2. | 201 | 101 | Patient Number | 6 | Text | 47 |
| 3. | 202 | 200 | Post-injury Year | 2 | Text | 198 |
| 4. | 203 | 201 | Category of Follow-up Care on the Anniversary | 1 | Text | 199 |
| 5. | 203A | 202 | Reason for Lost | 1 | Text | 201 |
| 6. | 204 | 203 | Place of Residence on the Anniversary | 2 | Text | 85 |
| 7. | 205 | 204 | Marital Status on the Anniversary | 1 | Text | 87 |
| 8. | 206 | 205 | Highest Formal Educational Level Completed on the Anniversary | 1 | Text | 88 |
| 9. | 207 | 206 | Primary Occupational, Educational or Training Status on the Anniversary | 1 | Text | 89 |
| 10. | New | 207 | Job Census Code | 2 | Text | 90 |
| 11. | 212 | 208 | Method of Bladder Management on the Anniversary | 2 | Text | 111 |
| 12. | New | 209 | Change in marital status since last Form II | 1 | Text | 202 |
| 13. | New | 210_1 | VA healthcare system services used since last Form II (1) | 1 | Text | 92 |
| 14. | New | 210_2 | VA healthcare system services used since last Form II (2) | 1 | Text | 92 |
| 15. | New | 210_3 | VA healthcare system services used since last Form II (3) | 1 | Text | 92 |
| 16. | New | 210_4 | VA healthcare system services used since last Form II (4) | 1 | Text | 92 |
| 17. | New | 210_5 | VA healthcare system services used since last Form II (5) | 1 | Text | 92 |
| 18. | 217 | 211 | Date of the Annual Examination | 8 | Text | 204 |
| 19. | 218 | 212 | Grade of Worst Pressure Ulcer Present at Annual Exam | 1 | Text | 207 |
| 20. | 219 | 213 | Number of Pressure Ulcers Present at Annual Exam | 2 | Text | 120 |
| 21. | 209_1 | 214_1 | Sponsors of SCI Care and Services During the Anniversary Year (1) | 2 | Text | 94 |
| 22. | 209_2 | 214_2 | Sponsors of SCI Care and Services During the Anniversary Year (2) | 2 | Text | 94 |
| 23. | 209_3 | 214_3 | Sponsors of SCI Care and Services During the Anniversary Year (3) | 2 | Text | 94 |
| 24. | 209_4 | 214_4 | Sponsors of SCI Care and Services During the Anniversary Year (4) | 2 | Text | 94 |
| 25. | 209_5 | 214_5 | Sponsors of SCI Care and Services During the Anniversary Year (5) | 2 | Text | 94 |
| 26. | 210_1 | 215_1 | Type of Reimbursement During the Anniversary Year(1) | 1 | Text | 96 |
| 27. | 210_2 | 215_2 | Type of Reimbursement During the Anniversary Year(2) | 1 | Text | 96 |
| 28. | 210_3 | 215_3 | Type of Reimbursement During the Anniversary Year(3) | 1 | Text | 96 |
| 29. | 210_4 | 215_4 | Type of Reimbursement During the Anniversary Year(4) | 1 | Text | 96 |
| 30. | 210_5 | 215_5 | Type of Reimbursement During the Anniversary Year(5) | 1 | Text | 96 |
| 31. | 211 | 216 | Medical Case Manager During the Anniversary Year | 1 | Text | 97 |
| 32. | New | 217D_1 | Number of Days Rehospitalized, Rehosp. #1 | 3 | Text | 208 |
| 33. | New | 217R_1 | Reason for Rehospitalization, Rehosp. #1 | 2 | Text | 208 |
| 34. | New | 217D_2 | Number of Days Rehospitalized, Rehosp. #2 | 3 | Text | 208 |
| 35. | New | 217R_2 | Reason for Rehospitalization, Rehosp. #2 | 2 | Text | 208 |
| 36. | New | 217D_3 | Number of Days Rehospitalized, Rehosp. #3 | 3 | Text | 208 |
| 37. | New | 217R_3 | Reason for Rehospitalization, Rehosp. #3 | 2 | Text | 208 |
| 38. | New | 217D_4 | Number of Days Rehospitalized, Rehosp. #4 | 3 | Text | 208 |
| 39. | New | 217R_4 | Reason for Rehospitalization, Rehosp. #4 | 2 | Text | 208 |
| 40. | New | 217D_5 | Number of Days Rehospitalized, Rehosp. #5 | 3 | Text | 208 |
| 41. | New | 217R_5 | Reason for Rehospitalization, Rehosp. #5 | 2 | Text | 208 |
| 42. | New | 217D_6 | Number of Days Rehospitalized, Rehosp. #6 | 3 | Text | 208 |
| 43. | New | 217R_6 | Reason for Rehospitalization, Rehosp. #6 | 2 | Text | 208 |
| 44. | New | 217D_7 | Number of Days Rehospitalized, Rehosp. #7 | 3 | Text | 208 |
| 45. | New | 217R_7 | Reason for Rehospitalization, Rehosp. #7 | 2 | Text | 208 |
| 46. | New | 217D_8 | Number of Days Rehospitalized, Rehosp. #8+ | 3 | Text | 208 |
| 47. | New | 217R_8 | Reason for Rehospitalization, Rehosp. #8+ | 2 | Text | 208 |
| 48. | 213 | 218 | Number of Rehospitalizations During the Anniversary Year | 1 | Text | 211 |
| 49. | 214 | 219 | Number of Days Rehospitalized During the Anniversary Year | 3 | Text | 213 |

| Form II Variables (Access table name: Form II S1) | | | | | | |
|---|-----------------|-----------|--|------------|------------------|---------------|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 | 2000-2005 | | | | |
| 50. | 215 | 220 | Number of Days in Nursing Home During the Anniversary Year | 3 | Text | 214 |
| 51. | 220D | 221A | Pulmonary Embolism | 1 | Text | 126 |
| 52. | 220E_1-220E_5 | 221B | Thrombophlebitis, Deep Vein Thrombosis | 1 | Text | 127 |
| 53. | 220C | 221C | Pneumonia | 1 | Text | 129 |
| 54. | 220G | 221D | Presence of Calculus in the Kidney and/or Ureter | 1 | Text | 130 |
| 55. | 221A | 222A | Closure of Decubitus Ulcer(s) | 1 | Text | 143 |
| 56. | 221B | 222B | Calculus Removal | 1 | Text | 144 |
| 57. | 221C | 222C | Bladder Neck Resection | 1 | Text | 145 |
| 58. | 221D | 222D | External Sphincterotomy or Other Sphincter Opening Procedures | 1 | Text | 146 |
| 59. | New | 223 | Date of Interview | 8 | Text | 215 |
| 60. | 235 | 224 | How was the interview conducted? | 1 | Text | 216 |
| 61. | 239_1 | 225 | Self-perceived Health Status | 1 | Text | 217 |
| 62. | 240 | 226 | Compared to 1 year ago, how would you rate your health in general now? | 1 | Text | 218 |
| 63. | 230A | 227A | FIM - Self Care: Eating | 1 | Text | 151 |
| 64. | 230B | 227B | FIM - Self Care: Grooming | 1 | Text | 152 |
| 65. | 230C | 227C | FIM - Self Care: Bathing | 1 | Text | 153 |
| 66. | 230D | 227D | FIM - Self Care: Dressing, Upper Body | 1 | Text | 154 |
| 67. | 230E | 227E | FIM - Self Care: Dressing, Lower Body | 1 | Text | 155 |
| 68. | 230F | 227F | FIM - Self Care: Toileting | 1 | Text | 156 |
| 69. | 230G | 227G | FIM - Sphincter Control: Bladder Management | 1 | Text | 157 |
| 70. | 230H | 227H | FIM - Sphincter Control: Bowel Management | 1 | Text | 159 |
| 71. | 230I | 227I | FIM - Mobility (Transfer): Bed, Chair, Wheelchair | 1 | Text | 161 |
| 72. | 230J | 227J | FIM - Mobility (Transfer): Toilet | 1 | Text | 162 |
| 73. | 230K | 227K | FIM - Mobility (Transfer): Tub, Shower | 1 | Text | 163 |
| 74. | 230L | 227L | FIM - Locomotion: Walking or Wheelchair | 1 | Text | 164 |
| 75. | 230LM | 227LM | FIM - Locomotion: Mode | 1 | Text | 166 |
| 76. | 230M | 227M | FIM - Locomotion: Stairs | 1 | Text | 167 |
| 77. | 230S | 227T | FIM - Total Score | 2 | Text | 168 |
| 78. | 232_1 | 228_1 | Satisfaction With Life Scale Question 1 | 1 | Text | 219 |
| 79. | 232_2 | 228_2 | Satisfaction With Life Scale Question 2 | 1 | Text | 219 |
| 80. | 232_3 | 228_3 | Satisfaction With Life Scale Question 3 | 1 | Text | 219 |
| 81. | 232_4 | 228_4 | Satisfaction With Life Scale Question 4 | 1 | Text | 219 |
| 82. | 232_5 | 228_5 | Satisfaction With Life Scale Question 5 | 1 | Text | 219 |
| 83. | 232 | 228T | Satisfaction With Life Scale - Total Score | 2 | Text | 219 |
| 84. | 238_1A | 229_1A | CHART- Number of Hours of Paid Assistance/Day | 2 | Text | 222 |
| 85. | 238_1B | 229_1B | CHART - Number of Hours of Unpaid Assistance/Day | 2 | Text | 222 |
| 86. | New | 229_2 | CHART- How much time is someone with you to assist you in the home? | 1 | Text | 223 |
| 87. | New | 229_3 | CHART- How much of the time is someone with you to help you when you go away from your home? | 1 | Text | 224 |
| 88. | 238_4 | 229_4 | CHART - Number of Hours Out of Bed/Day | 2 | Text | 225 |
| 89. | 238_5 | 229_5 | CHART - Number of Days Out of the House/Week | 1 | Text | 226 |
| 90. | 238_6 | 229_6 | CHART - Number of Nights Away from Home In the Past Year | 1 | Text | 227 |
| 91. | 238_13 | 229_7 | CHART - Number of Hours/Week at Paid Job | 2 | Text | 228 |
| 92. | 238_14 | 229_8 | CHART - Number of Hours/Week at School/Study | 2 | Text | 229 |
| 93. | 238_15 | 229_9 | CHART - Number of Hours/Week at Homemaking | 2 | Text | 230 |
| 94. | 238_16 | 229_10 | CHART - Number of Hours/Week at Home Maintenance | 2 | Text | 231 |
| 95. | 238_18 | 229_11 | CHART - Number of Hours/Week at Recreation | 2 | Text | 232 |
| 96. | New | 229_12 | CHART – How many people do you live with? | 2 | Text | 233 |
| 97. | New | 229_13 | CHART – Is one of them your spouse or significant other? | 1 | Text | 234 |
| 98. | New | 229_14 | CHART – Of the people you live with how many are relatives? | 2 | Text | 235 |

| Form II Variables (Access table name: Form II S1) | | | | | | |
|---|-----------------|-----------|--|------------|------------------|---------------|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 | 2000-2005 | | | | |
| 99. | 238_23 | 229_15 | CHART - Number of Business/Organizational Contacts/Month | 2 | Text | 236 |
| 100. | 238_24 | 229_16 | CHART - Number of Contacts/Month With Friends | 1 | Text | 237 |
| 101. | 238_25 | 229_17 | CHART - How Many Strangers Have You Initiated a Conversation With/Month? | 1 | Text | 238 |
| 102. | New | 229_18 | CHART - Combined Annual Family Income | 1 | Text | 239 |
| 103. | New | 229_19 | CHART – Unreimbursed Medical Care Expenses | 1 | Text | 240 |
| 104. | New | 229_20 | CHART - Physical Independence Total | 3 | Text | 241 |
| 105. | New | 229_21 | CHART- Cognitive Independence Total | 3 | Text | 242 |
| 106. | New | 229_22 | CHART - Mobility Total | 3 | Text | 243 |
| 107. | New | 229_23 | CHART - Occupation Total | 3 | Text | 244 |
| 108. | New | 229_24 | CHART - Social Integration | 3 | Text | 245 |
| 109. | New | 229_25 | The CHART - Economic Self-sufficiency | 3 | Text | 246 |
| 110. | New | 229_T | Total CHART Score | 3 | Text | 247 |

| Form II Variables (Access table name: Form II S2) | | | | | | |
|---|-----------------|-----------|--|------------|------------------|---------------|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 | 2000-2005 | | | | |
| | 200 | 100 | System ID | 2 | Text | 28 |
| | 201 | 101 | Patient Number | 6 | Text | 47 |
| | 202 | 200 | Post-injury Year | 2 | Text | 198 |
| 111. | New | 230_1 | CHIEF-1.In the past 12 months, how often has the availability of transportation been a problem for you? | 1 | Text | 249 |
| 112. | New | 230_1A | CHIEF-1A.When this problem occurs, has it been a big problem or little problem? | 1 | Text | 249 |
| 113. | New | 230_2 | CHIEF-2.In the past 12 months, how often has the natural environment – temperature, terrain, climate – made it difficult to do what you want or need to do? | 1 | Text | 250 |
| 114. | New | 230_2A | CHIEF-2A. When this problem occurs, has it been a big problem or little problem? | 1 | Text | 250 |
| 115. | New | 230_3 | CHIEF-3.In the past 12 months, how often have other aspects of your surroundings – lighting, noise, crowds, etc – made it difficult to do what you want or need to do? | 1 | Text | 251 |
| 116. | New | 230_3A | CHIEF-3A. When this problem occurs, has it been a big problem or little problem? | 1 | Text | 251 |
| 117. | New | 230_4 | CHIEF-4. In the past 12 months, how often has the information you wanted or needed not been available in a format you can use or understand? | 1 | Text | 252 |
| 118. | New | 230_4A | CHIEF-4A. When this problem occurs, has it been a big problem or little problem? | 1 | Text | 252 |
| 119. | New | 230_5 | CHIEF-5. In the past 12 months, how often has the availability of health care services and medical care been a problem for you? | 1 | Text | 253 |
| 120. | New | 230_5A | CHIEF-5A. When this problem occurs, has it been a big problem or little problem? | 1 | Text | 253 |
| 121. | New | 230_6 | CHIEF-6.In the past 12 months, how often did you need someone else’s help in your home and could not get it easily? | 1 | Text | 254 |
| 122. | New | 230_6A | CHIEF-6A. When this problem occurs, has it been a big problem or little problem? | 1 | Text | 254 |
| 123. | New | 230_7 | CHIEF-7.In the past 12 months, how often did you need someone else’s help at school or work and could not get it easily? | 1 | Text | 255 |
| 124. | New | 230_7A | CHIEF-7A. When this problem occurs, has it been a big problem or little problem? | 1 | Text | 255 |
| 125. | New | 230_8 | CHIEF-8.In the past 12 months, how often have other people’s attitudes toward you been a problem at home? | 1 | Text | 256 |
| 126. | New | 230_8A | CHIEF-8A. When this problem occurs, has it been a big problem or little problem? | 1 | Text | 256 |

| Form II Variables (Access table name: Form II S2) | | | | | | |
|---|-----------------|-----------|--|------------|------------------|---------------|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 | 2000-2005 | | | | |
| 127. | New | 230_9 | CHIEF-9..In the past 12 months, how often have other people's attitudes toward you been a problem at school or work? | 1 | Text | 257 |
| 128. | New | 230_9A | CHIEF-9A. When this problem occurs, has it been a big problem or little problem? | 1 | Text | 257 |
| 129. | New | 230_10 | CHIEF-10.In the past 12 months, how often did you experience prejudice or discrimination? | 1 | Text | 258 |
| 130. | New | 230_10A | CHIEF-10A. When this problem occurs, has it been a big problem or little problem? | 1 | Text | 258 |
| 131. | New | 230_11 | CHIEF-11.In the past 12 months, how often did the policies and rules of businesses and organizations make problems for you? | 1 | Text | 259 |
| 132. | New | 230_11A | CHIEF-11A. When this problem occurs, has it been a big problem or little problem? | 1 | Text | 259 |
| 133. | New | 230_12 | CHIEF-12.In the past 12 months, how often did government programs and policies make it difficult to do what you want or need to do? | 1 | Text | 260 |
| 134. | New | 230_12A | CHIEF-12A. When this problem occurs, has it been a big problem or little problem? | 1 | Text | 260 |
| 135. | New | 230_13 | CHIEF – Policies Subscale | 4 | Text | 261 |
| 136. | New | 230_14 | CHIEF – Physical/Structural Subscale | 4 | Text | 262 |
| 137. | New | 230_15 | CHIEF – Work/School Subscale | 4 | Text | 263 |
| 138. | New | 230_16 | CHIEF – Attitudes/Support Subscale | 4 | Text | 264 |
| 139. | New | 230_17 | CHIEF – Services/Assistance Subscale | 4 | Text | 265 |
| 140. | New | 230T | CHIEF - Total | 4 | Text | 266 |
| 141. | New | 231_1 | BPHQ-1. Over the last 2 weeks, how often have you been bothered by little interest or pleasure in doing things? | 1 | Text | 267 |
| 142. | New | 231_2 | BPHQ-2. Over the last 2 weeks, how often have you been bothered by feeling down, depressed, or hopeless? | 1 | Text | 268 |
| 143. | New | 231_3 | BPHQ-3. Over the last 2 weeks, how often have you been bothered by trouble falling or staying asleep, or sleeping too much? | 1 | Text | 269 |
| 144. | New | 231_4 | BPHQ-4. Over the last 2 weeks, how often have you been bothered by feeling tired or having little energy? | 1 | Text | 270 |
| 145. | New | 231_5 | BPHQ-5. Over the last 2 weeks, how often have you been bothered by poor appetite or overeating? | 1 | Text | 271 |
| 146. | New | 231_6 | BPHQ-6. Over the last 2 weeks, how often have you been bothered by feeling bad about yourself – or that you are a failure or have let yourself or your family down? | 1 | Text | 272 |
| 147. | New | 231_7 | BPHQ-7. Over the last 2 weeks, how often have you been bothered by trouble concentrating on things, such as reading the newspaper or watching television? | 1 | Text | 273 |
| 148. | New | 231_8 | BPHQ-8. Over the last 2 weeks, how often have you been bothered by moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual? | 1 | Text | 274 |
| 149. | New | 231_9 | BPHQ-9. Over the last 2 weeks, how often have you been bothered by thoughts that you would be better off dead or of hurting yourself in some way? | 1 | Text | 275 |
| 150. | New | 231_10 | BPHQ-10. If you had any of the problems in questions BPHQ1 through BPHQ9, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? | 1 | Text | 276 |
| 151. | New | 231M | Major Depressive Syndrome | 1 | Text | 277 |
| 152. | New | 231S | Severity of Depression Score | 2 | Text | 278 |
| 153. | New | 232_1 | During the past year, have you used illegal drugs or prescribed medications for non-medical purposes? (1) | 1 | Text | 279 |
| 154. | New | 232_2 | During the past year, have you used illegal drugs or prescribed medications for non-medical purposes? (2) | 1 | Text | 279 |
| 155. | New | 232_3 | During the past year, have you used illegal drugs or prescribed medications for non-medical purposes? (3) | 1 | Text | 279 |

| Form II Variables (Access table name: Form II S2) | | | | | | |
|---|-----------------|-----------|---|------------|------------------|---------------|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 | 2000-2005 | | | | |
| 156. | New | 232_4 | During the past year, have you used illegal drugs or prescribed medications for non-medical purposes? (4) | 1 | Text | 279 |
| 157. | New | 232_5 | During the past year, have you used illegal drugs or prescribed medications for non-medical purposes? (5) | 1 | Text | 279 |
| 158. | New | 232_6 | During the past year, have you used illegal drugs or prescribed medications for non-medical purposes? (6) | 1 | Text | 279 |
| 159. | New | 233 | Do you drink any alcoholic beverages, such as beer, wine, wine coolers or liquor? | 1 | Text | 280 |
| 160. | New | 234 | During the past month, how many days per week did you drink any alcoholic beverages, such as beer, wine, wine coolers or liquor, on the average? | 1 | Text | 281 |
| 161. | New | 235 | On the days you drank, about how many drinks did you drink, on the average? A drink is 1 can or bottle of beer, 1 glass of wine, 1 can or bottle of wine cooler, 1 cocktail, or 1 shot of liquor. | 2 | Text | 282 |
| 162. | New | 236 | Considering all types of alcoholic beverages, how many times during the past month did you have five (5) or more drinks on an occasion? | 2 | Text | 283 |
| 163. | New | 237_1 | CAGE-1. Have you ever felt you should cut down on your drinking? | 1 | Text | 284 |
| 164. | New | 237_2 | CAGE-2. Have people annoyed you by criticizing your drinking? | 1 | Text | 285 |
| 165. | New | 237_3 | CAGE-3. Have you ever felt bad or guilty about your drinking? | 1 | Text | 286 |
| 166. | New | 237_4 | CAGE-4. Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover (eye-opener)? | 1 | Text | 287 |
| 167. | New | 237T | CAGE Total Score | 1 | Text | 288 |
| 168. | New | 238 | What has been the usual level of pain over the past 4 weeks? | 2 | Text | 289 |
| 169. | 239_8 | 239 | During the past 4 weeks, how much did pain interfere with your normal work including both work outside the home and housework? | 1 | Text | 290 |
| 170. | New | 240_A | Injury to First Anniv. - Physical and/or Occupational Therapy - Prescribed | 1 | Text | 291 |
| 171. | New | 240_B | Injury to First Anniv. - Physical and/or Occupational Therapy – Hours Completed | 1 | Text | 291 |
| 172. | New | 240_C | Injury to First Anniv. - Physical and/or Occupational Therapy - Location | 1 | Text | 291 |
| 173. | New | 241_A | Injury to First Anniv. - Psychological and/or Vocational Counseling - Prescribed | 1 | Text | 293 |
| 174. | New | 241_B | Injury to First Anniv. - Psychological and/or Vocational Counseling - Hours Completed | 1 | Text | 293 |
| 175. | New | 241_C | Injury to First Anniv. - Psychological and/or Vocational Counseling - Location | 1 | Text | 293 |
| 176. | 231 | 242 | Utilization of Mechanical Ventilation at the First Anniversary | 1 | Text | 114 |
| 177. | 220A | 243 | Post-operative Wound Infection at the Site of the Spinal Surgery Post-discharge to First Anniversary | 1 | Text | 124 |
| 178. | 222 | 244 | Category of Neurologic Impairment at the Year 1 Annual Exam | 1 | Text | 100 |
| 179. | 228 | 245 | ASIA Impairment Scale at the Year 1 Annual Exam | 1 | Text | 102 |
| 180. | 229AL | 246AL | ASIA Motor Index Score at the Year 1 Annual Exam | 1 | Text | 104 |
| 181. | 229BL | 246BL | ASIA Motor Index Score, C6, Left | 1 | Text | 104 |
| 182. | 229CL | 246CL | ASIA Motor Index Score, C7, Left | 1 | Text | 104 |
| 183. | 229DL | 246DL | ASIA Motor Index Score, C8, Left | 1 | Text | 104 |
| 184. | 229EL | 246EL | ASIA Motor Index Score, T1, Left | 1 | Text | 104 |
| 185. | 229FL | 246FL | ASIA Motor Index Score, L2, Left | 1 | Text | 104 |
| 186. | 229GL | 246GL | ASIA Motor Index Score, L3, Left | 1 | Text | 104 |
| 187. | 229HL | 246HL | ASIA Motor Index Score, L4, Left | 1 | Text | 104 |
| 188. | 229IL | 246IL | ASIA Motor Index Score, L5, Left | 1 | Text | 104 |
| 189. | 229JL | 246JL | ASIA Motor Index Score, S1, Left | 1 | Text | 104 |
| 190. | 229L | 246L | ASIA Motor Index Score, Subtotal Left | 2 | Text | 104 |
| 191. | 229AR | 246AR | ASIA Motor Index Score, C5, Right | 1 | Text | 104 |

| Form II Variables (Access table name: Form II S2) | | | | | | |
|---|-----------------|-----------|--|------------|------------------|---------------|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 | 2000-2005 | | | | |
| 192. | 229BR | 246BR | ASIA Motor Index Score, C6, Right | 1 | Text | 104 |
| 193. | 229CR | 246CR | ASIA Motor Index Score, C7, Right | 1 | Text | 104 |
| 194. | 229DR | 246DR | ASIA Motor Index Score, C8, Right | 1 | Text | 104 |
| 195. | 229ER | 246ER | ASIA Motor Index Score, T1, Right | 1 | Text | 104 |
| 196. | 229FR | 246FR | ASIA Motor Index Score, L2, Right | 1 | Text | 104 |
| 197. | 229GR | 246GR | ASIA Motor Index Score, L3, Right | 1 | Text | 104 |
| 198. | 229HR | 246HR | ASIA Motor Index Score, L4, Right | 1 | Text | 104 |
| 199. | 229IR | 246IR | ASIA Motor Index Score, L5, Right | 1 | Text | 104 |
| 200. | 229JR | 246JR | ASIA Motor Index Score, S1, Right | 1 | Text | 104 |
| 201. | 229R | 246R | ASIA Motor Index Score, Subtotal Right | 2 | Text | 104 |
| 202. | 229T | 246T | ASIA Motor Index Score Total | 3 | Text | 104 |
| 203. | 224L | 247L | Sensory Level at the Year 1 Annual Exam, Left | 3 | Text | 107 |
| 204. | 224R | 247R | Sensory Level at the Year 1 Annual Exam, Right | 3 | Text | 107 |
| 205. | 225L | 248L | Motor Level at the Year 1 Annual Exam, Left | 3 | Text | 108 |
| 206. | 225R | 248R | Motor Level at the Year 1 Annual Exam, Right | 3 | Text | 108 |
| 207. | 223L | 249L | Level of Preserved Neuro Function at the Year 1 Annual Exam, Left | 3 | Text | 110 |
| 208. | 223R | 249R | Level of Preserved Neuro Function at the Year 1 Annual Exam, Right | 3 | Text | 110 |
| 209. | QCSTAT2 | QCSTAT2 | Quality Control Status | Byte | Number | 297 |
| 210. | BATCH2 | BATCH2 | Batch Number | 10 | Text | 298 |
| 211. | INDATE2 | INDATE2 | Date Record Originally Entered | Short date | Date | 299 |
| 212. | UPDATE2 | UPDATE2 | Last Date Record Updated | Short date | Date | 300 |
| 213. | New | 250A | Walk for 150 feet in your home? | 1 | Text | 301 |
| 214. | New | 250B | Walk for one street block outside? | 1 | Text | 301 |
| 215. | New | 250C | Walk up one flight of steps? | 1 | Text | 301 |
| 216. | New | 251_1 | Mobility Aid(s) (1) | 1 | Text | 302 |
| 217. | New | 251_2 | Mobility Aid(s) (2) | 1 | Text | 302 |
| 218. | New | 251_3 | Mobility Aid(s) (3) | 1 | Text | 302 |
| 219. | New | 251_4 | Mobility Aid(s) (4) | 1 | Text | 302 |
| 220. | New | 251_5 | Mobility Aid(s) (5) | 1 | Text | 302 |
| 221. | New | 252 | Wheelchair or Scooter Use | 1 | Text | 303 |
| 222. | New | 253 | Type of Wheelchair (or Scooter) Used Most Often | 1 | Text | 304 |
| 223. | New | 254A | Wheelchair (or Scooter) Used Most Often – Manufacturer | 2 | Text | 305 |
| 224. | New | 254B | Wheelchair (or Scooter) Used Most Often - Model | 3 | Text | 305 |
| 225. | New | 255 | Primary Funding Source for Wheelchair (or Scooter) Used Most Often | 2 | Text | 307 |
| 226. | New | 256_1 | Features on Wheelchair (or Scooter) Used Most Often (1) | 1 | Text | 308 |
| 227. | New | 256_2 | Features on Wheelchair (or Scooter) Used Most Often (2) | 1 | Text | 308 |
| 228. | New | 256_3 | Features on Wheelchair (or Scooter) Used Most Often (3) | 1 | Text | 308 |
| 229. | New | 256_4 | Features on Wheelchair (or Scooter) Used Most Often (4) | 1 | Text | 308 |
| 230. | New | 256_5 | Features on Wheelchair (or Scooter) Used Most Often (5) | 1 | Text | 308 |
| 231. | New | 256_6 | Features on Wheelchair (or Scooter) Used Most Often (6) | 1 | Text | 308 |
| 232. | New | 257 | Number of Repairs on Wheelchair (or Scooter) Used Most Often | 2 | Text | 309 |
| 233. | New | 258_1 | Consequences Breakdown Wheelchair/Scooter Used Most Often(1) | 1 | Text | 310 |
| 234. | New | 258_2 | Consequences Breakdown Wheelchair/Scooter Used Most Often(2) | 1 | Text | 310 |
| 235. | New | 258_3 | Consequences Breakdown Wheelchair/Scooter Used Most Often(3) | 1 | Text | 310 |
| 236. | New | 258_4 | Consequences Breakdown Wheelchair/Scooter Used Most Often(4) | 1 | Text | 310 |

| Form II Variables (Access table name: Form II S2) | | | | | | |
|---|-----------------|-----------|--|------------|------------------|---------------|
| Variable Count | Variable Number | | Variable Name | Field Size | Access Data Type | Syllabus Page |
| | 1995-2000 | 2000-2005 | | | | |
| 237. | New | 259A | Number of Additional Wheelchairs or Scooters: Manual | 2 | Text | 311 |
| 238. | New | 259B | Number of Additional Wheelchairs or Scooters: Power | 2 | Text | 311 |
| 239. | New | 259C | Number of Additional Wheelchairs or Scooters: Power Assisted | 2 | Text | 311 |
| 240. | New | 259D | Number of Additional Wheelchairs or Scooters: Other | 2 | Text | 311 |
| 241. | New | 259E | Number of Additional Wheelchairs or Scooters: Scooters | 2 | Text | 311 |
| 242. | New | 260 | Use a Computer? | 1 | Text | 312 |
| 243. | New | 261_1 | Type of Computer Access Device(s) (1) | 2 | Text | 313 |
| 244. | New | 261_2 | Type of Computer Access Device(s) (2) | 2 | Text | 313 |
| 245. | New | 261_3 | Type of Computer Access Device(s) (3) | 2 | Text | 313 |
| 246. | New | 261_4 | Type of Computer Access Device(s) (4) | 2 | Text | 313 |
| 247. | New | 261_5 | Type of Computer Access Device(s) (5) | 2 | Text | 313 |
| 248. | New | 261_6 | Type of Computer Access Device(s) (6) | 2 | Text | 313 |
| 249. | New | 261_7 | Type of Computer Access Device(s) (7) | 2 | Text | 313 |
| 250. | New | 261_8 | Type of Computer Access Device(s) (8) | 2 | Text | 313 |
| 251. | New | 261_9 | Type of Computer Access Device(s) (9) | 2 | Text | 313 |
| 252. | New | 261_10 | Type of Computer Access Device(s) (10) | 2 | Text | 313 |
| 253. | New | 262 | Internet or Email Usage | 1 | Text | 314 |
| 254. | New | 263_1 | Location of Internet /Email Use (1) | 1 | Text | 315 |
| 255. | New | 263_2 | Location of Internet /Email Use (2) | 1 | Text | 315 |
| 256. | New | 263_3 | Location of Internet /Email Use (3) | 1 | Text | 315 |
| 257. | New | 264A | Internet Categories:Employment/vocation information | 1 | Text | 316 |
| 258. | New | 264B | Internet Categories: Disability/health information | 1 | Text | 316 |
| 259. | New | 264C | Internet Categories: Email | 1 | Text | 316 |
| 260. | New | 264D | Internet Categories: Chat rooms | 1 | Text | 316 |
| 261. | New | 264E | Internet Categories: Games | 1 | Text | 316 |
| 262. | New | 264F | Internet Categories: Shopping | 1 | Text | 316 |
| 263. | New | 264G | Internet Categories: Other | 1 | Text | 316 |
| 264. | New | 265 | Modified Vehicle? | 1 | Text | 318 |
| 265. | New | 266 | Driving a Modified Vehicle? | 1 | Text | 319 |
| 266. | New | 267 | Cell Phone? | 1 | Text | 320 |

| Summary – Form II File | |
|---------------------------|-----|
| Total Number of Variables | 266 |

blank page

PERSONAL DATA, REGISTRY, FORM I and FORM II

VARIABLE NAME: Reporting Model SCI System Identification Code (System ID)

DESCRIPTION: An alphabetic code is assigned to each reporting system by the National Spinal Cord Injury Statistical Center (NSCISC).

The Reporting Model System Identification Code and the Patient Number (Variables 100 and 101) are the only patient identification variables submitted to the NSCISC and stored in the Registry, Form I and Form II data files.

CHARACTERS: 2

CODES: Assigned individually to each reporting system by the NSCISC.

| | | | |
|-----------|-------------------------------|-----------|-------------------------------|
| A | Atlanta | MW | Wisconsin |
| AA | Ann Arbor | NJ | New Jersey |
| B | Birmingham | NO | New Orleans |
| BN | Boston | NY | New York (NYU) |
| C | Chicago | P | Phoenix |
| CM | Columbia, Missouri | PA | Philadelphia |
| CO | Cleveland, Ohio | PI | Pittsburgh |
| D | Denver (Englewood, CO) | R | Rancho (Downey, CA) |
| DM | Detroit | RO | Rochester |
| H | Houston | RV | Richmond, Virginia |
| MI | Miami | S | Seattle |
| MS | Mt. Sinai, New York | SJ | San Jose |
| | | V | Fishersville, Virginia |

COMMENTS: Use only uppercase letters. For systems with a one-character code, use the first box only (leave the second box blank).

A data form/record must have a Patient Number and Reporting System Identification Code before it will be processed by the National Spinal Cord Injury Statistical Center.

PERSONAL DATA, REGISTRY, FORM I and FORM II

VARIABLE NAME: Patient Number

DESCRIPTION: The Patient Number is assigned to each patient at the discretion of the reporting System. No designated numbers are assigned by the NSCISC. Each Patient Number may contain a maximum of 6 characters.

The Reporting System Identification Code and the Patient Number (Variables 100 and 101) are the only patient identification variables submitted to the NSCISC and stored in the main Registry, Form I and Form II data files.

CHARACTERS: 6

CODES: **To be assigned by the individual reporting system.**

COMMENTS: A data form/record must have a Patient Number and Reporting System Identification Code before it will be processed by the National Spinal Cord Injury Statistical Center.

PERSONAL DATA

VARIABLE NAME: Alternate ID

DESCRIPTION: The Alternate ID is an optional variable that may be used by Systems to computerize another patient identifier (such as a medical record number).

Although this variable is not included on the Personal Data data collection form (and the data will never be exported to the NSCISC) this information is being provided for the benefit of those who will be analyzing their local database. This is information that resides only locally, on the System's computer.

CHARACTERS: 12

CODES: **To be assigned by the individual reporting System.**

PERSONAL DATA

VARIABLE NAME: Patient Name

DESCRIPTION: This variable documents the patient's first name, middle initial and last name.

CHARACTERS: 36 characters (12 for first name, 1 for middle initial, 23 for last name)

CODES: **Any letter of the alphabet**
Blanks are allowed.

COMMENTS: The Name, Social Security Number, Date of Birth and Zip Codes are stored in the Personal Data file and available (with the patient's permission) for export to the NSCISC. The Name, SS# and Date of Birth are used only by the Director of NSCISC to link data from the National SCI Database with data from other sources and to avoid duplicate entry into the National SCI Database. The information is also used to help systems identify study patients after there has been a gap in funding.

REVISIONS: October 2000: this variable was added to the database.
Systems are encouraged to add this information to the records of patients who are currently in the database. A separate consent must be obtained from the patient before this information is exported to the NSCISC.

SOFTWARE: Enter the name then check the Name box to select this item for export. See the Users' Manual for details.

Name ✓ SSN Birth Date Zip Codes

PERSONAL DATA

VARIABLE NAME: Social Security Number

DESCRIPTION: This variable documents the patient's Social Security Number.

CHARACTERS: 9

CODES: **Any valid Social Security number**

Blanks are allowed

COMMENTS: The Name, Social Security Number, Date of Birth and Zip Codes are stored in the Personal Data file and available (with the patient's permission) for export to the NSCISC. The Name, SS# and Date of Birth are used only by the Director of NSCISC to link data from the National SCI Database with data from other sources and to avoid duplicate entry into the National SCI Database. The information is also used to help systems identify study patients after there has been a gap in funding.

SOFTWARE: Enter the Social Security Number then check the SSN box to select this item for export. See the Users' Manual for details.

| | | | | |
|------|-----|-------------------------------------|------------|-----------|
| Name | SSN | <input checked="" type="checkbox"/> | Birth Date | Zip Codes |
|------|-----|-------------------------------------|------------|-----------|

REVISIONS: October 2000: this variable was added to the database.

Systems are encouraged to add this information to the records of patients who are currently in the database. A separate consent must be obtained from the patient before this information is exported to the NSCISC.

PERSONAL DATA

VARIABLE NAME: Date of Birth

DESCRIPTION: This variable documents the patient's date of birth.

CHARACTERS: 8

FORMAT: mmddyyyy

CODES: **Any valid date**

99 Unknown day of the month or unknown month of the year

9999 Unknown year

Blanks are allowed

COMMENTS: Record the month, day and year of birth.

The Name, Social Security Number, Date of Birth and Zip Codes are stored in the Personal Data file and available (with the patient's permission) for export to the NSCISC. The Name, SS# and Date of Birth are used only by the Director of NSCISC to link data from the National SCI Database with data from other sources and to avoid duplicate entry into the National SCI Database. The information is also used to help systems identify study patients after there has been a gap in funding.

This variable cannot be stored in date format since non-valid parts of the date are allowed.

SOFTWARE: Enter the Date of Birth then check the Birth Date box to select this item for export. See the Users' Manual for details.

Name SSN Birth Date ✓ Zip Codes

REVISIONS: October 2000: this variable was added to the database.

Systems are encouraged to add this information to the records of patients who are currently in the database. A separate consent must be obtained from the patient before this information is exported to the NSCISC.

EXAMPLE 1: The patient was born in 1998. The month and day are unknown.

V014. Date of Birth 9 9 / 9 9 / 1 9 9 8

EXAMPLE 2: The patient was born in May 1999. The day of the month is unknown.

V014. Date of Birth 0 5 / 9 9 / 1 9 9 9

QC: Age at Injury (V111) = number of years between Date of injury and Date of Birth.

PERSONAL DATA

VARIABLE NAME: Current Address

DESCRIPTION: The Current Address1 and Address2 are optional variables that may be used by Systems to computerize the patient's current address.

Although this variable is not included on the Personal Data data collection form (and the data will never be exported to the NSCISC) this information is being provided for the benefit of those who will be analyzing their local database. This is information that resides only locally, on the System's computer.

CHARACTERS: 30 for each entry, 2 entries

CODES: **Any valid address**
Blanks are allowed

PERSONAL DATA

VARIABLE NAME: Current City of Residence

DESCRIPTION: The Current City of Residence is an optional variable that may be used by Systems to computerize the patient's current city of residence.

Although this variable is not included on the Personal Data data collection form (and the data will never be exported to the NSCISC) this information is being provided for the benefit of those who will be analyzing their local database. This is information that resides only locally, on the System's computer.

CHARACTERS: 20

CODES: **Any valid city**

Blanks are allowed

PERSONAL DATA

VARIABLE NAME: Current State of Residence

DESCRIPTION: The Current State of Residence is an optional variable that may be used by Systems to computerize the patient's current state of residence.

Although this variable is not included on the Personal Data data collection form (and the data will never be exported to the NSCISC) this information is being provided for the benefit of those who will be analyzing their local database. This is information that resides only locally, on the System's computer.

CHARACTERS: 2

CODES: **Any valid state abbreviation**
Blanks are allowed

PERSONAL DATA

VARIABLE NAME: Current Zip Code and Extended Zip Code

DESCRIPTION: The Current Zip Code is an optional variable that may be used by Systems to computerize the zip code for the patient's current residence.

Although this variable is not included on the Personal Data data collection form (and the data will never be exported to the NSCISC) this information is being provided for the benefit of those who will be analyzing their local database. This is information that resides only locally, on the System's computer.

CHARACTERS: 5 for the zip code, 4 for the extended zip code.

CODES: Any valid zip code

COMMENTS: Variable 105 (page 57) documents the zip codes for the patient's place of residence at the time of injury and on the anniversary of injury in follow-up years 1, 5, 10, 15, 20, 25 and 30. The data in V105 may be exported to the NSCISC (with the patient's consent).

Extended zip codes may be found using the following website:

www.usps.com

PERSONAL DATA

VARIABLE NAME: Current Telephone Number

DESCRIPTION: The Telephone Number is an optional variable that may be used by Systems to computerize the patient's current area code and telephone number.

Although this variable is not included on the Personal Data data collection form (and the data will never be exported to the NSCISC) this information is being provided for the benefit of those who will be analyzing their local database. This is information that resides only locally, on the System's computer.

CHARACTERS: 10

CODES: **Any valid telephone number**
Blanks are allowed

PERSONAL DATA

VARIABLE NAME: Zip Code for Place of Residence

DESCRIPTION: This variable documents the zip codes for the patient's place of residence at the time of injury and on the anniversary of injury at follow-up years 1, 5, 10, 15, 20, 25 and 30.

CHARACTERS: 5 for each entry

CODES: **Any valid zip code**
9999 Unknown

Blanks are allowed

COMMENTS: The Zip Code will be used only by the Director of NSCISC to track changes in residence and link data to other databases.

REVISIONS: October 2000: this variable was added to the database.
Systems are encouraged to add this information to the records of patients who are currently in the database. A separate consent must be obtained from the patient before this information is exported to the NSCISC.

SOFTWARE: Enter data in the Zip Code variables then check the Zip Codes box to select these items for export. See the Users' Manual for details. Note: checking the Zip Codes box means all data in V105I through V105_30 (and V105EI through V105E_30) will be exported to the NSCISC.

Name SSN Birth Date Zip Codes ✓

PERSONAL DATA

VARIABLE NAME: Extended Zip Code for Place of Residence

DESCRIPTION: This variable documents the extended zip codes for the patient's place of residence at the time of injury and on the anniversary of injury at follow-up years 1, 5, 10, 15, 20, 25 and 30.

CHARACTERS: 4 for each entry

CODES: **Any valid extended zip code**

9999 Unknown

Blanks are allowed

COMMENTS: The Zip Code will be used only by the Director of NSCISC to track changes in residence and link data to other databases.

REVISIONS: October 2000: this variable was added to the database.

Systems are encouraged to add this information to the records of patients who are currently in the database. A separate consent must be obtained from the patient before this information is exported to the NSCISC.

SOFTWARE: See [page57](#).

EXAMPLE 1: The patient's zip code (for residence at injury) is 35124 and the extended zip code is unknown.

105I. Zip Code for Residence at Injury..... 3 5 1 2 4 / 9 9 9 9

EXAMPLE 2: The patient has refused to have his personal information included in the database.

105I. Zip Code for Residence at Injury..... _ _ _ _ / _ _ _ _

PERSONAL DATA

VARIABLE NAME: Current Follow-up Status

DESCRIPTION: This variable indicates the reason future follow up records will not be required for a patient. If this field is empty, future Form IIs are required (unless there is only a Registry record). This information is provided primarily for the user as a quick method to determine a patient's follow-up data submission status.

This variable is generated by the NSCISC's software and users are not allowed to modify this data. This variable is needed by the software for data management/data reporting purposes and the data will never be exported to the NSCISC.

This is information that resides only locally, on the System's computer.

CHARACTERS: 13

CODES: **Deceased** V145 = a valid date
 Lost V201 on the last Form II = "5"
 Normal V131D = "7"
 Minimal V131D = "3" or "6"
 Norm-Min V201 on the last Form II = "8" or,
 if no Form IIs, V131D = "8"
 Personal Data only Personal Data have been entered (more than just the
 patient number)
 Blank future follow-up is required (unless there is only a Registry
 record)

PERSONAL DATA

VARIABLE NAME: Registry

DESCRIPTION: This variable indicates if a Registry record exists for the patient.

This variable is generated by the NSCISC's software and users are not allowed to modify this data. This variable is needed by the software for data management/data reporting purposes and the data will never be exported to the NSCISC.

This is information that resides only locally, on the System's computer.

CHARACTERS: 1

CODES: **0** No Registry record
1 Registry record is present

PERSONAL DATA

VARIABLE NAME: Form I

DESCRIPTION: This variable indicates if a Form I record exists for the patient.

This variable is generated by the NSCISC's software and users are not allowed to modify this data. This variable is needed by the software for data management/data reporting purposes and the data will never be exported to the NSCISC.

This is information that resides only locally, on the System's computer.

CHARACTERS: 1

CODES: **0** No Form I record
1 Form I record is present

PERSONAL DATA

VARIABLE NAME: Total Number of Form IIs

DESCRIPTION: This variable tallies the number of Form II records available for a patient.

This variable is generated by the NSCISC's software and users are not allowed to modify this data. This variable is needed by the software for data management/data reporting purposes and the data will never be exported to the NSCISC.

This is information that resides only locally, on the System's computer.

CHARACTERS: 2

CODES: **0** No Form II records

0 to 30 Valid range

VARIABLE Last Form II

PERSONAL DATA

VARIABLE NAME: Anniversary Year for the Last Form II

DESCRIPTION: This is V200 (Post-injury Year) for the last Form II that has been entered for the patient.

This variable is generated by the NSCISC's software and users are not allowed to modify this data. This variable is needed by the software for data management/data reporting purposes and the data will never be exported to the NSCISC.

This is information that resides only locally, on the System's computer.

CHARACTERS: 2

CODES: **0** No Form II records

0 to 30 Valid range

PERSONAL DATA

VARIABLE NAME: Patient Notes

DESCRIPTION: This is an optional variable that allows systems to computerize any additional patient data that is not included in the national database file (e.g. test results that may be needed for an in-house study but are not included in the national database; notes on a patient's preference for appointment time, etc.).

The data in this variable will never be exported to the NSCISC. It is information that resides only locally, on the System's computer.

CHARACTERS: unlimited

PERSONAL DATA

VARIABLE NAME: Complete Name for Contact 1, Contact 2 and Contact 3

DESCRIPTION: This variable documents the complete name for 3 persons who may know the whereabouts of the patient.

CHARACTERS: 128 characters for each entry, 3 entries

CODES: **Any character**

Blanks are allowed.

COMMENTS: These variables are not included on the Personal Data data collection form (and the data will never be exported to the NSCISC). This information resides only locally, on the System's computer.

This information should be obtained at the time the patient agrees to participate in this study and it should be updated as needed.

REVISIONS: March 2005: these variables were added to the (local) database.
Systems are encouraged to add this information to the records of patients who are currently in the database.

VARIABLES Contact1Address1, Contact2Address1, Contact3Address1,
Contact1Address2, Contact2Address2, Contact3Address2

PERSONAL DATA

VARIABLE NAME: Address Lines 1 and 2 for Contact 1, Contact 2 and Contact 3

DESCRIPTION: Current addresses for 3 persons who may know the whereabouts of the patient.

CHARACTERS: 128 for each entry, 6 entries

CODES: **Any character**
Blanks are allowed

COMMENTS: These variables are not included on the Personal Data data collection form (and the data will never be exported to the NSCISC). This information resides only locally, on the System's computer.

This information should be obtained at the time the patient agrees to participate in this study and it should be updated as needed.

REVISIONS: March 2005: these variables were added to the (local) database.
Systems are encouraged to add this information to the records of patients who are currently in the database.

VARIABLES Contact1City, Contact2City, Contact3City

PERSONAL DATA

VARIABLE NAME: City of Residence for Contact 1, Contact 2 and Contact 3

DESCRIPTION: The Current City of Residence for 3 persons who may know the whereabouts of the patient.

CHARACTERS: 50 for each entry, 3 entries

CODES: **Any character**

Blanks are allowed

COMMENTS: These variables are not included on the Personal Data data collection form (and the data will never be exported to the NSCISC). This information resides only locally, on the System's computer.

This information should be obtained at the time the patient agrees to participate in this study and it should be updated as needed.

REVISIONS: March 2005: these variables were added to the (local) database.
Systems are encouraged to add this information to the records of patients who are currently in the database.

VARIABLES Contact1State, Contact2State, Contact3State

PERSONAL DATA

VARIABLE NAME: State of Residence for Contact 1, Contact 2, and Contact 3

DESCRIPTION: The Current State of Residence for 3 persons who may know the whereabouts of the patient.

CHARACTERS: 2 for each entry, 3 entries

CODES: **Any valid state abbreviation**

Blanks are allowed

COMMENTS: These variables are not included on the Personal Data data collection form (and the data will never be exported to the NSCISC). This information resides only locally, on the System's computer.

This information should be obtained at the time the patient agrees to participate in this study and it should be updated as needed.

REVISIONS: March 2005: these variables were added to the (local) database.
Systems are encouraged to add this information to the records of patients who are currently in the database.

VARIABLES Contact1Zip, Contact2Zip, Contact3Zip

PERSONAL DATA

VARIABLE NAME: Zip Code for Contact 1, Contact 2 and Contact 3

DESCRIPTION: The Current Zip Code of Residence for 3 persons who may know the whereabouts of the patient.

CHARACTERS: 5 for each entry, 3 entries

CODES: **Any valid zip code**

Blanks are allowed

COMMENTS: These variables are not included on the Personal Data data collection form (and the data will never be exported to the NSCISC). This information resides only locally, on the System's computer.

This information should be obtained at the time the patient agrees to participate in this study and it should be updated as needed.

REVISIONS: March 2005: these variables were added to the (local) database.

Systems are encouraged to add this information to the records of patients who are currently in the database.

VARIABLES Contact1ZipE, Contact2ZipE, Contact3ZipE

PERSONAL DATA

VARIABLE NAME: Extended Zip Code for Contact 1, Contact 2 and Contact 3

DESCRIPTION: This variable documents the extended zip codes for 3 persons who may know the whereabouts of the patient.

CHARACTERS: 4 for each entry, 3 entries

CODES: **Any valid extended zip code**

Blanks are allowed

VARIABLES Contact1Phone, Contact2phone, Contact3phone

PERSONAL DATA

VARIABLE NAME: Telephone Number for Contact 1, Contact 2 and Contact 3

DESCRIPTION: The Current Telephone Number for 3 persons who may know the whereabouts of the patient.

CHARACTERS: 25 for each entry, 3 entries

CODES: **Any valid telephone number**

Blanks are allowed

COMMENTS: These variables are not included on the Personal Data data collection form (and the data will never be exported to the NSCISC). This information resides only locally, on the System's computer.

This information should be obtained at the time the patient agrees to participate in this study and it should be updated as needed.

REVISIONS: March 2005: these variables were added to the (local) database. Systems are encouraged to add this information to the records of patients who are currently in the database.

VARIABLES Contact1LastUpdated, Contact2LastUpdated, Contact3LastUpdated

PERSONAL DATA

VARIABLE NAME: Last Date Information Entered for Contact 1, Contact 2 and Contact 3

DESCRIPTION: The date on which information was last entered for each contact person.

CHARACTERS: 10 for each entry, 3 entries

CODES: **Any valid date**

Blanks are allowed

COMMENTS: These variables are not included on the Personal Data data collection form (and the data will never be exported to the NSCISC). This information resides only locally, on the System's computer.

This information should be obtained at the time the patient agrees to participate in this study and it should be updated as needed.

REVISIONS: March 2005: these variables were added to the (local) database. Systems are encouraged to add this information to the records of patients who are currently in the database.

REGISTRY and FORM I

VARIABLE NAME: Date of Injury

DESCRIPTION: This variable specifies the date the spinal cord injury occurred.

CHARACTERS: 8

FORMAT: mmddyyyy

CODES: **Any valid date**

COMMENTS: Record the month, day and year of injury.

Unknowns or partial dates are not allowed in this variable.

EXAMPLE: The patient was injured on December 11, 1974.

V106. Date of Injury 1 2 / 1 1 / 1 9 7 4

REGISTRY and FORM I

VARIABLE NAME: Date of First System Admission

DESCRIPTION: This variable identifies the date of initial admission to the System.

CHARACTERS: 8

FORMAT: mmddyyyy

CODES: **Any valid date**

88888888 Not applicable, was never a System inpatient
NOT a valid code in Form Is with Indates after 03/31/2005

COMMENTS: Record the month, day and year. Unknowns are not allowed in this variable.

This date may be the admission to the System's acute medical, subacute medical, acute rehab or subacute rehab unit. However, to qualify for this database, the patient must receive System acute inpatient rehab [unless the patient expires or achieves full recovery or minimal deficit status while in the System's acute (or subacute) medical care unit].

If the patient was admitted directly to the System's inpatient rehab unit, use the same date in this variable as the date used in variable 108 (Date of First System Inpatient Rehab Admission).

This variable cannot be stored in date format since a non-valid date (code 88888888) was allowed in records with Indates up to March 31, 2005.

ELIGIBILITY: All patients must receive System inpatient acute rehab unless they expire or achieve complete recovery or minimal deficit status during system acute care.

REVISIONS: January 2005: All patients must be admitted to System acute rehab (unless they expire or achieve complete recovery or minimal deficit status during system acute care). Code 88888888 is not valid in Registry or Form I records with Indates after March 31, 2005.

FORM I

VARIABLE NAME: Date of First System Inpatient Rehab Admission

DESCRIPTION: This variable identifies the date of the first admission to the System's inpatient (acute or subacute) rehab unit.

CHARACTERS: 8

FORMAT: mmddyyyy

CODES: **Any valid date**

88888888 Not applicable, not admitted to System inpatient rehab unit

NOT a valid code in Form Is with Indates after 03/31/2005 unless the patient expired or achieved complete recovery or minimal deficit status during System acute care

COMMENTS: Record the month, day and year. Unknowns are not allowed in this variable.

For patients who are admitted to the System's acute (or subacute) rehab unit then transferred back to the System's acute (or subacute) medical/surgical unit followed by return to the System's acute (or subacute) rehab unit:

- V108 (Date of First System Inpatient Rehab Admission) = the first rehab admission date
- all variables to be collected "during rehab" document all that happened from the Date of First System Inpatient Rehab Admission to the Date of Discharge (V110) - even if the event occurred when the patient was back in the acute medical/surgical unit.
- For the Treatment Phase variables (V148-V155) – record each acute and each rehab admission as separate phases.

See example 3 on page 72.

This variable cannot be stored in date format since a non-valid date (code 88888888) is allowed.

ELIGIBILITY: All patients must receive System inpatient acute rehab unless they expire or achieve complete recovery or minimal deficit status during system acute care.

REVISIONS: January 2005: Code 88888888 is not valid in records with Indates after March 31, 2005 unless the patient expired or achieved complete recovery or minimal deficit status during System acute care.

FORM I

VARIABLE NAME: Date of First System Inpatient Rehab Admission

QC: If Indate1 > 03/31/2005 and <V110> not equal <V145> and <V131D> not equal 3, 6 or 7 THEN V108 must not = 88888888.

If the patient is not admitted to inpatient rehab then, Days from Injury to Rehab Admission, Neuro Exam, Mechanical Ventilation, Pressure Ulcers, Complications, Operative Procedures, FIM, and Length of Stay in Rehab must all be coded “Not Applicable, no inpatient rehab admission” AND

there must not be any “Inpatient Rehab” treatment phases that occurred in the System.

If this variable is coded 88888888 then, use the following codes for the listed items:

| Variable # | Variable Name (During Rehab or at Rehab Admit) | Codes | |
|--|--|----------|--------|
| | | Day-1 | Others |
| V109R | Number of Days from Injury to the First System Inpatient Acute Rehab Admission | 888 | 888 |
| 134RL, 134RR 135RL, 135RR 136RL, 136RR | Sensory Level Motor Level Level of Function, Left and Right | X99 | blank |
| 132R | ASIA Impairment Scale | U | blank |
| 133RT | ASIA Motor Index Score, Total | 999 | blank |
| 144AT, 144RT | FIM Totals | 99 | 99 |
| 133RR, 133RL 140R 142RB | ASIA Motor Index Score, Sub-totals Number of Ulcers, Rehab Episodes of Pneumonia, Rehab | 99 | blank |
| 130R | Date of the Neuro Exam | 88888888 | blank |
| 138R 144AA - 144RM | Mechanical Ventilation FIM items | 9 | 9 |
| 131R 133RA - 133RJ 139R_1-139R_27 141 142RA 142RC 142RD 143RA 143RB_1 143RC_1 143RD_1 143RE_1 143RF_1 143RG 143RH 143RI 143RJ 143RK | Category of Neuro Impairment ASIA Motor Index Score, C5-S1, Left and Right Location and Grade of Pressure Ulcers Grade of Worst Pressure Ulcer Post-op Wound Infection Pulmonary Embolism Thrombophlebitis, Deep Vein Thrombosis Laminectomy Spinal Decompression Spinal Fusion Internal Fixation of the Spine Surgical Repair of Failed Spinal Fusion Surg. Repair, Correction, or Rem. of Int. Fix. Device Number of OR Visits for Spine Surgeries Laparotomy Traction Halo Vest or Halo Brace or Other Orthosis for the Neck Closure of Decubitus Ulcer(s) | 9 | blank |
| 163R | Number of Days Hospitalized in Inpt. Rehab Unit | 8888 | 8888 |
| AND | no V148 can be coded “3” (with V149 = “1”) or no V148 can be coded “5” (with V149= ”1”). | | |

EXAMPLES: See examples beginning on [page 71](#).

REGISTRY and FORM I

VARIABLE NAME: Number of Days from Injury to First System Admission

DESCRIPTION: This variable documents the number of days from the date of injury (V106) to the Date of the First System Admission (V107).

This variable can be computer-generated by the NSCISC's software.

CHARACTERS: 3

CODES: **1-366 Valid range**

888 Not applicable, was not a System inpatient

NOT a valid code in Form Is with Indates after 03/31/2005

COMMENTS: All patients admitted to the System less than 24 hours of injury should be recorded as 1 day.

The code "0" is not acceptable. Code "1" should be interpreted to mean the patient was admitted to the reporting System during the first day following injury.

REVISIONS: October 2000: added to the Registry database.

SOFTWARE: During the PROCESS function, the computer calculates variable 109A using the dates in variables 106 and 107.

QC: See [page 65](#).

FORM I

VARIABLE NAME: Number of Days from Injury to the First System Inpatient Acute (or Subacute) Rehab Admission

DESCRIPTION: This variable documents the number of days from the date of injury (V106) to the first admission to the System's inpatient acute rehabilitation (V108) unit.

This variable can be computer-generated by the NSCISC's software.

CHARACTERS: 3

CODES: **1-366 Valid range**

888 Not applicable, not admitted to System inpatient rehab

NOT a valid code in Form Is with Indates after 03/31/2005 unless the patient expired, achieved complete recovery or minimal deficit status during System acute care

SOFTWARE: During the PROCESS function, the computer calculates variable 109R using the dates in variables 106 and 108.

QC: See [page 67](#).

REGISTRY and FORM I

VARIABLE NAME: Date of Discharge

DESCRIPTION: This variable identifies the date of discharge from the System. This is the date of completion of the System inpatient rehab process (or the date of death for patients who die during the initial hospitalization period).

This date may be

✓ discharge from the system's acute (or subacute) medical/surgical unit (only if the patient expires or achieves full recovery or minimal deficit status during acute care)

or

✓ discharge from the inpatient acute (or subacute) rehab unit at the completion of the System inpatient rehab process.

CHARACTERS: 8

FORMAT: mmddyyyy

CODES: **Any valid date**

88888888 Not applicable, was never a System inpatient

NOT a valid code in Form Is with Indates after 03/31/2005

COMMENTS: Record the month, day and year. Unknowns are not allowed in this variable.

If the patient expires during a System inpatient treatment phase, this date is the same as the Date of Death (variable 145).

This variable cannot be stored in date format since a non-valid date (code 88888888) was allowed in records with Indates up to March 31, 2005.

REGISTRY and FORM I

VARIABLE NAME: Date of Discharge

EXAMPLE 1: The patient was admitted to a non-System acute unit on October 10, 2000 and discharged on October 15, 2000. He was admitted to the System's acute rehab unit on October 17, 2000 and discharged on November 20, 2000.

| | | |
|------|--|------------|
| 107. | Date of Initial System Admission | 10/17/2000 |
| 108. | Date of Initial System Inpatient Rehab Admission | 10/17/2000 |
| 110. | Date of Discharge | 11/20/2000 |

| | | Treatment Phase # | |
|------|-------------------------------------|-------------------|------------|
| | | <u>1</u> | <u>2</u> |
| 148. | Treatment Phase | 1 | 3 |
| 149. | System or Non-system | 0 | 1 |
| 150. | Date of Admission | 10/10/2000 | 10/17/2000 |
| 151 | Date of Discharge | 10/15/2000 | 11/20/2000 |
| 152 | Number of Short-term Discharge Days | 0 | 0 |

EXAMPLE 2: The patient was admitted to a System acute unit on October 10, 2000. On October 15th he was discharged home with a halo with plans for him to return to the system to begin rehab. On October 25, 2000 he began inpatient acute rehab at the system from which he was discharged to a non-System inpatient subacute rehab unit on November 10, 2000.

On November 28, 2000 he was discharged from that unit and readmitted to the System inpatient acute rehab unit. He was discharged home on December 15, 2000.

| | | |
|------|--|------------|
| 107. | Date of First System Admission | 10/10/2000 |
| 108. | Date of First System Inpatient Rehab Admission | 10/25/2000 |
| 110. | Date of Discharge | 11/10/2000 |

| | | Treatment Phase # | |
|------|-------------------------------------|-------------------|------------|
| | | <u>1</u> | <u>2</u> |
| 148. | Treatment Phase | 1 | 3 |
| 149. | System or Non-system | 1 | 1 |
| 150. | Date of Admission | 10/10/2000 | 10/25/2000 |
| 151 | Date of Discharge | 10/15/2000 | 11/10/2000 |
| 152 | Number of Short-term Discharge Days | 0 | 0 |

REGISTRY and FORM I

VARIABLE NAME: Date of Discharge

EXAMPLE 3: The patient was admitted to the System acute unit on October 15, 2000 and he was he was transferred to the System's acute rehab unit October 25, 2000. Less than a week later (on October 30, 2000) he returned to the System's acute unit for treatment. He returned to the System's acute rehab unit on November 5, 2000, completed rehab and was discharged home on November 20, 2000.

| | | |
|------|--|------------|
| 107. | Date of Initial System Admission | 10/15/2000 |
| 108. | Date of Initial System Inpatient Rehab Admission | 10/25/2000 |
| 110. | Date of Discharge | 11/20/2000 |

| | | Treatment Phase # | | | |
|------|----------------------|-------------------|------------|------------|------------|
| | | <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> |
| 148. | Treatment Phase | 1 | 3 | 1 | 3 |
| 149. | System or Non-system | 1 | 1 | 1 | 1 |
| 150. | Date of Admission | 10/15/2000 | 10/25/2000 | 10/30/2000 | 11/05/2000 |
| 151. | Date of Discharge | 10/25/2000 | 10/30/2000 | 11/05/2000 | 11/20/2000 |

REGISTRY and FORM I

VARIABLE NAME: Age at Injury

DESCRIPTION: This variable specifies the age of the patient (in years) on the date the spinal cord injury occurred.

CHARACTERS: 3

CODES: **000 Newborn or less than 1 year of age**

000-120 Valid range

999 Unknown

REGISTRY and FORM I

VARIABLE NAME: Sex

DESCRIPTION: This variable specifies the sex of the patient.

CHARACTERS: 1

CODES: **1 Male**
 2 Female
 9 Unknown

REGISTRY and FORM I

VARIABLE NAME: Racial or Ethnic Group

DESCRIPTION: This variable specifies the patient's racial or ethnic group. There is no attempt to identify all mixed races.

CHARACTERS: 1

CODES:

| | |
|----------|--|
| 1 | Caucasian |
| 2 | African American |
| 3 | Native American, Eskimo, or Aleut |
| 4 | Asian or Pacific Islander |
| 5 | Other, unclassified |
| 9 | Unknown |

COMMENTS: The following Bureau of the Census guidelines will be used:

In the event of a mixed white and other race, the other race is used. In the event of mixed races other than white, the race of the father is used.

Asian/Pacific Islander includes Chinese, Filipino, Polynesian, Japanese, Thai, Asian, Indian, Oriental, Korean, Vietnamese, Hawaiian, Samoan and Guamanian.

If the racial group of the patient does not fit into any of the above classifications, document it as "Other, unclassified".

CONVERSIONS: When the Hispanic origin variable was added in November 1995 the records in the database at that time that were coded "4 - Spanish origin" in this variable were changed to code "9 Unknown". The code "1, Yes Hispanic origin" was then inserted in these records in the Hispanic origin variable.

REGISTRY and FORM I

VARIABLE NAME: Hispanic Origin

DESCRIPTION: This variable specifies if the patient is of Hispanic origin.

CHARACTERS: 1

CODES: **0 Not of Hispanic origin**
1 Hispanic origin (includes Mexican, Cuban, Puerto Rican and other Latin American and Spanish)
9 Unknown

COMMENTS: Persons of Hispanic origin may be of any race. In 1991, 91.3% of all persons of Hispanic origin in the United States were Caucasian, 5.4% were African American, 1.2% were American Indian and 2.1% were Asian/Pacific Islander.

REVISIONS: November 1995: This variable was added to the database using the Bureau of Census Guidelines.

FORM I

VARIABLE NAME: Is English the patient's primary language?

DESCRIPTION: This variable documents whether or not the patient's primary language is English.

CHARACTERS: 1

CODES: **0 Patient does not speak English**
1 Patient's primary language is English
2 Primary language is not English but, patient speaks and understands sufficient English for the interview
9 Unknown

COMMENTS: This variable documents the patient's use of the English language.

REVISIONS: February 1996: variable added to Form II.
October 2000: variable moved from Form II to Form I.

REGISTRY and FORM I

VARIABLE NAME: Traumatic Etiology

DESCRIPTION: This variable identifies the etiology of the trauma.

Traumatic spinal cord injury is impairment of the spinal cord or cauda equina function resulting from the application of an external force of any magnitude. The Model System's' National Spinal Cord Injury Database collects data on traumatic cases only.

CHARACTERS: 2

CODES: VEHICULAR

- 01 Auto accident: includes jeep, truck, dune buggy, and bus**
- 02 Motorcycle accident: 2-wheeled, motorized vehicles including mopeds and motorized dirt bikes**
- 04 Boat**
- 05 Fixed-wing aircraft**
- 06 Rotating wing aircraft**
- 07 Snowmobile**
- 08 Bicycle (includes tricycles and unicycles)**
- 09 All-terrain vehicle (ATV) and all-terrain cycle (ATC) - include both 3-wheeled and 4-wheeled vehicles**
- 03 Other vehicular, unclassified: includes tractor, bulldozer, go-cart, steamroller, train, road grader, forklift.**

If two vehicles are involved, the etiology should be coded according to the vehicle on which the patient was riding.

VIOLENCE

- 10 Gunshot wound**
- 11 All other penetrating wounds: Includes stabbing, impalement.**
- 12 Person-to-person contact: includes being hit with a blunt object, falls as a result of being pushed (as an act of violence)**
- 15 Explosion: includes that caused by bomb, grenade, dynamite, and gasoline**

Note: distinctions in falls (for codes 12 and 30) were made beginning in March 1996.

REGISTRY and FORM I

VARIABLE NAME: Traumatic Etiology

CODES: SPORTS/RECREATION

- 20 Diving**
- 21 Football**
- 22 Trampoline**
- 23 Snow skiing**
- 24 Water skiing**
- 26 Wrestling**
- 27 Baseball/softball**
- 28 Basketball/volleyball**
- 29 Surfing: includes body surfing**
- 70 Horseback riding**
- 71 Gymnastics: includes all gymnastic activities other than trampoline, break-dancing**
- 72 Rodeo: includes bronco/bull riding**
- 73 Track and field: includes pole vault, high jump, etc.**
- 74 Field sports: includes field hockey, lacrosse, soccer, and rugby**
- 75 Hang gliding**
- 76 Air sports: includes parachuting, para-sailing**
- 77 Winter sports: includes sled, snow tube, toboggan, ice hockey, snow boarding**
- 78 Skateboard**
- 25 Other sport, unclassified: includes auto racing, glider kite, slide, swimming, bungee jumping, scuba diving, roller blading, jet-skiing, cheerleading, etc.**

FALLS/FLYING OBJECTS

- 30 Fall: includes jumping and being pushed accidentally (not as an act of violence)**
- 31 Hit by falling/flying object: includes ditch cave in, avalanche, rockslide.**

PEDESTRIAN

- 40 Pedestrian (includes falling/jumping into the path of a vehicle)**

REGISTRY and FORM I

VARIABLE NAME: Traumatic Etiology

CODES: MEDICAL/SURGICAL COMPLICATION

50 Medical/surgical complication: Impairment of spinal cord function resulting from adverse effects of medical, surgical or diagnostic procedures and treatment for non-spinal cord conditions.

Examples are: spinal cord contusion during surgery, spinal cord arterial occlusion during angiography, overexposure to radiation, spinal cord hemorrhage resulting from over anticoagulation, hypoxia of the spinal cord from cardiac arrest during surgery, and hypoxia of the spinal cord from other medical complications such as pulmonary embolus, rupture of aortic aneurysm, hypovolemic shock, etc.

There are pathological medical conditions of the vertebral spinal column such as rheumatoid spondylitis, ankylosing spondylosis, severe osteoarthritis, spinal tumors, disc problems, Paget's disease, osteoporosis, etc., which predispose an individual to traumatic spinal cord injury. In some instances the trauma may be only slight or minimal. In such cases the etiology coded would be governed by the nature of the trauma, i.e., fall, auto accident

Do not include paralysis due to: a progressive disease with no traumatic event, herniated disc or transverse myelitis.

OTHER

60 Other unclassified: includes lightning, kicked by an animal, machinery accidents (excluding falls or hit by falling/flying objects).

UNKNOWN

99 Unknown

COMMENTS: If the patient's traumatic etiology does not fit into any of the above classifications, document it as "03" (Other vehicular, unclassified); "25" (Other sport, unclassified); or, "60" (Other, unclassified).

When there are questions of eligibility, it is the responsibility of the system's Project Director to make the decision (considering the criteria specified above and reviewing the patient's records).

FORM I

CHARACTERS: 5 for each entry (2 entries)
REVISIONS: January 2005: These fields are unused.

FORM I

VARIABLE NAME: External Cause of Injury

DESCRIPTION: This variable provides information on the classification of environmental events and circumstances as the cause of injury and other adverse effects.

CHARACTERS: 6

CODES: **V00-X58 Accidents**
Transport Accidents
 V00-V09 Pedestrian injured in transport accident
 V10-V19 Pedal cyclist injured in transport accident
 V20-V29 Motorcycle rider injured in transport accident
 V30-V39 Occupant of three-wheeled motor vehicle injured in transport accident
 V40-V49 Car occupant injured in transport accident
 V50-V59 Occupant of pick-up truck or van injured in transport accident
 V60-V69 Occupant of heavy transport vehicle injured in transport accident
 V70-V79 Bus occupant injured in transport accident
 V80-V89 Other land transport accidents
 V90-V94 Water transport accidents
 V95-V97 Air and space transport accidents
 V98-V99 Other and unspecified transport accidents
Other external causes of accidental injury
 W00-W19 Falls
 W20-W49 Exposure to inanimate mechanical forces
 W50-W64 Exposure to animate mechanical forces
 W65-W74 Accidental drowning and submersion
 W85-W99 Exposure to electric current, radiation and extreme ambient air temperature and pressure
 X00-X09 Exposure to smoke, fire, and flames
 X10-X19 Contact with heat and hot substances
 X30-X39 Exposure to forces of nature
 X52,X58 Accidental exposure to other specified factors
X71-X83 Intentional self-harm
X92-Y08 Assault
Y21-Y33 Event of undetermined intent
Y35-Y38 Legal intervention, operations of war, military operations, and terrorism
Y62-Y69 Misadventures to patients during surgical and medical care
Y70-Y82 Medical devices associated with adverse incidents in diagnostic and therapeutic use
Y83-Y84 Surgical and other medical procedures as the cause of abnormal reaction of the patient, or of later complication, without mention of misadventure at the time of the procedure
999.999 Unknown

COMMENTS: See Appendix C (beginning on page C10) for the complete listing of codes.

This variable should be coded as specific as possible. If you only have limited information as to how the person was injured, the software will accept partial codes. At minimum, the first 3 spaces should be completed.

The software will accept the following coding variations:

- V00._ _ _
- V00.0 _ _
- V00.00 _
- V00.000

SOURCE: International Classification of Diseases (ICD-10CM) pre-release version.

QC: See information below.

| <u>IF V118_1 is coded</u> | then | <u>V116 must be coded</u> |
|---------------------------|------|---------------------------|
| V00 to V09 | | 40 |
| V10 to V19 | | 08 |
| V20 to V29 | | 02 |
| V30 to V39 | | 09 |
| V40 to V59 | | 01 |
| V60 to V69 | | 03 |
| V70 to V79 | | 01 |
| V80 to V89 | | 03 |
| V90 to V94 | | 24, 25, or 29 |
| V95 | | 05 or 06 |
| V96 | | 25, 75, or 76 |
| V97 | | 25, 76, or 60 |
| V98 to V99 | | 03 |
| W00 to W19 | | 30 or 31 |
| W20 to W22 | | 12 or 31 |

| | |
|------------------|-------------------|
| W23 to W25 | 60 |
| W26..... | 11 |
| W27 to W31 | 60 |
| W32 to W34 | 30 |
| W35 to W40 | 15 |
| W42..... | 60 |
| W45 to W49 | 60 |
| W94..... | 60 |
| X34 to X37 | 60 |
| X52, X58..... | 60 |
| X72 to X74 | 80 |
| X75 | 15 |
| X78 | 11 |
| X79 | 12 |
| X80 | 30 |
| X81 | 40 |
| X82 | 01 |
| X83 | 60 |
| X93 to X95 | 10 |
| X96 | 15 |
| X99 | 11 |
| Y00 to Y05 | 12 |
| Y08 | 12 |
| Y22 to Y24 | 10 |
| Y25 | 15 |
| Y28 | 11 |
| Y29 | 12 |
| Y30-Y31 | 12, 30, 31, or 40 |
| Y32 | 01 |
| Y33 | 60 |
| Y62 to Y84 | 50 |

REVISIONS: This variable was activated in April 2005. Data collection began in August 2005.

EXAMPLE 1:

An individual is hit by a car while running an errand on skateboard.

V116 = '40, Pedestrian'

V118_1 = 'V03.12, Pedestrian on skateboard injured in collision with car, pick-up truck, or van in traffic accident'

When coding V118_1 please adhere to the broad topic:

In this case, V116 should be coded as "40, pedestrian" unless it is indicated that the individual was participating in skateboarding as a sport.

EXAMPLE 2:

An individual is skateboarding in a skate park, and collides with a wall or other stationary object.

V116 = '78, Skateboard'

V118_1 = 'V00.132, Skateboarder colliding with stationary object'

*Remember when coding this variable, be as specific as possible.

FORM I

VARIABLE NAME: SCI Nature of Injury

DESCRIPTION: This variable documents the type and level of spinal cord injury at the time of discharge.

CHARACTERS: 6

CODES:

| S14.--- | | C1 | C2 | C3 | C4 | C5 | C6 | C7 | C8 | Cervical Level Unspec. |
|-------------------------|-------------|-----|-----|-----|-----|-----|-----|-----|-----|------------------------|
| | Unspecified | 101 | 102 | 103 | 104 | 105 | 106 | 107 | 108 | 109 |
| Complete | 111 | 112 | 113 | 114 | 115 | 116 | 117 | 118 | 119 | |
| Central Cord | 121 | 122 | 123 | 124 | 125 | 126 | 127 | 128 | 129 | |
| Anterior Cord | 131 | 132 | 133 | 134 | 135 | 136 | 137 | 138 | 139 | |
| Brown-Sequard | 141 | 142 | 143 | 144 | 145 | 146 | 147 | 148 | 149 | |
| Other Incomplete Lesion | 151 | 152 | 153 | 154 | 155 | 156 | 157 | 158 | 159 | |

| S24.--- | | T1 | T2-T6 | T7-T10 | T11-T12 | Thoracic Level Unspec. |
|-------------------------|-------------|-----|-------|--------|---------|------------------------|
| | Unspecified | 101 | 102 | 103 | 104 | 109 |
| Complete | 111 | 112 | 113 | 114 | 119 | |
| Anterior Cord | 131 | 132 | 133 | 134 | 139 | |
| Brown-Sequard | 141 | 142 | 143 | 144 | 149 | |
| Other Incomplete Lesion | 151 | 152 | 153 | 154 | 159 | |

| S34.--- | | L1 | L2 | L3 | L4 | L5 | Lumbar Level Unspec. | Sacral |
|------------|-------------|-----|-----|-----|-----|-----|----------------------|--------|
| | Unspecified | 101 | 102 | 103 | 104 | 105 | 109 | 139 |
| Complete | 111 | 112 | 113 | 114 | 115 | 119 | 131 | |
| Incomplete | 121 | 122 | 123 | 124 | 125 | 129 | 132 | |

| | |
|----------------|-----------------------------------|
| S34.000 | Injury of the Cauda Equina |
|----------------|-----------------------------------|

COMMENTS: This variable is a combination of information from the Category of Neurologic Impairment (V131D), ASIA Impairment Scale (V132D), and Level of Preserved of Neurologic Impairment (V136D) variables. When the right and left sides of the level variable differ, always use the information from the higher side. (i.e. if V136DL = C07 and V136DR = C06, you should choose C06 to code V118_2)

QC: See information below.

| <u>If V131D</u> | <u>AND</u> | <u>V132D</u> | <u>AND</u> | <u>V136DR</u> | <u>AND/OR</u> | <u>V136DL</u> | <u>THEN</u> | <u>V118_2</u> must = |
|-----------------|------------|--------------|------------|---------------|---------------|---------------|-------------|---------------------------------------|
| 1 | | B | | T01 to T12 | | | | S24.131 to S24.154 |
| 1 | | B | | T99 | | | | S24.139, S24.149, or S24.159 |
| 1 | | B | | L01 to L05 | | | | S34.121 to S34.125 |
| 1 | | B | | L99 | | | | S34.129 |
| 1 | | B | | S01 to S05 | | | | S34.132 |
| 1 | | B | | S99 | | | | S34.132 |
| 2 | | A | | T01 to T12 | | | | S24.111 to S24.114 |
| 2 | | A | | T99 | | | | S24.119 |
| 2 | | A | | L01 to L05 | | | | S34.111 to S34.115 |
| 2 | | A | | L99 | | | | S34.119 |
| 2 | | A | | S01 to S05 | | | | S34.131 |
| 2 | | A | | S99 | | | | S34.131 |
| 4 | | B | | C01 to C08 | | | | S14.121 to S14.158 |
| 4 | | B | | C99 | | | | S14.129, S14.139, S14.149, or S14.159 |
| 5 | | A | | C01 to C08 | | | | S14.111 to S14.118 |
| 5 | | A | | C99 | | | | S14.119 |
| 9 | | U | | C99 | | | | S14.109 |
| 9 | | U | | T99 | | | | S24.109 |
| 9 | | U | | L99 | | | | S34.109 |
| 9 | | U | | S99 | | | | S34.139 |

NOTE: If the medical records do not state the type of injury (Central Cord, Anterior Cord, etc) code this variable according to the level of injury, unspecified.

SOURCE: International Classification of Diseases (ICD-10CM) pre-release version.

REVISIONS: This variable was activated in April 2005. Data collection began in August 2005.

EXAMPLES: See QC information.

Blank page

FORM I

VARIABLE NAME: Work Relatedness

DESCRIPTION: This variable specifies whether the spinal cord injury occurred in the course of employment.

CHARACTERS: 1

CODES: **0 No**
1 Yes
9 Unknown

COMMENTS: If the Sponsor is Worker's Compensation, assume the injury was work-related.

If medical records or other injury reports contain additional information pertaining to work-relatedness, the "Operational Guidelines for Determination of Injury at Work" developed jointly by the Association for Vital Records and Health Statistics and CDC, should be used to code this variable. The guidelines may be found on the next page.

If Worker's Compensation is not listed as a hospital payment source and if no other information regarding work-relatedness is available, use the unknown code (code 9).

REVISIONS: October 2000: This variable was added to the database.

FORM I

VARIABLE NAME: WORK RELATEDNESS

Operational Guidelines for Determination of Injury at Work

Consider possibility of work injury regardless of whether injury occurred in the course of work in "usual" or other occupation and/or industry. If the patient's "usual" occupation is housewife, student, or retired consider possible injury during other employment. If occupation is transportation-related, suspect injury at work and evaluate per criteria.

Consider available information with regard to location and activity at time of injury. If location is farm, suspect work-related and evaluate per criteria.

| Criteria | INJURY AT WORK | |
|--|----------------|----|
| | Yes | No |
| On Employer Premises | | |
| • Engaged in work activity, apprentice, vocational training | ✓ | |
| • On break; in hallways, rest room, cafeteria, storage area | ✓ | |
| • In employer parking lots while working, arriving, or leaving | ✓ | |
| • Engaged in recreational activities on employer controlled facilities (games, etc.) for personal enjoyment | | ✓ |
| • As a visitor for non-work purposes, not on official business | | ✓ |
| Off Employer Premises | | |
| • Working for pay or compensation, including at home | ✓ | |
| • Working as a volunteer EMS, firefighter, or law enforcement officer | ✓ | |
| • Working in family business, including family farm. Activity should be clearly related to a profit-oriented business. | ✓ | |
| • Traveling on business, including to and from customer/business contacts | ✓ | |
| • Engaged in work activity where vehicle is considered the work environment (e.g., taxi driver, truck driver, etc.) | ✓ | |
| • Homemaker working at homemaking activities | | ✓ |
| • Working for self-non profit, i.e., mowing lawn, repairing own roof, hobby, or recreation activities | | ✓ |
| • Student engaged in school activities | | ✓ |
| • Operating vehicle (personal or commercial) for non-work purposes | | ✓ |
| • Commuting to or from work site | | ✓ |

SOURCE: These guidelines were developed jointly by: The Association for Vital Records and Health Statistics (AVRHS) and the Centers for Disease Control (CDC).

EXAMPLE: The person was injured in a motor vehicle crash while working.

V119. Work Relatedness

FORM I and FORM II

VARIABLE NAME: Place of Residence

DESCRIPTION: This variable specifies where the patient is actually residing

- 1) **at the time of injury** (V120I)
- 2) **at discharge from the System** (V120D) and,
- 3) **on the anniversary date being reported** (V203).

This place may not necessarily coincide with the patient's legal residence.

CHARACTERS: 2 for each entry

- CODES:
- 01 Private Residence:** includes house, apartment, hogan, mobile home, foster home, condominium, boat, individual residence in a retirement village
 - 02 Hospital:** includes mental hospital, hospital in a retirement village
 - 03 Nursing Home:** includes medi-center, skilled nursing facilities, institutions licensed as hospitals but providing essentially long-term, custodial, chronic disease care, assisted living unit in a retirement village, etc.
 - 04 Group Living Situation:** includes transitional living facility, dormitory (school, church, college), military barracks, boarding school, boarding home, bunkhouse, boys' ranch, fraternity/sorority house, labor camp, commune, shelter, convent, monastery, or other religious order residence, etc.
 - 05 Correctional Institution:** includes prison, penitentiary, jail, correctional center, etc.
 - 06 Hotel/motel:** includes YWCA, YMCA, guest ranch, inn
 - 07 Deceased** (*valid in V120D only*)
 - 08 Other, unclassified**
 - 09 Homeless:** cave, car, tent, etc.
 - 99 Unknown**

Blank (*on Form II - only if V201 = "5"*)

FORM I and FORM II

VARIABLE NAME: Place of Residence

COMMENTS: If the patient's place of residence does not fit into any of the above classifications, document it as "Other, unclassified". "Hospital" should not be used in the case of a patient who is temporarily rehospitalized on his anniversary.

Variable 120D documents place of residence at discharge from initial hospitalization.

If, at the time of discharge from the System, the patient is transferred and admitted to a hospital for custodial care only, use code "3" (Nursing home). Do NOT use Nursing Home if the stay is temporary.

REVISIONS: November 1995: Residence at time of injury and code 09 for homeless were added. Cave, car and tent were moved from code 01 to code 09.

October 2000: *convent, monastery, or other religious order residence* were added to code "4". *Collection at discharge* was changed to *at discharge or end of last System or non-System outpatient treatment phase*.

January 2005: *Collection at discharge or end of last System or non-System outpatient treatment phase* was changed back to *at discharge*.

CONVERSIONS: In January 1985: the category *deceased* (old code "7") **on Form II** was deleted. Form II records using old code "7" now contain code "99".

FORM I and FORM II

VARIABLE NAME: Marital Status

DESCRIPTION: This variable specifies the patient's marital status
 1) **at the time of the spinal cord injury** (V121) and
 2) **on the anniversary date being reported** (V204).

CHARACTERS: 1 for each entry

CODES:

- 1 Single:** a person who has never married
- 2 Married:** a person who is legally married
- 3 Divorced:** a person who is legally divorced
- 4 Separated:** includes both legal separations and living apart from a married partner
- 5 Widowed**
- 6 Other, unclassified**
- 9 Unknown**

Blank (on Form II - only if V201 = "5")

COMMENTS: Common-law marriages should be ignored. Code the marital status as if the common-law marriage did not exist. Disregard "living with" situations.

If the patient's marital status does not fit into any of the above classifications, document it as "Other, unclassified".

QC: When a patient = "1" (*single, never married*) on a Form II, V121 (Marital Status at Injury) and all previous V204's should be coded "1" (*single, never married*).

REVISIONS: October 2000: Marital Status at Discharge was deleted.

EXAMPLE: The patient is being interviewed for his year 01 anniversary. He was married at the time of injury but is now separated.

121. Marital Status at Injury.....2
 204. Marital Status on Year 01 Anniversary.....4
 209. Change in Marital Status since last Form II (or since Form I for anniversary year 01).....0

There was no legal change in marital status since the patient was only separated (not legally divorced)

FORM I and FORM II

VARIABLE NAME: Highest Formal Educational Level Completed

DESCRIPTION: This variable specifies the highest formal educational level completed

- 1) **at the time of injury** (V122) and
- 2) **on the anniversary date being reported** (V205).

This is level completed and does not include partial completion.

This variable does not include trade or technical schools.

CHARACTERS: 1 for each entry

- CODES:
- 1 8th grade or less** (includes pre-school)
 - 2 9th through 11th grade**
 - 3 High School Diploma or G.E.D.**
 - 4 Associate Degree** (A.A. - Junior College Degree)
 - 5 Bachelors Degree**
 - 6 Masters Degree**
 - 7 Doctorate:** includes Ph.D., M.D., law degrees, etc.
 - 8 Other, unclassified:** includes 3-year nursing degree, special education
 - 9 Unknown**

Blank (on Form II - only if V201 = "5")

COMMENTS: If a person has 2 or more degrees, report the highest degree achieved.

If the patient's educational level completed does not fit into any of the above classifications, document it as "Other, unclassified."

EXAMPLE 1: At the time of injury, the patient had a Bachelor of Science degree and was working on a masters in public health.

V122. Level of Education..... 5

EXAMPLE 2: On her 5th anniversary of injury, the patient had an associate degree and a Bachelor's degree.

V205. Level of Education..... 5

FORM I and FORM II

VARIABLE NAME: Primary Occupational, Educational or Training Status

DESCRIPTION: This variable specifies the primary occupational, educational or training status of the patient

- 1) **at the time of injury** (V123) and,
- 2) **on the anniversary date being reported** (V206).

Since these sub-categories are not mutually exclusive, the primary occupational, educational or training status should be selected **on the basis of the injured person's opinion as to what was primary.**

CHARACTERS: 1 for each entry

- CODES:
- 1 Working** - competitive labor market: includes military (gainfully and legally employed)
 - 2 Homemaker**
 - 3 On-the-job training**
 - 4 Sheltered workshop**
 - 5 Retired**
 - 6 Student (includes pre-school)**
 - 7 Unemployed**
 - 8 Other, unclassified:** includes volunteer, disability or medical leave
 - 9 Unknown**

Blank (on Form II - only if V201 = "5")

COMMENTS: If the patient's primary occupational, educational, or training status does not fit into any of the above classifications, document it as "Other, unclassified".

QC: If V123 = "1" (*working*) then, V124 must not = "88" (*not applicable, not working*).

EXAMPLE 1: At the time of injury, the patient was a college student who worked 30 hours a week as a waitress. The patient considered herself a "student".

V123. Primary Occupational, Ed or Training Status 6
 V124. Job Census Code 88

EXAMPLE 2: At the time of injury, the patient was a college student who worked 30 hours a week as a stock clerk. The patient considered himself as "working".

V123. Primary Occupational, Ed or Training Status 1
 V124. Job Census Code 05

FORM I and FORM II

VARIABLE NAME: Job Census Code

DESCRIPTION: This variable specifies the major census occupational category for the patient's occupation:

- 1) **at the time of injury** (V124) and
- 2) **on the anniversary date being reported** (V207).

CHARACTERS: 2 for each entry

CODES:

| | |
|--------------|--|
| 01 | Executive, administrative, and managerial |
| 02 | Professional specialty |
| 03 | Technicians and related support |
| 04 | Sales |
| 05 | Administrative support including clerical |
| 06 | Private household |
| 07 | Protective service |
| 08 | Service, except protective and household |
| 09 | Farming, forestry, and fishing |
| 10 | Precision production, craft, and repair |
| 11 | Machine operators, assemblers, and inspectors |
| 12 | Transportation and material moving |
| 13 | Handlers, equipment cleaners, helpers, and laborers |
| 14 | Military occupations |
| 88 | Not applicable, not working |
| 99 | Unknown |
| Blank | <i>(on Form II - only if V201 = "5")</i> |

COMMENTS: Refer to Appendix C of this syllabus for a listing of the specific occupational classifications included under each major occupational category listed above. If the patient is working (even if "working" is not the primary occupation coded in V123), code the job in this variable.

SOURCE: 1990 Occupational Classification System, Alphabetical Index of Industries and Occupations, 1990 Census of Population and Housing, Bureau of the Census, U.S. Department of Commerce. A complete listing is available at this web site: www.stats.bls.gov/soc/soc_home.htm.

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

EXAMPLE: See [page 89](#).

FORM I

VARIABLE NAME: Are You a Veteran of the U.S. Military Forces?

DESCRIPTION: This variable documents whether or not the patient is a veteran of the United States military forces (i.e., Air Force, Army, Coast Guard, Marine Corp and Navy).

CHARACTERS: 1

CODES: **0 No**
1 Yes, service-connected for traumatic spinal cord injury
2 Yes, service-connected for a condition other than spinal cord injury
3 Yes, non-service connected veteran
4 Yes, service connection unknown
9 Unknown

COMMENTS: A “service-connected” veteran is one receiving financial compensation for the “loss of, or loss of use of” an anatomical, sensory or mental condition incurred or resulting from their military service. A “non-service connected” veteran is one not receiving compensation, but may be receiving health care benefits (typically due to low income). These terms are similar to a “workman’s compensation” system.

A reservist who never served on active duty (“serving” means more than just training time) is NOT considered a veteran.

A reservist who is (1) "called up" to active duty or is (2) engaged in active duty military training and is hurt or injured during that period is considered a veteran.

An active duty military personnel who concludes his or her career with time in the reserves is considered a veteran.

If the patient is a veteran, document services received in variables 126 and 210.

QC: If this variable = “0” then, V126_1 and all V210_1’s must = “8” and vice versa.

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

EXAMPLES: See [page 93](#).

FORM I and FORM II

VARIABLE NAME: Veterans' Administration Healthcare System Services Used

DESCRIPTION: This variable documents the healthcare system services received if the patient is a veteran of the U.S. military forces. Document services received:

1) **during System** (V126_1 to V126_5)

and

2) **since the last Form II** (V210_1 to V210_5).

See [page 95](#) for the definition of **during System**.

On Form II, this variable documents VA services received since the last Form II with known VA services data. When coding the year 01 Form II, this variable documents the VA services received since the spinal cord injury.

CHARACTERS: 1 for each entry (up to 5 entries for V126 and V210)

CODES:

- 0 None** (*Valid in coding position #1 only*)
- 1 Pharmacy**
- 2 Prosthetics, orthotics, wheelchairs**
- 3 SCI center** (*VA hospital with an SCI center*)
- 4 Non-SCI center** (*VA hospital without an SCI center*)
- 5 SCI outpatient clinic**
- 8 Not applicable (not a veteran)** (*Valid in coding position #1 only*)
- 9 Unknown** (*Valid in coding position #1 only*)

Blank (*on Form II - only if V201 = "5"*)

COMMENTS: Document up to 5 different services used during the data collection period being reported. Codes 0, 8 and 9 are allowed only in coding position #1. When one of these codes is entered in coding position #1, no codes are allowed in coding positions 2 to 5. For services such as psychiatric counseling, code the facility in which the services were received (i.e., SCI center, non-SCI center and/or SCI outpatient clinic).

When asking the patient this question, the interviewer will need to cue the patient concerning the appropriate time period. For example, if data are being collected for year 10 and the patient has Form IIs for years 5 and 1 but VA Services was unknown in year 5, the interviewer should ask for the services received since year 1. See [example # 3 on page 93](#).

FORM I and FORM II

VARIABLE NAME: Sponsors of SCI Care and Services

DESCRIPTION: This variable documents sponsors who have contributed towards the payment of

- 1) **expenses during System** (V127_1 through V127_5) and
- 2) **on-going care for the spinal cord injured patient during the anniversary year being reported** (V214_1 through V214_5).

This care includes hospitalization, outpatient medical and rehabilitation services, vocational rehabilitation, education, training, equipment, medications and supplies, attendant care and custodial care. It does not include income maintenance. Record all sponsors who have contributed to the above. For variable 214, document all sponsors available for ongoing care.

In position 1 code the Primary Sponsor (i.e., the sponsor contributing the largest proportion of support).

CHARACTERS: 2 for each entry (up to 5 entries for V127 and V214)

CODES:

- 01 Private Insurance**
- 02 Department of Vocational Rehab (DVR)**
- 03 Medicaid** [including Medicaid administered by another sponsor (e.g. an HMO); see [page 95](#)]
- 04 Worker's Compensation**
- 05 Medicare** [including Medicare administered by another sponsor (e.g. an HMO); see [page 95](#)]
- 06 County medical**
- *07 Self-pay - personal funds**
- 08 Veterans Administration**
- 09 Public Health Service** (e.g., Bureau of Indian Affairs)
- 10 Crippled Children's Service**
- *11 No Pay** (*indigent, no resources*)
- 12 Other insurance, unclassified: includes Champus/Tricare**
- 13 Other private funds** (e.g., hometown fund raisers)
- 14 Prepaid health plans:** *includes HMOs, PPOs, Kaiser Foundation, etc.*
- 15 Other, unclassified** (e.g., SCI system patient care funds, Homebound, victim's assistance funds, etc.)
- 99 Unknown**
- Blank** (*on Form II - only if V201 = "5"*)

* valid in Primary Sponsor position only and, no other codes are allowed

FORM I and FORM II

VARIABLE NAME: Sponsors of SCI Care and Services

COMMENTS: **During System** is the time between the first System admission and discharge from the last System inpatient treatment phase.

Do not include sources of support received prior to initial admission to the System. If the sponsor is any other than those listed on the previous page, document it as "Other, unclassified."

Self-pay (code 07) should be used only if there are no other sponsors. This code should be used for those who have no coverage but are expected to pay the bill because they have personal resources. When this is the case, put code 07 in coding position #1 and, leave all other coding positions blank.

No Pay (code 11) should be used only if there are no sponsors and the patient did not pay for anything. Code 11 must be in coding position #1 and, all other coding positions must be blank.

When Medicaid or Medicare is administered through another sponsor (e.g., an HMO) use the Medicaid or Medicare code (03 or 05, respectively). Code the sponsor that administers the Medicaid or Medicare only if that sponsor also contributed towards the payment of expenses.

When Blue Cross is administered by an HMO, use Private Insurance (code 01). For the Type of Reimbursement (V128/V215):

> if the provider is part of the HMO, then code 6 (capitated) would typically apply

> if the provider is not part of the HMO, then it will probably be code 2 (approved fee for service) or code 4 (limited per diem) depending on the terms of the contract between the HMO and the patient with a larger than usual deductible/copayment that the patient may be responsible for paying.

QC: If the Sponsor variable = "11", then Type of Reimbursement must = "0" and Medical Case Manager must = "8".

If the Sponsor variable = "07", then Type of Reimbursement must = "1" and Medical Case Manager must = "8".

REVISIONS: Beginning in 1987 coding position #1 was designated for the Primary Sponsor. For most records in existence at that time, all codes were moved down one position and the unknown code ("99") was inserted in coding position #1. At that time, there were no records containing codes for 5 sponsors.

FORM I

VARIABLE NAME: Type of Reimbursement

DESCRIPTION: This variable documents the type of reimbursement plan of every sponsor providing coverage

during System (V128_1 to V128_5)

Code all reimbursement plans for all sponsors documented in variable 127.

CHARACTERS: 1 for each entry (up to 5 entries)

CODES:

- 0 Indigent** - no payment is anticipated.
- 1 Charges** - Includes self-pay and other situations when all charges are reimbursable.
- 2 Approved Fee for Service** - Reimbursement is based on usual and customary charges in the community for services rendered (e.g. Blue Cross/Blue Shield).
- 3 Unlimited Per Diem.** - Reimbursement is based on a fixed amount per day hospitalized for the entire length of hospitalization.
- 4 Limited Per Diem** - Reimbursement is based on a fixed amount per day hospitalized and is limited to a certain number of days. Medicare is in this category.
- 5 Negotiated Fee Schedule** - Each service has a fixed negotiated fee that the provider knows in advance and that may vary from one provider to another.
- 6 Capitated Reimbursement** - A lump sum fixed amount is paid to the provider each month or year for each member covered by the plan regardless of whether any services are provided to that member. The provider is obligated to provide all necessary care to each member of the plan (includes HMOs and PPOs).
- 7 Other**
- 9 Unknown**

COMMENTS: Code all reimbursement mechanisms that apply for each sponsor. This information is available through the hospital admissions/billing office, the responsible third party, the social worker, case managers, face sheet and sometimes in the physician's notes (i.e., contact info between the physician and the case manager). Medicare is code 4 (limited per diem); Medicaid rules vary by state.

See [page 95](#) for the definition of **during System**.

REVISIONS: November 1995: variable was added to the database.
February 1996: coding scheme was expanded.
July 2001: the Form II variable (V215) was deleted.

QC: See [page 95](#).

FORM I and FORM II

VARIABLE NAME: Medical Case Manager

DESCRIPTION: This variable documents whether the patient's primary financial sponsor of care has assigned a medical case manager to handle the patient's case:

- 1) **during System** (V129) and
- 2) **during the anniversary year being reported** (V216)

CHARACTERS: 1 for each entry

CODES:

- 0** No medical case manager affiliated with the primary sponsor of care
- 1** Yes, a medical case manager has been assigned by the primary sponsor of care
- 8** Not applicable - there is no financial sponsor of care, the patient is either self-pay or indigent
- 9** Unknown
- Blank** (on Form II - only if V201 = "5")

COMMENTS: This variable refers only to the primary sponsor of care identified in the Sponsors of Care variable.

This information is available from the hospital's billing office.

This is not the hospital's case manager.

See [page 95](#) for the definition of **during System**.

REVISIONS: November 1995: this variable was added to the database.

QC: See [page 95](#).

FORM I

VARIABLE NAME: Dates of the Neurologic Examinations

DESCRIPTION: These variables document the dates on which the neurologic examinations were performed:

- 1) **initial system examination (for day-1 admissions only)** (V130A)
- 2) **admission to System inpatient rehab (for day-1 admissions only)** (V130R) and
- 3) **at discharge (for all patients)** (V130D).

Although the initial system exam should be performed within 72 hours of system admission, data for exams performed later than that are included in the database.

The neurologic exam consists of the items documented in variables 131 through 136 and must be performed by a physician or a designated person who has been trained using the guidelines in the latest version of the International Standards for Neurological Classification of Spinal Cord Injury, published by the American Spinal Injury Association (ASIA).

CHARACTERS: 8 for each entry

FORMAT: mmddyyyy

CODES: **Any valid date**

88888888 **Not Done** (V130A, V130R, V130D)

OR

*** Not applicable, not admitted to inpatient rehab**
(V130R)

99999999 **Unknown**

Blank *For non day-1 admissions (in V130A and V130R only)*

* For Form Is newly entered (i.e., with Indates) after 03/31/2005 the ***Not applicable, not admitted to inpatient rehab*** code is allowed only for patients who expire or achieve complete recovery or minimal deficit status during System acute care.

FORM I

VARIABLE NAME: Dates of the Neurologic Examinations

COMMENTS: Record the month, day and year. Partial unknown dates (i.e., unknown in the month, day or year) are not allowed in this variable. Use the unknown code (“99999999”) when it is not known if there was a neurologic exam. When parts of the exam are done on different dates, the date of the exam should be the day on which most parts of the exam were done.

When the patient is not fully testable: When a key sensory point or key muscle is not testable for any reason, the examiner should record the neurologic exam as “not done”. In such cases, sensory and motor scores for the affected side of the body, as well as total sensory and motor scores, cannot be generated with respect to the injury at that point in treatment. Further, when associated injuries (e.g., traumatic brain injury, brachial plexus injury, limb fracture, etc., interfere with the completion of the neurological examination, the neurological level should still be determined as accurately as possible. However, obtaining the sensory/motor scores and impairment grades should be deferred to later examinations.

This variable cannot be stored in date format since non-valid dates (codes “88888888” and “99999999”) are allowed.

REVISIONS: November 1995: dates at system admission and discharge were added to the database and data was required of patients who are admitted to the system on or after December 1, 1995.

October 2000: date at rehab admission was added. Neuro exam items at rehab admission (except ASIA Motor Index Score) were also added. Data are required for patients admitted to the System after 10/31/2000.

January 2005: Code 88888888 may be used if the Neuro Exam was *Not Done*. It may also be used for *Not applicable, not admitted to inpatient rehab* only for patients who expire, or achieve complete recovery or minimal deficit status during System acute care.

QC: If variable 130A= “88888888”, variables 131A through 136A should = *Unknown*. If variable 130R = ‘88888888’, variables 131R through 136R should = *Unknown*. If variable 130D = “88888888”, variables 131D through 136D should = *Unknown*.

REGISTRY, FORM I and FORM II

VARIABLE NAME: Category of Neurologic Impairment

DESCRIPTION: This variable documents the degree of neurologic damage present:

- 1) **at initial system examination (for day-1 admissions only)** (V131A)
- 2) **at admission to inpatient rehab (for day-1 admissions only)** (V131R)
- 3) **at discharge (for all patients)** (V131D) and
- 4) **on the date of the year 01 (or year 02, see [page 16](#)) examination** (V244).

The neurologic exam must be performed by a physician or a designated person who has been trained using the guidelines in the latest version of the International Standards for Neurological Classification of Spinal Cord Injury, published by the American Spinal Injury Association (ASIA).

CHARACTERS: 1 for each entry

CODES:

- 1 Paraplegia, incomplete**
- 2 Paraplegia, complete**
- 3 Paraplegia, minimal deficit** (see [page 101](#))
- 4 Tetraplegia, incomplete**
- 5 Tetraplegia, complete**
- 6 Tetraplegia, minimal deficit** (see [page 101](#))
- 7 Normal neurologic** (see [page 101](#))
- 8 Normal neurologic, minimal neurologic deficit** (code "5" prior to 10/15/87) This is a CONVERSION CODE ONLY. Data collectors may NOT use this code. This information is provided for data analyses purposes only.
- 9 Unknown** (V131A, V131R, V131D, V224);
Not admitted to System inpatient rehab (V131R) See note on page 98 for Form Is entered after 03/31/2005.

Blank (on Form I - for non day-1 admissions in V131A and V131R only)

Blank (on Form II - only if V201 = "5")

COMMENTS: Paraplegia is impairment or loss of motor and/or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord secondary to damage of neural elements within the spinal canal. With paraplegia, arm functioning is spared, but, depending on the level of injury, the trunk, legs and pelvic organs may be involved. The term is used in referring to cauda equina and conus medullaris injuries, but not to lumbosacral plexus lesions or injury to peripheral nerves outside the neural canal.

Tetraplegia (preferred to *quadriplegia*) is impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord due to damage of neural elements within the spinal canal. Tetraplegia results in impairment of function in the arms as well as in the trunk, legs and pelvic organs. It does not include brachial plexus lesions or injury to peripheral nerves outside the neural canal.

Complete injury means an absence of sensory and motor function in the lowest sacral segment.

REGISTRY, FORM I and FORM II

COMMENTS: Incomplete injury means partial preservation of sensory and/or motor function is found below the neurological level and includes the lowest sacral segment. Sacral sensation includes sensation at the anal mucocutaneous junction as well as deep anal sensation. The test of motor function is the presence of voluntary contraction of the external anal sphincter upon digital examination.

Minimal deficit refers to abnormal reflexes, to transitional neurologic symptoms, or neurologic damage so minimal the patient has no significant or incapacitating loss of function. Reflexes may still be abnormal. If the patient is coded minimal deficit on Form I, no Form IIs are required. Once a patient is coded minimal deficit on a Form II, no subsequent Form IIs are required.

Normal neurologic status refers to those patients who have no demonstrable muscular weakness or impaired sensation. This subcategory must be included in the database to document those patients who achieve recovery from initial injury. If the patient is coded normal on Form I, no Form IIs are required. Once a patient is coded normal on a Form II, no subsequent Form IIs are required.

Monoplegia should be coded "1" (Paraplegia, incomplete).

Triplesia should be coded "4" (Tetraplegia, incomplete).

The sacral area must be checked for this variable.

SOURCE: International Standards for Neurological Classification of Spinal Cord Injury, Revised 2002.

REVISIONS: January, 1998: Data on Form II are now required only in annual years 1 and 2.

October 2000: Data on Form II are now required only in annual year 1 and, data collection at rehab admission was added. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If this variable = "1" (*Paraplegia, incomplete*), "2" (*Paraplegia, complete*), or "3" (*Paraplegia, minimal deficit*), then the Level of Preserved Neuro Function variable should = "T" (*Thoracic*), "L" (*Lumbar*), "S" (*Sacral*) or "X99" (*Unknown*).

If this variable = "4" (*Tetraplegia, incomplete*), "5" (*Tetraplegia, complete*), or "6" (*Tetraplegia, minimal deficit*), then the Level of Preserved Neuro Function variable should = "C" (*Cervical*) or "X99" (*Unknown*).

Patients with *minimal deficit* status must be coded:

Neuro Impairment = "3" or "6",

Level Left and/or Level Right = any code other than "X00" and,

ASIA Impairment Scale = "3" or "D".

Patients with *normal neurologic* status must be coded:

Neuro Impairment = "7" and,

ASIA Impairment Scale = "4" or "E" and,

all muscles in the ASIA Motor Index Score = "5" and,

all ASIA Motor Index Score Subtotals = "50" and,

ASIA Motor Index Score Total = "100".

REGISTRY, FORM I and FORM II

VARIABLE NAME: ASIA Impairment Scale (modified from Frankel)

DESCRIPTION: This variable attempts to quantitate the degree of impairment

- 1) **at initial system examination (for day-1 admissions only)** (V132A)
- 2) **at admission to inpatient rehab (for day-1 admissions only)** - (V132R)
- 3) **at discharge (for all patients)** (V132D) and
- 4) **on the date of the year 01 (or year 02, see [page 16](#)) examination** (V245).

CHARACTERS: 1 for each entry

CODES:

A Complete Injury.

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

B Incomplete.

Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5.

C Incomplete.

Motor function is preserved below the neurological level, and more than half of the key muscles below the neurological level have a muscle grade less than 3 (grades 0-2).

D Incomplete.

Motor function is preserved below the neurological level, and **at least half** of key muscles below the neurological level have a muscle grade greater than or equal to 3.

E Normal.

Sensory and motor function are normal. (*see [page 101](#)*)

U Unknown (V132A, V132R, V132D, V245); OR

Not admitted to System inpatient rehab (V132R) *See note on page 98 for Form Is entered after 03/31/2005.*

Blank (*on Form I - for non day-1 admissions in V132A and V132R only*)

Blank (*on Form II - only if V201 = "5"*)

NOTE: For an individual to receive a grade of C or D, he/she must be incomplete, that is, have sensory or motor function in the sacral segments S4-S5. In addition, the individual must have either (1) voluntary anal sphincter contraction or (2) sparing of motor function more than three levels below the motor level. This is new text added to the 2000 edition of the International Standards booklet

SOURCE:

International Standards for Neurological Classification of Spinal Cord Injury, Revised 2002, pages 18-19.

REGISTRY, FORM I and FORM II

COMMENTS: See page 99 for guidelines to administering the neurological exam when the patient is not fully testable.

REVISIONS: August 1993: The Frankel Grading system was changed to the ASIA Impairment Scale.

January, 1998: Data on Form II are required only at annual years 1 and 2.

October 2000: Data on Form II are required only at annual year 1 and data collection at rehab admission was added. This variable (at Discharge) was added to the Registry database. Code “U” was inserted in this variable in the Registry records that existed when this variable was added. Form I and Registry data are required for patients admitted to the System after 10/31/2000.

CONVERSIONS: August 1993: All records in which the Frankel Grading system was used have numeric codes in this variable. Records in which the ASIA Impairment Scale was used contain alphabetic codes.

The following Frankel Grade codes are provided for analysis purposes only. The numeric Frankel Grade codes are not allowed in records entered into the database after August 1993

Frankel Grade codes:

- 1 Incomplete - Preserved Sensation Only (Frankel Grade B): Preservation of any demonstrable, reproducible sensation, excluding phantom sensations. Voluntary motor functions are absent.
- 2 Incomplete - Preserved Motor - Non-functional (Frankel Grade C): Preservation of voluntary motor function that is minimal and performs no useful purpose. Minimal is defined as preserved voluntary motor ability below the level of injury where the majority of the key muscles tests less than a grade of 3.
- 3 Incomplete, Preserved Motor - Functional (Frankel Grade D): Preservation of voluntary motor function which is useful functionally. This is defined as preserved voluntary motor ability below the level of injury, where the majority of the key muscles tests at least a grade of 3.
- 4 Complete Recovery (Frankel Grade E): Complete return of all motor and sensory function, but there may still be abnormal reflexes.
- 5 Complete (Frankel Grade A): All motor and sensory function is absent below the Zone of Partial Preservation.
- 9 Unknown

QC: See [page 101](#) for coding instructions for patients with *normal neurologic* or *minimal deficit* status.

FORM I and FORM II

VARIABLE NAME: ASIA Motor Index Score

DESCRIPTION: This variable documents (1) the individual scores for each key muscle, (2) the subtotal scores for the left and right sides and (3) the total ASIA Motor Index Scores:

- 1) **at initial system examination (for day-1 admissions only)** (V133AAL through V133AJL, V133AAR through V133AJR, V133AR, V133AL, V133AT);
- 2) **within 1 week of the beginning of the inpatient rehabilitation phase (for day-1 admissions only)** (V133RAL through V133RJL, V133RAR through V133RJR, V133RR, V133RL, V133RT);
- 3) **at discharge (for all patients)** (V133DAL through V133DJL, V133DAR through V133DJR, V133DR, V133DL, V133DT); and
- 4) **on the date of the year 01 (or year 02, see [page 16](#)) examination** (V246AL through V246JL, V246AR through V246JR, V246R, V246L, V246T).

This motor index score provides a numerical scoring system to document changes in motor function.

CHARACTERS: 1 for each key muscle, Left and Right
2 for each Subtotal, Left and Right
3 for each Total

| | | |
|--------|---------------------------------|--|
| CODES: | <u>Each Key Muscle</u> | <p>0-5 Valid range (see notes on page 105 for grade 5*)</p> <p>8 Not applicable, unable to test; infants</p> <p>9 Unknown, Not Done (V133AAL-V133AJL, V133AAR- V133AJR; V133RAL-V133RJL, V133RAR-V133RJR; V133DAL-V133DJL, V133DAR-V133DJR, V246AR-V246JR) ; no System rehab admission (V133RAL-V133RJL and V133RAR-V133RJR)*</p> <p>Blank (on Form I - for non day-1 admissions in V133A and V133R only)</p> <p>Blank (on Form II - only if V201 = "5")</p> |
| | <u>Right and Left Subtotals</u> | <p>00 – 50 Valid range</p> <p>88 Not applicable, unable to test; infants</p> <p>99 Unknown, Not Done (V133AR, V133AL, V133RR, V133RL, V133DR, V133DL, V246R, V246L); no System rehab admission (V133RR and V133RL)*</p> <p>Blank (on Form I - for non day-1 admissions in V133A and V133R only)</p> <p>Blank (on Form II - only if V201 = "5")</p> |
| | <u>Total</u> | <p>000 – 100 Valid range</p> <p>888 Not applicable, unable to test; infants</p> <p>999 Unknown, Not Done (V133AT, V133RT, V133DT, V246T); no System rehab admission (V133RT) *</p> <p>Blank (on Form I - for non day-1 admissions in V133A and V133R only)</p> <p>Blank (on Form II - only if V201 = "5")</p> |

* See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.

SOFTWARE: The software includes a function key to calculate the Subtotals and totals in this variable. To use: place the cursor on the variable to be calculated (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

FORM I and FORM II

VARIABLE NAME: ASIA Motor Index Score

REVISIONS: October 1986: Acute, Discharge and Form II Sub-Totals and Totals were added to the database.
 August 1993: The individual muscle scores were added to Acute, Discharge & Form II; all items were added for the inpatient rehabilitation phase.
 January 1998: data on Form II required only in annual years 1 and 2.
 October 2000: data on Form II required only on the date of the year 1 examination.

COMMENTS: The strength of each key muscle is graded according to the following ASIA scale from the International Standards for Neurological Classification of Spinal Cord Injury, Revised 2002, pages 13-15.

- 0 total paralysis
- 1 palpable or visible contraction
- 2 active movement, full Range of Motion (ROM) with gravity eliminated
- 3 active movement, full ROM against gravity
- 4 active movement, full ROM against moderate resistance
- 5 (normal) active movement, full ROM against full resistance
- 5* (normal) active movement, full ROM against sufficient resistance to be considered normal if identified inhibiting factors were not present
- NT not testable

Minus grades are to be coded as the next lower grade. For example, a grade of 3- should be coded 2; 2- should be coded 1, and, 1- should be coded 0. Plus grades should be ignored. For example, a grade of 3+ should be coded 3, 2+ should be coded 2, etc.

A normal exam is a score of 5 for each key muscle, Subtotals on the left and right of 50, and, a total score of 100.

Key Muscles for Motor Level Classification - The required portion of the motor examination is completed through the testing of the following key muscles (bilaterally):

- C5 Elbow flexors (biceps, brachialis)
- C6 Wrist extensors (extensor carpi radialis longus and brevis)
- C7 Elbow extensors (triceps)
- C8 Finger flexors - (flexor digitorum profundus) to the middle finger
- T1 Small finger abductors (abductor digiti minimi)
- L2 Hip flexors (iliopsoas)
- L3 Knee extensors (quadriceps)
- L4 Ankle dorsiflexors (tibialis anterior)
- L5 Long toe extensors (extensor hallucis longus)
- S1 Ankle plantarflexors (gastrocnemius, soleus)

Each key muscle should be examined in a rostral-caudal sequence.

In addition to bilateral testing of these muscles, the external anal sphincter should be tested on the basis of contractions around the examiner's finger and graded as being present or absent. If there is voluntary contraction of the anal sphincter then the patient is motor incomplete.

To be documented by the attending physician or the physician's designee. All the key muscles identified for the ASIA Motor Index Score must be tested to provide a valid left, right and total score.

SOURCE: International Standards for Neurological Classification of Spinal Cord Injury, Revised 2002, pages 13-15.

FORM I and FORM II

VARIABLE NAME: ASIA Motor Index Score

COMMENTS: See page 99 for guidelines to administering the neurological exam when the patient is not fully testable. When the patient is an infant, the ASIA Motor Index score should be coded Unable to Test (888).

QC: See [page 101](#) for coding instructions for patients with *normal neurologic* or *minimal deficit* status.

See [page 99](#) for coding instructions when the Neuro Exam is not done or when there is no admission to System inpatient rehab.

EXAMPLE 1: Each muscle score is known; and the Subtotal on the left side is 45, on the right side the Subtotal is 37, and the total score is 82.

Each muscle has a score from "0" to "5", and

| | Left | Right |
|-----------|------|-------|
| Sub-total | 45 | 37 |
| Total | 82 | |

EXAMPLE 2: The left side cannot be tested completely because the patient's hand is in a cast. All muscles on the right side were tested and the total score for the right side is 32.

Each muscle on the left side (that was not tested) is coded "8"; tested muscles on the left and each muscle on the right have a score from "0" to "5"; and,

| | Left | Right |
|-----------|------|-------|
| Sub-total | 88 | 32 |
| Total | 888 | |

EXAMPLE 3: Only the total score (082) is known. All muscles are coded 9, and

| | Left | Right |
|-----------|------|-------|
| Sub-total | 99 | 99 |
| Total | 82 | |

EXAMPLE 4: The Left Subtotal is unknown (because 2 muscles are coded "9") and, the right side was not testable (all muscles on the right are coded "8").

| | Left | Right |
|-----------|------|-------|
| Sub-total | 99 | 88 |
| Total | 888 | |

FORM I and FORM II

VARIABLE NAME: Sensory Level

DESCRIPTION: The sensory level (which may differ by side of body) is the most caudal segment of the spinal cord with normal sensory function for pinprick and light touch on both sides of the body. Right and left levels are documented

- 1) **at initial system examination** (*for day-1 admissions only*) (V134AR, V134AL)
- 2) **at admission to inpatient rehab** (*for day-1 admissions only*) (V134RR, V134RL)
- 3) **at discharge** (*for all patients*) (V134DR, V134DL) and
- 4) **on the date of the year 01 (or year 02, see [page 16](#)) examination** (V247R, V247L).

CHARACTERS: 3 for each entry

CODES:

- C** Cervical (C1 - C8)
- T** Thoracic (Dorsal, T1 - T12)
- L** Lumbar (L1 - L5)
- S** Sacral (S1 - S5)
- X00** Normal neurologic (*see [page 101](#)*)
- X99** Unknown, Not Done (V134AR, V134AL, V134RR, V134RL, V134DR, V134DL, V247R, V247L); OR
No System rehab admission (V134RR, V134RL) See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.
- Blank** (*on Form I - for non day-1 admissions in V134A and V134R only*)
- Blank** (*on Form II - only if V201 = "5"*)

COMMENTS: If only the alphabetic part of the level is known, it is permissible to use code C, L, T, or S followed by numeric code "99". Use code X99 if the level is completely unknown, the exam was not done, there was no System admission or there was no admission to System inpatient rehab.

SOURCE: Refer to The International Standards for Neurological Classification of Spinal Cord Injury, Revised 2002, (pages 6 to 15) for complete information on the sensory examination and a listing of all key points. In addition to bilateral testing of the key points, the external anal sphincter should be graded as being present or absent. Any sensation felt in the anal area during this part of the exam signifies that the patient is sensory incomplete.

REVISIONS: Data in these variables are required of patients who are admitted to the system on or after August 15, 1993.
 January 1998: Data on Form II are required only in annual years 1 and 2.
 October 2000: data on Form II required only on the date of the year 1 examination and, data collection at rehab admission was added. Form I data are required for patients admitted to the System after 10/31/2000.

QC: See pages 99 and 101.

FORM I and FORM II

VARIABLE NAME: Motor Level

DESCRIPTION: The motor level (the lowest normal motor segment - which may differ by side of body) is defined by the lowest key muscle that has a grade of at least 3, provided the key muscles represented by segments above that level are judged to be normal (5). Right and left levels are documented

- 1) **at initial system examination** (*for day-1 admissions only*) (V135AR, V135AL)
- 2) **at admission to inpatient rehab** (*for day-1 admissions only*) (V135RR, V135RL)
- 3) **at discharge** (*for all patients*) (V135DR, V135DL) and
- 4) **on the date of the year 01 (or year 02, see [page 16](#)) examination** (V248R, V248L).

The software can calculate this variable. **Data collectors are encouraged to use this software function to calculate this variable.** See [page 109](#).

CHARACTERS: 3 for each entry

CODES:

- C** Cervical (C1 - C8)
- T** Thoracic (Dorsal, T1 - T12)
- L** Lumbar (L1 - L5)
- S** Sacral (S1 - S5)
- X00** Normal (*see [page 101](#)*)
- X99** Unknown, Not Done (V135AR, V135AL, V135RR, V135RL, V135DR, V135DL, V248R, V248L);
No System rehab admission (V135RR and V135RL) *See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.*
- Blank** (*on Form I - for non day-1 admissions in (V135A and V135R only)*)
- Blank** (*on Form II - only if V201 = "5"*)

COMMENTS: The examiner's judgment is relied upon to determine whether a muscle that tests as less than normal (5) may in fact be fully innervated. This may occur when full effort from the patient is inhibited by factors such as pain, positioning and hypertonicity or when weakness is judged to be due to disuse. If any of these or other factors impeded standardized muscle testing, the muscle should be graded as *not testable*. However, if these factors do not prevent the patient from performing a forceful contraction and the examiner's best judgment is that the muscle would test normally (5) were it not for these factors, it may be graded as 5. For those myotomes that are not clinically testable by a manual muscle exam (i.e., C1 to C4, T2 to L1 and S2 to S5), the motor level is presumed to be the same as the sensory level.

FORM I and FORM II

VARIABLE NAME: Motor Level

COMMENTS: If only the alphabetic part of the level is known, it is permissible to use code C, L, T, or S followed by numeric code "99". Use code X99 if the level is completely unknown, the exam was not done or there was no admission to System inpatient rehab.

SOURCE: See pages 6 to 18 of the International Standards for Neurological Classification of Spinal Cord Injury, Revised 2002 for complete information on the motor examination and a listing of all key muscles.

SOFTWARE: The software uses the data entered in the Sensory Level and ASIA Motor Index Score to determine this variable. To use: place the cursor on the variable to be calculated (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

 Caution: If the software's Motor Level differs from the Physician's determination, always confer with the physician to verify the correct level since there are several circumstances that cannot be "programmed" into this software function. The user is allowed to overwrite the level that is calculated by the software.

REVISIONS: Data in these variables are required of patients who are admitted to the system on or after August 15, 1993.

January 1998: Data on Form II are now required only in annual years 1 and 2. "Normal" was changed from 4 or 5 to 5 only.

October 2000: data on Form II required only on the date of the year 1 examination and, data collection at rehab admission was added. Form I data are required for patients admitted to the System after 10/31/2000.

QC: See [page 101](#) for coding instructions for patients with "normal neurologic" or "minimal deficit" status.

See [page 99](#) for coding instructions when the Neuro Exam is not done or when there is no admission to System inpatient rehab.

REGISTRY, FORM I and FORM II

VARIABLE NAME: Level of Preserved Neurologic Function

DESCRIPTION: The neurological level of preservation (injury) is the most caudal segment of the spinal cord with normal sensory and motor function on both sides of the body. Right and left levels are documented.

- 1) **at initial system examination** (*for day-1 admissions only*) (V136AR, V136AL)
- 2) **at admission to inpatient rehab** (*for day-1 admissions only*) (V136RR, V136RL)
- 3) **at discharge** (*for all patients*) (V136DR, V136DL) and
- 4) **on the date of the year 01 (or year 02, see [page 16](#)) examination** (V249R, V249L).

CHARACTERS: 3 for each entry

CODES:

- C** Cervical (C1 - C8)
- T** Thoracic (Dorsal, T1 - T12)
- L** Lumbar (L1 - L5)
- S** Sacral (S1 - S5)
- X00** Normal neurologic (*see [page 101](#)*)
- X99** Unknown, Not Done (V136AR, V136AL, V136RR, V136RL, V136DR, V136DL, V247R, V247L); OR
No System rehab admission (V136RR, V136RL) See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.
- Blank** (*on Form I - for non day-1 admissions in V136A and V136R only*)
- Blank** (*on Form II - only if V201 = "5"*)

COMMENTS: If only the alphabetic part of the level is known, it is permissible to use code C, L, T, or S followed by numeric code "99". Use code X99 if the level is completely unknown, the exam was not done or there was no admission to System inpatient rehab.

ELIGIBILITY: If this variable = "X00" (*Normal*), bilaterally, at system admission, the patient is ineligible for the National SCI Database.

SOURCE: Refer to page 6 of the International Standards for Neurological Classification of Spinal Cord Injury, Revised 2002 for additional information.

REVISIONS: January 1998: Data on Form II are required only at annual years 1 and 2.
 October 2000: data on Form II required only on the date of the year 1 examination and, data collection at rehab admission was added. Form I data are required for patients admitted to the System after 10/31/2000.

QC: If this variable = "C", then variable Neurologic Impairment must be coded "4", "5", "6" or "9".
 If this variable = "T", "L", or "S", then Neurologic Impairment must be coded "1", "2", "3" or "9".
 The level in this variable must be equal to the motor level and/or the sensory level AND neither the motor level nor the sensory level can be higher than the level in this variable.
 See pages 99 and 101.

FORM I and FORM II

VARIABLE NAME: Method of Bladder Management

DESCRIPTION: This variable defines the primary method of bladder management being used

- 1) **at discharge** (*for all patients*) (V137) and
- 2) **on the anniversary date being reported** (V208).

CHARACTERS: 1 for each entry

- CODES:
- 00 None:** The patient has a neurogenic bladder but does not follow any established program of bladder management. This includes diapers, pampers, etc.
 - 01 Indwelling urethral catheter:** Bladder is emptied by any type of catheter which is maintained through the urethra.
 - 02 Indwelling catheter after augmentation or continent diversion:** Bladder is emptied by any type of catheter which is maintained through the stoma.

Catheter Free With External Collector

The patient voids satisfactorily using any method of reflex stimulation or any form of extrinsic pressure. However, an external collector is utilized to control incontinence.

- 03 Catheter free with external collector, no sphincterotomy**
- 04 Catheter free with external collector and sphincterotomy**
- 05 Catheter free with external collector, sphincterotomy unknown**
- 06 Catheter free without external collector:** The patient voids satisfactorily using any method of reflex stimulation or any form of extrinsic pressure. An external collector is not required in that the patient has developed adequate continence.

FORM I and FORM II

VARIABLE NAME: Method of Bladder Management

CODES: Intermittent Catheterization Program (ICP):

The patient empties the bladder by frequent insertion of a urethral catheter in an on-going program of chronic management. Intermittent catheterizations using this technique are done several times a day. This category does not pertain to infrequent periodic catheterizations for the purpose of checking urinary residual.

07 ICP only

08 ICP with external collector

09 ICP after augmentation or continent diversion

10 ICP - external collector, augmentation or continent diversion unknown

11 Conduit: The bladder is drained by any of the surgical techniques using various portions of the intestinal tract that are not categorized as bladder augmentation.

12 Suprapubic Cystostomy: The bladder is drained by any of the surgical techniques using a catheter through a suprapubic orifice.

13 Normal Micturition (old code 4): The patient voids satisfactorily without using reflex stimulation or extrinsic bladder pressure voiding techniques. The bladder, however, may or may not have completely normal function.

14 Other: All other bladder drainage techniques such as ureterocutaneostomy (pyelostomy), electro-stimulation, electro-magnetic ball valve, detrusor stimulation, sacral implants, conus implants, vesicostomy, ureteral catheterization, etc.

99 Unknown

Blank (*on Form II - only if V201 = "5"*)

FORM I and FORM II

VARIABLE NAME: Method of Bladder Management

COMMENTS: No attempt should be made to document all the various types of bladder management that may have been used during the anniversary year being reported. Only the management used on the anniversary should be reported.

REVISIONS: In November 1995: New categories (codes 2, 3, 4, 7, 8 and 9) were added.; and, Bladder Management at System Admission was changed to Bladder Management at Admission to Inpatient Rehab.

January 1998 - Bladder Management at Admission to Inpatient Rehab was deleted.

CONVERSIONS: November 1995: For records in existence at this time -

Old admission data were moved into the new rehab variable if the patient's initial system admission was directly to the system's rehab unit.

Old discharge data were moved into the new discharge variable.

Additionally, the following code conversions were made if old data were moved into the new variables:

| Old Code | Current Code |
|----------|--------------|
| 1 | 01 |
| 2 | 05 |
| 3 | 06 |
| 4 | 13 |
| 5 | 10 |
| 6 | 11 |
| 7 | 12 |
| 8 | 14 |
| 9 | 99 |

REGISTRY, FORM I and FORM II

VARIABLE NAME: Utilization of Mechanical Ventilation

DESCRIPTION: This variable documents any use of any type of mechanical ventilation used to sustain respiration

- 1) **at admission to System inpatient rehab** (V138R)
- 2) **at discharge** (V138D) and
- 3) **at the anniversary of injury, year 1 only*** (V242).

* If a year 02 Form II is substituted for the year 01 Form II (because the patient was still in the initial acute/rehab process past his first anniversary), this variable documents use of mechanical ventilation after injury to the end of the last treatment phase documented on Form I.

CHARACTERS: 1 for each entry

- CODES:
- 0 No**
 - 1 Yes, limited, short-term use for pulmonary complications**
 - 2 Yes, ventilator-dependent or ventilator use requiring a weaning process**
 - 3 Yes, phrenic nerve stimulator**
 - 4 Yes, used mechanical ventilation, length of time and type unknown**
This is a CONVERSION CODE ONLY (code "1" prior to 10/86). Data collectors may NOT use this code. This information is provided for data analyses purposes only.
 - 9 Unknown (V138R, V138D, V242);**
no System rehab admission (V138R) See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.

Blank (on Form II - only if V201 = "5")

COMMENTS: Limited, short-term use (code 1) is defined as respiratory support used as part of the medical treatment for other pulmonary complications.

Do NOT include emergency mouth-to-mouth or machine resuscitation; routine administration of oxygen; emergency "bagging"; periodic IPPB administration; or operative/post-operative ventilatory support used for less than 7 days. Do use code 1 for post-op support lasting more than 7 days.

Use code 2 for those who need partial or total respiratory support on a daily basis and (1) require a weaning process or (2) are vent-dependent. Do not use code 2 for vent support used for less than 7 days.

When the patient dies during the initial system admission period (i.e., the Date of Discharge = Date of Death) – vent use should reflect what’s being used at the time of death (even if the patient was never admitted to rehab). “At Discharge” can be at discharge from the Acute Care unit if there was no rehab admit.

REVISIONS: October 2000: data collection during System was deleted; data collection at System inpatient acute rehab admission was added (data are required for patients admitted to the System after 10/31/2000). Form II data collection required only for annual year 1. Data at discharge added to the Registry.

QC: See [page 67](#).

FORM I

VARIABLE NAME: Locations and Grades of Pressure Ulcer(s)

DESCRIPTION: This variable documents pressure ulcers by grade and location.

- 1) **during acute (or subacute) medical/surgical care (for day-1 admissions only)** - V139A_1 through V139A_27
- 2) **during inpatient acute (or subacute) rehab for day-1 admissions only** - V139R_1 through V139R_27.

CHARACTERS: 1 for each entry

CODES:

- 0** None and redness that does blanch to the touch
- 1** **Grade 1:** Limited to the superficial epidermal and dermal layers. Include redness that does not blanch to the touch and redness that requires intervention.
- 2** **Grade 2:** Involving the epidermal and dermal layers and extending into the adipose tissue.
- 3** **Grade 3:** Extending through superficial structures and adipose tissue down to and including muscle.
- 4** **Grade 4:** Destruction of all soft tissue structures and communication with bone or joint structures.
- 8** Pressure ulcer present - **grade unknown**
- 9** **Unknown** (V139A, V139R);
no System rehab admission (V139R) See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.

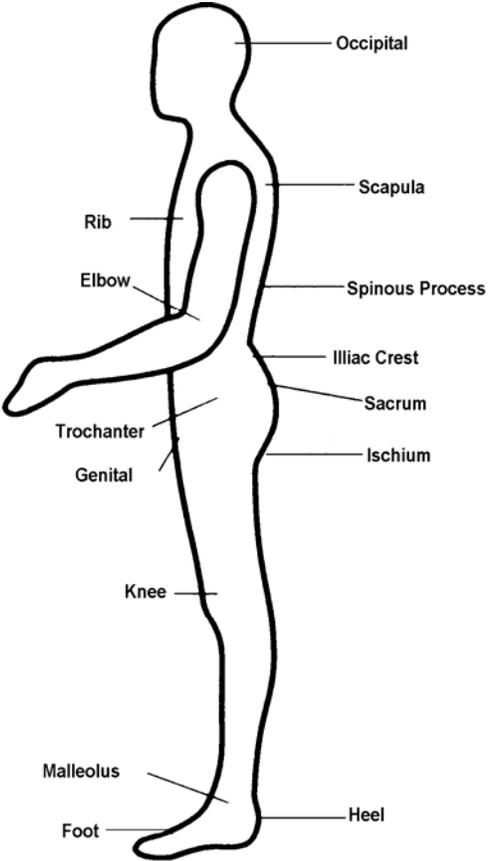
Blank (For non day-1 admissions only)

SOURCE: Enis, J.E., and Sarmiento, A. (1973). The pathophysiology and management of pressure sores. Orthopaedic Review, 2 (10): 25-34.

FORM I

VARIABLE NAME: Locations and Grades of Pressure Ulcer(s)

- COMMENTS:
- Occiput: includes back of head
 - Scapula: includes shoulder
 - Ribs: includes chest, thorax
 - Sacral: includes sacroiliac, coccygeal, tail bone
 - Ischium: includes gluteal, intergluteal, buttocks areas
 - Trochanter: includes hip
 - Knee: includes pre-tibial, tibial and fibular condyles, shin and popliteal areas
 - Heel: includes calcaneus
 - Foot: includes any part of the foot other than heel



FORM I

VARIABLE NAME: Locations and Grades of Pressure Ulcer(s)

COMMENTS: Place the grade of the pressure ulcer in the appropriate location box on the form. Place a code in all location boxes.

The purpose of this variable is primary prevention and quality assurance. **Therefore, each ulcer should be documented once, at onset, and the worst grade should be recorded.** The following reporting guidelines are to be used on all patients who are admitted to the system on or after December 1, 1995:

- > Any ulcer developed "During Acute" that worsens or recurs (i.e., heals and subsequently breaks down again in the same location) "During Rehab" should NOT be documented again "During Rehab". Record the worst grade of that ulcer in "During Acute".

If there is an ulcer at the time of first System admission, do not count this ulcer unless it worsens during System. When there are multiple ulcers in the same location, document the grade of the worst ulcer.

If a pressure ulcer does not fit into any of the classifications listed on the following page, document it as "Location unclassified". If the patient has more than one "unclassified" ulcer on the same side, code only the most severe ulcer.

When a patient is not admitted to the System's acute (or subacute) medical unit (and the patient is a day-1 admit), code V139A_1 through V139A_27 all 9's.

When a patient is not admitted to the System's inpatient acute inpatient (or subacute) inpatient rehab unit (and the patient is a day-1 admit), code V139R_1 through V139R_27 all 9's.

FORM I

VARIABLE NAME: Locations and Grades of Pressure Ulcer(s)

REVISIONS: **Form I:**

November 1995: the reporting of Form I Pressure Ulcers that worsened during the next data collection period was revised. Such ulcers were not counted again if they worsened during the next data collection period. Also, Pressure Ulcers Developing During System (old variable 133D) was separated into Ulcers Developed During Acute Care (or Present at Rehab Admit) and Ulcers Developing During Rehab. The revised reporting guidelines have been used on all patients admitted to the system on or after December 1, 1995.

October 2000: data collection at the time of admission to inpatient rehab was deleted; data collection during rehab changed from all patients to day-1 admissions only.

Form II:

1986: this variable was changed from Locations and Grades of Pressure Ulcers During the Follow-up Year to Locations and Grades of Pressure Ulcers Present at the Time of the Annual Exam.

January 1998: Locations and Grades of Pressure Ulcer(s) Present at the Time of the Annual Examination was deleted. It was replaced by the new variable, Grade of Worst Pressure Ulcer Present at the Time of the Annual Examination.

CONVERSIONS: November 1995 - For records in existence at this time, all data were retained from old variables #133 (Locations and Grades of Pressure Sores) and 138G (Number of Pressure Sores). During data entry the user is not allowed to modify these fields - **in these "old records"**. In order to change these fields the user must delete the entire record and enter a new Form I, using the current reporting guidelines. These "old records" have Indates prior to 19960201.

QC: If variable 139A = all "0"s, then variable 140A must = "00". If variable 139A = all "9"s, then variable 140A must = "99".

If variable 139R = all "0"s, then variable 140AR must = "00". If variable 139R = all "9"s, then variable 140R must = "99".

See pages 65 and 67.

FORM I

VARIABLE NAME: Locations and Grades of Pressure Ulcer

EXAMPLE: The patient was admitted to the system on the day of injury. At the time he entered the system's inpatient rehab unit he had a grade 2 ulcer on the left elbow and a grade 1 ulcer on the right knee. The ulcer on the left elbow worsened to a grade 3 during inpatient rehab and the ulcer on the right knee resolved during inpatient rehab. He did not develop any new ulcers during inpatient rehab.

| <u>During Acute</u> | | | <u>Location</u> | <u>During Inpatient Rehab</u> | | |
|---------------------|----------|----------|------------------|-------------------------------|----------|----------|
| <u>L</u> | <u>C</u> | <u>R</u> | | <u>L</u> | <u>C</u> | <u>R</u> |
| | <u>0</u> | | Occiput | | <u>0</u> | |
| <u>0</u> | | <u>0</u> | Scapula | <u>0</u> | | <u>0</u> |
| <u>3</u> | | <u>0</u> | Elbow | <u>0</u> | | <u>0</u> |
| <u>0</u> | | <u>0</u> | Ribs | <u>0</u> | | <u>0</u> |
| | <u>0</u> | | Spinous process | | <u>0</u> | |
| <u>0</u> | | <u>0</u> | Iliac crest | <u>0</u> | | <u>0</u> |
| | <u>0</u> | | Sacral | | <u>0</u> | |
| <u>0</u> | | <u>0</u> | Ischium | <u>0</u> | | <u>0</u> |
| <u>0</u> | | <u>0</u> | Trochanteric | <u>0</u> | | <u>0</u> |
| | <u>0</u> | | Genital | | <u>0</u> | |
| <u>0</u> | | <u>1</u> | Knee | <u>0</u> | | <u>0</u> |
| <u>0</u> | | <u>0</u> | Malleolar | <u>0</u> | | <u>0</u> |
| <u>0</u> | | <u>0</u> | Heel | <u>0</u> | | <u>0</u> |
| <u>0</u> | | <u>0</u> | Foot | <u>0</u> | | <u>0</u> |
| <u>0</u> | <u>0</u> | <u>0</u> | Location unclass | <u>0</u> | <u>0</u> | <u>0</u> |

FORM I and FORM II

VARIABLE NAME: Number of Pressure Ulcers

DESCRIPTION: This variable documents the number of pressure ulcers

- 1) **during acute (or subacute) medical/surgical (for day-1 admissions only) - V140A**
- 2) **during acute (or subacute) inpatient rehab (for day-1 admissions only) - V140R**
- 3) **present upon visual inspection on the date of the annual examination (V213)**

CHARACTERS: 2 for each entry

CODES:

- 00** No ulcers
- 00-86** Valid range
- 87** 87 or more ulcers
- 88** Yes ulcers present, number unknown
- 99** Unknown (V140A, V140R, V213);
no System rehab admission (V140R) See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.
- Blank** (on Form I - for non day-1 admissions only)
- Blank** (on Form II - only if V201 = "5")

COMMENTS: At the time of first System admission: If there is an ulcer, do not count this ulcer unless it worsens during System.

After system admission: Each ulcer is to be counted only once (at onset). Therefore, an ulcer that developed "During Acute Care" is counted "during Acute". If that same ulcer worsens or recurs (i.e., heals and subsequently breaks down again in the same location) "During Rehab" do NOT count that ulcer again "During Rehab". Record the worst grade of that ulcer in "During Acute".

When there are multiple ulcers in the same location count all ulcers at the same location.

During the annual exam (V212): document the grade of the worst pressure ulcer present at the time of the annual exam.

- ✓ If the patient was never scheduled for an Annual Exam but came into the clinic due to pressure ulcer(s): code the Annual Exam as being done and document the grade of the worst ulcer.
- ✓ If the patient had an Annual Exam (with no ulcers) then came back for a visit (due to ulcers), code the Annual Exam as being done and sore(s) = None (since they were not present at the time of the Annual Exam).

QC: See pages [65](#), [67](#) and [118](#).

REVISIONS: October 2000: data collection at the time of admission to inpatient rehab was deleted; data collection during rehab changed from all patients to day-1 admissions only.

FORM I

VARIABLE NAME: Grade of the Worst Pressure Ulcer at Admission to System Inpatient Rehab

DESCRIPTION: This variable documents the grade of the worst sore present at the time of first admission to the System's inpatient rehab unit.

CHARACTERS: 1

CODES: **0 No pressure ulcers present at the time of rehab admission**

1 Grade 1

2 Grade 2

3 Grade 3

4 Grade 4

8 Pressure ulcer present, grade unknown*

9 Unknown or no System rehab admission *See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.*

* When there are multiple ulcers AND at least 1 ulcer is "8" (grade unknown):

if one of the ulcers is a grade "4", code this variable "4"

otherwise, code this variable "8".

COMMENTS: Document the worst ulcer present on the date specified in Variable 108 (Date of First System Inpatient Rehab Admission).

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

QC: See [page 67](#).

FORM I and FORM II

VARIABLE NAME: Medical Complications

DESCRIPTION: This variable documents a select group of medical complications (identified and/or treated) during System Acute (or Subacute) Medical/Surgical care; during System Inpatient Acute (or Subacute) Rehab; and, during Follow-up.

FORM I (V142):

For the day-1 admissions only

document these complications with onset occurring during System acute (and subacute) medical/surgical care and with onset occurring during System acute (and subacute) inpatient rehab.

During System Acute Medical/Surgical Care is the interval between admission to and discharge from the System's acute medical/surgical care unit. This period includes time in the System's subacute medical/surgical care unit.

During Rehabilitation is the period of time between the admission to and discharge from the System's inpatient acute rehabilitation unit. This period includes time in the System's inpatient subacute rehab unit and any transfers back to the acute (or subacute) medical unit after admission to rehab.

- ✓ If a complication developed during acute care AND was still present at rehab admission:code Yes During Acute
- ✓ If a complication developed during acute care AND resolved prior to rehab admission and did NOT develop again during rehab:code Yes During Acute AND.....code No During Rehab
- ✓ If a complication developed during acute care AND resolved prior to rehab admission AND developed again during rehab:code Yes During Acute AND.....code Yes During Rehab
- ✓ If a complication developed during rehab onlycode No During Acute ANDcode Yes During Rehab
- ✓ If a complication developed during rehab only and the patient was transferred from rehab back to the acute unit for treatmentcode No During Acute ANDcode Yes During Rehab

FORM II (V221):

For those items to be documented "during the anniversary year being reported":

- use the "Yes" code if the complication occurred or diagnosis was made **anytime between the beginning and the end of the anniversary year for which the Form II is being completed.**

If a particular complication occurred during one anniversary year and was still present during subsequent anniversary year(s), **use the "Yes" code for each year in which the complication existed**. For the year 1 Form II, the interval is after discharge to the first anniversary.

COMMENTS:

For those complications requiring documentation of the number of episodes, count each episode only once.

FORM I and FORM II

VARIABLE NAME: Medical Complications - During System Acute (or Subacute) Medical/Surgical Care; During System Inpatient Acute (or Subacute) Rehab; and, During Follow-up

The following is a list of all items to be reported:

| Form I | Form II | Variable Name | Syllabus Page |
|--------|---------|--|---------------|
| 142A | 243 | Post-operative Wound Infection at the Site of the Spinal Surgery | 124 |
| 142B | | Number of Episodes of Pneumonia | 125 |
| 142C | 221A | Pulmonary Embolism | 126 |
| 142D | 221B | Thrombophlebitis, Deep Vein Thrombosis | 127 |
| | 221C | Pneumonia | 129 |
| | 221D | Presence of Calculus in the Kidney and/or Ureter | 130 |

- If the patient IS NOT a day-1 admission to the System:
leave all the Form I complication variables (V142A to V142D) blank.
- If the patient IS a day-1 admission to the System but is not admitted to the System's Acute (or Subacute) Medical/Surgical unit:
code all the Form I ("during acute") complication variables unknown.
- If the patient IS a day-1 admission to the System but is not admitted to the System's Acute (or Subacute) Inpatient Rehab unit:
code all the Form I ("during rehab") complication variables unknown.
- Number of Episodes of Pneumonia are collected on Form I only. The Form II Pneumonia variable does not count number of episodes.
- Presence of Calculus in the Kidney and/or Ureter is collected on Form II only.
- On Form II, Post-operative Wound Infection at the Site of the Spinal Surgery is collected only during annual year 1 (or 2).
- If the patient is coded "lost" (V201 = "5") then, leave all variables after V202 blank.

QC:

If the patient is not admitted to the System's acute unit - see [page 65](#).

If the patient is not admitted to the System's inpatient acute rehab unit - see [page 67](#).

FORM I

VARIABLE NAME: Number of Episodes of Pneumonia

DESCRIPTION: Pneumonia is a state of lung tissue inflammation of infectious etiology with radiographic demonstration of parenchymal disease.

Document pneumonia:

- 1) with onset **during acute (or subacute) medical/surgical care (for day-1 admissions only)** - V142AB;
- 2) with onset **during inpatient (or subacute) rehab (for day-1 admissions only)** -V142RB.

CHARACTERS: 2 for each entry

CODES: **00 None**

00-87 Valid range

88 Yes, number unknown

99 Unknown (V142AB, V142RB);

no System rehab admission (V142RB) See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.

Blank (on Form I - for non day-1 admissions only)

Blank (on Form II - only if V201 = "5")

QC: See pages [65](#) and [67](#).

REVISIONS: November 1995: Separate atelectasis and pneumonia variables were combined.

January 1998: Number of Episodes is no longer documented on Form II. Variable 221 was revised and may be found on page 103.

October 2000: Data collection during rehab changed from all patients to only day-1 admissions. Changed from episodes of Atelectasis and/or Pneumonia to Episodes of Pneumonia.

FORM I and FORM II

VARIABLE NAME: Pulmonary Embolism (PE)

DESCRIPTION: Condition resulting when a pulmonary artery becomes acutely obstructed by a clot formed upstream from the pulmonary arterial vascular tree.

Document clinical impression or confirmed clinical diagnoses of pulmonary embolism followed by definitive anticoagulation therapy:

- 1) with onset **during acute (or subacute) medical/surgical care (for day-1 admissions only)** - V142AC;
- 2) with onset **during inpatient (or subacute) rehab (for day-1 admissions only)** -V142RC; and
- 3) present **during the anniversary year being reported** - V221A.

CHARACTERS: 1 for each entry

- CODES:
- 0 No pulmonary embolism**
 - 1 Yes, confirmed by ventilation-perfusion lung scan**
 - 2 Yes, confirmed by pulmonary angiogram or helical CT scan**
 - 3 Yes, confirmed by ventilation-perfusion lung scan and pulmonary angiogram or helical CT scan**
 - 4 Yes, confirmed by other than the above techniques**
 - 5 Yes, but not confirmed by any specific diagnostic technique or procedure**
 - 6 Yes, confirmed by an unknown diagnostic technique or procedure**
 - 9 Unknown (V142AC, V142RC, V221A);**

no System rehab admission (V142RC) See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.

Blank (on Form I - for non day-1 admissions only)

Blank (on Form II - only if V201 = "5")

QC: See pages [65](#) and [67](#).

REVISIONS: November 1995: Code "6" was added to this variable.

January 1998: Data required only in annual years 1 and 2 on Form II.

October 2000: Data collection during rehab changed from all patients to only day-1 admissions. Form II data collection changed from years 1 and 2 only to year 1 and every 5th anniversary.

FORM I and FORM II

VARIABLE NAME: Thrombophlebitis, Deep Vein Thrombosis

DESCRIPTION: Deep-vein thrombosis (DVT) of the lower extremity is an occlusion of the venous system of the lower extremity. Positive DVT with definitive therapy instituted.

Document DVT:

- 1) with onset **during acute (or subacute) medical/surgical care (for day-1 admissions only)** - V142AD;
- 2) with onset **during inpatient (or subacute) rehab (for day-1 admissions only)** -V142RD; and
- 3) present **during the anniversary year being reported** - V221B.

CHARACTERS: 1 for each entry

- CODES:
- 0 No thrombophlebitis, DVT**
 - 1 Filter placed in inferior vena cava**
 - 2 DVT therapy instituted without confirmation of actual DVT by test result**
 - 3 DVT confirmed by test other than those listed here**
 - 4 DVT confirmed by impedance plethysmography (IPG)**
 - 5 DVT confirmed by I-125 labeled fibrinogen uptake (I-125)**
 - 6 DVT confirmed by duplex/doppler, ultrasound**
 - 7 DVT confirmed by venography**
 - 9 Unknown (V142AD, V142RD, V221B);**
no System rehab admission (V142RD) See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.

Blank (on Form I - for non day-1 admissions only)

Blank (on Form II - only if V201 = "5")

COMMENTS: Code the highest number that applies. The intent is to document DVT occurrence, not prophylaxis (except for the filter placement). If anticoagulant therapy is instituted after a DVT is suspected but no confirmation is obtained, then code 2. For prophylaxis only, code 0.

QC: See pages [65](#) and [67](#).

EXAMPLE: DVT therapy was instituted (without test results) on the 7th day the patient was in the System's acute care unit. On day 10 in the acute care unit DVT was confirmed by venography. DVT was confirmed by ultrasound at follow-up years 1 and 5.

| | <u>During Acute</u> | <u>During Rehab</u> |
|---|---------------------|---------------------|
| | <u>Year 01</u> | <u>Year 05</u> |
| 142D. Thrombophlebitis, Deep Vein Thrombosis..... | <u>7</u> | <u>0</u> |
| 221B. DVT during follow-up | <u>6</u> | <u>6</u> |

FORM I and FORM II

VARIABLE NAME: Thrombophlebitis, Deep Vein Thrombosis

REVISIONS: August 1993: Code 7 (Filter placed in inferior vena cava) was added.

January 1998: Data required only in annual years 1 and 2 on Form II.

October 2000: Data collection during rehab changed from all patients to only day-1 admissions. Form II data collection changed from years 1 and 2 only to year 1 and every 5th anniversary. The coding positions were reduced from 5 to 1 on Form I and Form II.

June 2001: codes were changed since Filter was moved to the lowest position in the coding hierarchy. The following chart lists the old (March 2001) and current (June 2001) codes.

| Codes | | |
|------------|---------|--|
| March 2001 | Current | |
| 0 | 0 | No thrombophlebitis, DVT |
| 7 | 1 | Filter placed in inferior vena cava |
| 1 | 2 | DVT therapy instituted without confirmation of actual DVT by test result |
| 2 | 3 | DVT confirmed by test other than those listed here |
| 3 | 4 | DVT confirmed by impedance plethysmography (IPG) |
| 4 | 5 | DVT confirmed by I-125 labeled fibrinogen uptake (I-125) |
| 5 | 6 | DVT confirmed by duplex/doppler, ultrasound |
| 6 | 7 | DVT confirmed by venography |

FORM II

VARIABLE NAME: Pneumonia

DESCRIPTION: Pneumonia is a state of lung tissue inflammation of infectious etiology with radiographic demonstration of parenchymal disease. Copies of the x-rays results are not required.

Document pneumonia:

occurring **during the anniversary year being reported.**

CHARACTERS: 1

CODES: **0** **No**
 1 **Yes**
 9 **Unknown**

Blank *(on Form II - only if V201 = "5")*

REVISIONS: November 1995: Separate atelectasis and pneumonia variables were combined.

January 1998: Number of episodes no longer counted in this Form II variable.

October 2000: Changed from Atelectasis and/or Pneumonia to Pneumonia only.

CONVERSION: The following conversion was made to records in existence at the time this variable was revised in January 1998:

| Old Code | Current Code |
|----------|--------------|
| 00 | 0 |
| 01-88 | 1 |
| 99 | 9 |

FORM II

VARIABLE NAME: Presence of Calculus in the Kidney and/or Ureter

DESCRIPTION: Abnormal concretion in the kidney and/or ureter.

Document calculus:

present **during the anniversary year being reported.**

CHARACTERS: 1

CODES:

0 No calculus

1 Yes, right kidney or ureter

2 Yes, left kidney or ureter

3 Yes, bilateral

4 Yes, unspecified location in the kidney or ureter

9 Unknown

Blank (*on Form II - only if V201 = "5"*)

COMMENTS: If a stone of unknown origin is passed spontaneously before x-ray evidence of its location is obtained, code this variable "9" (Unknown). Code the calculus even if it was removed during the anniversary year being reported.

REVISIONS: 1993: Separate Calculus of the Kidney and Calculus of the Ureter variables were combined into this single variable.

October 2000: this variable was deleted on Form I.

FORM I and FORM II

VARIABLE NAME: Operative Procedures

DESCRIPTION: This variable documents a select group of operative procedures performed During System and During Follow-up.

FORM I (V143):

For the day-1 admissions only

document these procedures performed during System acute medical/surgical care and performed during System acute inpatient rehab.

During System Acute Medical Care is the interval between admission to and discharge from the System's acute medical care unit. This period includes time in the System's subacute medical care unit.

During Rehabilitation is the period of time between the admission to and discharge from the System's inpatient acute rehabilitation unit. This period includes time in the System's inpatient subacute rehab unit and any transfers back to the acute (or subacute) medical unit after admission to rehab. After the patient is admitted to rehab, all operative procedures are recorded as having been performed "during rehab" (even if the patient returns to the acute medical/surgical unit for the surgery).

However, in the Treatment Phase variables (V148 to V155), return to the acute (or subacute) medical/surgical unit (after admission to rehab) is reported as a separate treatment phase. Then, subsequent return to the rehab unit (following surgery in acute) is another separate treatment phase.

FORM II (V222):

Use the "Yes" code if the operative procedure was performed **anytime between the beginning and the end of the anniversary year for which the Form II is being completed.**

If the operative procedure was performed during one anniversary year and repeated during a subsequent anniversary year, **use the "Yes" code for each year in which the procedure was performed.**

If the patient is coded "lost" (V201 = "5") then, leave all variables after V202 blank.

FORM I and FORM II

VARIABLE NAME: Operative Procedures

The following is a list of all procedures to be reported:

| Form I | Form II | Variable Name | Syllabus Page |
|--------|---------|---|---------------|
| 143A | | Laminectomy | 133 |
| 143B | | Spinal Decompression | 134 |
| 143C | | Spinal Fusion | 135 |
| 143D | | Internal Fixation of the Spine | 136 |
| 143E | | Surgical Repair of Failed Spinal Fusion | 137 |
| 143F | | Surgical Repair, Correction, or Removal of Internal Fixation Device | 138 |
| 143G | | Number of Operating Room Visits for Spinal Surgeries | 139 |
| 143H | | Laparotomy | 140 |
| 143I | | Traction | 141 |
| 143J | | Halo Vest, Halo Brace or Other Orthosis for the Neck | 142 |
| 143K | 222A | Closure of Decubitus Ulcer(s) | 143 |
| | 222B | Calculus Removal | 144 |
| | 222C | Bladder Neck Resection | 145 |
| | 222D | External Sphincterotomy or Other Sphincter Opening Procedures | 146 |

If the patient IS NOT a day-1 admission to the System:

leave all the Form I operative procedure variables (V143A to V143K) blank.

If the patient IS a day-1 admission to the System but is not admitted to the System's Acute (or Subacute) Medical/Surgical unit:

code all the Form I ("during acute") operative procedure variables unknown.

If the patient IS a day-1 admission to the System but is not admitted to the System's Acute (or Subacute) Inpatient Rehab unit:

code all the Form I ("during rehab") operative procedure variables unknown. See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.

QC: If the patient is not admitted to the System's acute unit, use the "Unknown" code in all Operative Procedures "During Acute".

If the patient is not admitted to the System's inpatient acute rehab unit, use the "Unknown" code in all Operative Procedures "During Inpatient Rehab".

FORM I

VARIABLE NAME: Laminectomy Performed During System

DESCRIPTION: Removal of normal intact lamina or foreign body at the site of spinal cord damage. Excision of the posterior arch of the vertebra.

Document laminectomy performed

- 1) **during acute (or subacute) medical/surgical care (for day-1 admissions only)** – V143AA and
- 2) **during inpatient acute (or subacute) rehab (for day-1 admissions only)**– V143RA

CHARACTERS: 1 for each entry

CODES: **0** **No**
 1 **Yes**
 9 **Unknown** (V143AA, V143RA);

no System rehab admission (V143RA) *See note on page 98 regarding “no System rehab admission” for Form Is entered after 03/31/2005.*

Blank *(on Form I - for non day-1 admissions only)*

COMMENTS: Removal of any bone or disk fragment from the spinal canal should be coded in spinal decompression.

All operative procedures performed after the patient is admitted to System rehab must be recorded as having been performed “during rehab” (even if the patient returns to the acute medical/surgical unit for the surgery).

QC: See pages 65 and 67.

REVISIONS: November 1995: Dates were added to this variable.
 October 2000: Dates were removed from this variable.

FORM I

VARIABLE NAME: Spinal Decompression Performed During System

DESCRIPTION: The removal of bone or disk fragments or foreign bodies (such as bullet fragments) from the spinal canal. Includes discectomy.

It is possible for a patient with posterior bone or disk fragments in the canal to have a laminectomy and a posterior spinal decompression.

Document spinal decompressions performed

- 1) **during acute (or subacute) medical/surgical care** (for day-1 admissions only) – V143AB and
- 2) **during inpatient acute (or subacute) rehab** (for day-1 admissions only)– V143RB

CHARACTERS: 1 for each entry (up to 3 entries for V143AB and V143RB)

CODES: **0 No decompression surgery** (*Valid in coding position #1 only*)

1 Yes, anterior approach

2 Yes, posterior approach

3 Yes, both approaches, simultaneously

4 Yes, posterolateral

5 Yes decompression, approach unknown

9 Unknown (*V143AB, V143RB*);

no System rehab admission (*V143RB*) See note on page 98 regarding “no System rehab admission” for Form Is entered after 03/31/2005.

Blank (*for non day-1 admissions only*)

COMMENTS: Document up to 3 procedures performed during acute and up to 3 procedures performed during rehab. When this procedure is performed **more than once USING THE SAME APPROACH**, code each procedure separately only if they occur during separate OR visits.

All operative procedures performed after the patient is admitted to System rehab must be recorded as having been performed “during rehab” (even if the patient returns to the acute medical/surgical unit for the surgery).

QC: See pages [65](#) and [67](#).

REVISIONS: November 1995: Dates were added to this variable.

October 2000: Dates were removed from this variable.

SOFTWARE: Codes 0 and 9 are allowed only in coding position #1. When one of these codes is entered in coding position #1 the software advances the user to the next variable.

FORM I

VARIABLE NAME: Spinal Fusion Performed During System

DESCRIPTION: The addition of a bone graft to the vertebrae for the purpose of achieving intervertebral fusion or stability.

Document spinal fusions performed

- 1) **during acute (or subacute) medical/surgical care (for day-1 admissions only)** – V143AC and
- 2) **during inpatient acute (or subacute) rehab (for day-1 admissions only)**– V143RC

CHARACTERS: 1 for each entry (up to 3 entries for V143AC and V143RC)

CODES: **0 No spinal fusion** (*Valid in coding position #1 only*)

1 Yes, anterior approach

2 Yes, posterior approach

3 Yes, both approaches, simultaneously

4 Yes, posterolateral

5 Yes spinal fusion, approach unknown

9 Unknown (*V143AC, V143RC*);

no System rehab admission (*V143RC*) See note on page 98 regarding “no System rehab admission” for Form Is entered after 03/31/2005.

Blank (*for non day-1 admissions only*)

COMMENTS: Document up to 3 procedures performed during acute and up to 3 procedures performed during rehab. When this procedure is performed **more than once USING THE SAME APPROACH,** code each procedure separately only if they occur during separate OR visits.

Document only post-SCI fusions.

All operative procedures performed after the patient is admitted to System rehab must be recorded as having been performed “during rehab” (even if the patient returns to the acute medical/surgical unit for the surgery).

QC: See pages [65](#) and [67](#).

If the patient did not have spinal fusion during acute, code variable 143AC “0” and code variable 143AE “8”.

REVISIONS: November 1995: Dates and code “4” for posterolateral were added to this variable.

October 2000: Dates were removed from this variable.

SOFTWARE: Codes 0 and 9 are allowed only in coding position #1. When one of these codes is entered in coding position #1 the software advances the user to the next variable.

FORM I

VARIABLE NAME: Internal Fixation of the Spine Performed During System

DESCRIPTION: The fixation may be attached to the spine by one or more methods (rods, plates, wires, etc.) - individually or in combination - to provide internal surgical stabilization of the vertebral column.

Document internal fixations performed

- 1) **during acute (or subacute) medical/surgical care (for day-1 admissions only)** – V143AD and
- 2) **during inpatient acute (or subacute) rehab (for day-1 admissions only)**– V143RD

CHARACTERS: 1 for each entry (up to 3 entries for V143AD and V143RD)

CODES: **0 No internal fixation** (*Valid in coding position #1 only*)

1 Yes, anterior approach

2 Yes, posterior approach

3 Yes, both approaches, simultaneously

4 Yes, posterolateral

5 Yes internal fixation, approach unknown

9 Unknown (*V143AD, V143RD*);

no System rehab admission (*V143RD*) See note on page 98 regarding “no System rehab admission” for Form Is entered after 03/31/2005.

Blank (*for non day-1 admissions only*)

COMMENTS: Document up to 3 procedures performed during acute and up to 3 procedures performed during rehab. When this procedure is performed **more than once USING THE SAME APPROACH,** code each procedure separately only if they occur during separate OR visits.

Document only post-SCI fixations.

All operative procedures performed after the patient is admitted to System rehab must be recorded as having been performed “during rehab” (even if the patient returns to the acute medical/surgical unit for the surgery).

QC: See pages [65](#) and [67](#).

If variable 143AD_1 = “0” then, variable 143AF_1 must = “8”.

REVISIONS: November 1995: Dates and the code “4” for posterolateral were added; reduced from 5 to 3 coding positions.

October 2000: Dates were removed from this variable.

SOFTWARE: Codes 0 and 9 are allowed only in coding position #1. When one of these codes is entered in coding position #1 the software advances the user to the next variable.

FORM I

VARIABLE NAME: Surgical Repair of Failed Spinal Fusion Performed During System

DESCRIPTION: Surgical repair of displaced graft, malalignment or pseudoarthrosis resulting from spinal fusion performed during the initial hospitalization period.

Document repairs performed

- 1) **during acute (or subacute) medical/surgical care (for day-1 admissions only)** - V143AE_1 through V143AE_3;
- 2) **during inpatient acute (or subacute) rehab (for day-1 admissions only)** -V143RE_1 through V143RE_3.

CHARACTERS: 1 for each entry (up to 3 entries for V143AE and V143RE)

CODES: **0 Surgical repair of spinal fusion not necessary** (*Valid in coding position #1 only*)

1 Yes, anterior repair of failed posterior spinal fusion

2 Yes, anterior repair of failed anterior spinal fusion

3 Yes, posterior repair of failed anterior spinal fusion

4 Yes, posterior repair of failed posterior spinal fusion

5 Yes, surgical repair - unknown approach and/or unknown failed fusion site

8 Not applicable, no fusion (*Valid in coding position #1 only*)

9 Unknown (*V143AE, V143RE*);

no System rehab admission (*V143RE*) See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.

Blank (*for non day-1 admissions only*)

COMMENTS: Document only repairs of post-SCI fusions. Document up to 3 procedures performed during acute and up to 3 procedures performed during rehab. When this procedure is performed **more than once USING THE SAME APPROACH**, code each procedure separately only if they occur during separate OR visits.

If the patient did not have any spinal fusion During System, use code "8" in both V143AE and V143RE.

If repair of failed spinal fusion was not necessary, use code "0" (Surgical repair of spinal fusion not necessary).

All operative procedures performed after the patient is admitted to System rehab must be recorded as having been performed "during rehab" (even if the patient returns to the acute medical/surgical unit for the surgery).

QC: See pages [65](#) and [67](#).

If variable 143AC_1 = "0" then, variable 143AE_1 must = "8".

SOFTWARE: Codes 0, 8 and 9 are allowed only in coding position #1. When one of these codes is entered in coding position #1 the software advances the user to the next variable.

FORM I

VARIABLE NAME: Surgical Repair, Correction, or Removal of Internal Fixation Device During System

DESCRIPTION: Any surgical procedure to repair, correct or remove an internal fixation device (of the spine).

Document repairs performed

- 1) **during acute (or subacute) medical/surgical care (for day-1 admissions only)** - V143AF_1 through V143AF_3;
- 2) **during inpatient acute (or subacute) rehab** (for day-1 admissions only) -V143RF_1 through V143RF_3.

CHARACTERS: 1 for each entry (up to 3 entries for V143AF and V143RF)

CODES: **0 No repair, correction, nor removal of internal fixation device**
(Valid in coding position #1 only)

1 Repair for hardware breakage or dislodgement from bone

2 Removal for any reason

8 Not applicable, no internal fixation (Valid in coding position #1 only)

9 Unknown (V143AF, V143RF);

no System rehab admission (V143RF) See note on page 98 regarding “no System rehab admission” for Form Is entered after 03/31/2005.

Blank (for non day-1 admissions only)

COMMENTS: Document only post-SCI fixations. Document up to 3 procedures performed during acute and up to 3 procedures performed during rehab.

If the patient did not have an internal fixation device During System, use code “8” in both V143AF and V143RF.

If surgical repair, correction, or removal of an internal fixation device was not necessary, use code "0" (No repair, correction nor removal of internal fixation device).

All operative procedures performed after the patient is admitted to System rehab must be recorded as having been performed “during rehab” (even if the patient returns to the acute medical/surgical unit for the surgery).

QC: See pages [65](#) and [67](#).

If variable 143AD_1 = “0” then, variable 143AF_1 must = “8”.

SOFTWARE: Codes 0, 8 and 9 are allowed only in coding position #1. When one of these codes is entered in coding position #1 the software advances the user to the next variable.

FORM I

VARIABLE NAME: Number of Operating Room Visits for Spinal Surgeries Performed During System

DESCRIPTION: Document the total number of OR visits for surgery performed on the vertebral column or its contents:

- 1) **during acute (or subacute) medical/surgical care (for day-1 admissions only)** - V143AG;
- 2) **during inpatient acute (or subacute) rehab (for day-1 admissions only)** - V143RG.

CHARACTERS: 2 for each entry

CODES: **00** **No spinal surgery procedures**
 00-87 **Valid range**
 88 **Spinal surgery performed but number of OR visits unknown**
 99 **Unknown** (V143AG, V143RG);
 no System rehab admission (V143RG) See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.

Blank (for non day-1 admissions only)

COMMENTS: Document the total number of times the patient was "on the table" for spinal surgery.

Include all procedures documented in variables 143A (Laminectomy), 143B Spinal Decompression, 143C (Spinal Fusion), 143D (Internal Fixation), 143E (Surgical Repair of Failed Spinal Fusion), 143F (Surgical Repair, Correction, or Removal of Internal Fixation Device).

Also include OR visits for other spinal surgeries performed during acute care or during inpatient rehab but not documented in this database (i.e., not collected in variables 143A through 143K).

Do not include skeletal traction, halo vest or halo brace.

All operative procedures performed after the patient is admitted to System rehab must be recorded as having been performed "during rehab" (even if the patient returns to the acute medical/surgical unit for the surgery).

QC: See pages [65](#) and [67](#).

If this variable = "00" (*none*) then, V143A, V143B, V143C and V143D, must = "0" and V143E and V143F must = "8".

FORM I

VARIABLE NAME: Laparotomy Performed During System

DESCRIPTION: Laparotomy for closure/excision.

Document laparotomy performed

- 1) **during acute (or subacute) medical/surgical care (for day-1 admissions only)** - V143AH;
- 2) **during inpatient acute (or subacute) rehab (for day-1 admissions only)** -V143RH.

CHARACTERS: 1 for each entry

CODES: **0 No**
 1 Yes
 9 Unknown (V143AH, V143RH);

no System rehab admission (V143RH) See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.

Blank (for non day-1 admissions only)

COMMENTS: Do NOT include laparoscopy.

All operative procedures performed after the patient is admitted to System rehab must be recorded as having been performed "during rehab" (even if the patient returns to the acute medical/surgical unit for the surgery).

QC: See pages [65](#) and [67](#).

REVISIONS: In November 1995 the three "Yes" codes in old Laparotomy variable were collapsed to one "Yes" code in this variable and coding positions were decreased from 3 to 1.

CONVERSION: November 1995 - for records in existence at that time:

If old During System variable was coded "1", 2 or "3", code "1" was placed in this variable.

If old During System variable was coded "0" (or "9"), these codes were moved into this variable.

FORM I

VARIABLE NAME: Traction Performed During System

DESCRIPTION: Longitudinal skull traction via percutaneous cranial pins.

Document traction performed:

- 1) **during acute (or subacute) medical/surgical care (for day-1 admissions only)** - V143AI;
- 2) **during inpatient acute (or subacute) rehab (for day-1 admissions only)** -V143RI.

CHARACTERS: 1 for each entry

CODES: **0** **No**
 1 **Yes**
 9 **Unknown** (V143AI, V143RI);

no System rehab admission (V143RI) See note on page 98 regarding “no System rehab admission” for Form Is entered after 03/31/2005.

Blank (for non day-1 admissions only)

COMMENTS: Includes various types of tongs and halo without the vest.

All operative procedures performed after the patient is admitted to System rehab must be recorded as having been performed “during rehab” (even if the patient returns to the acute medical/surgical unit for the surgery).

QC: See pages [65](#) and [67](#).

FORM I

VARIABLE NAME: Halo Vest, Halo Brace or Other Orthosis for the Neck Performed During System

DESCRIPTION: Spinal column stabilization using a halo or other orthosis (i.e., Philadelphia or similar hard collar) for the neck.

Document halo vest, halo brace or other orthosis for the neck applied:

- 1) **during acute (or subacute) medical/surgical care (for day-1 admissions only)** - V143AJ;
- 2) **during inpatient acute (or subacute) rehab (for day-1 admissions only)** -V143RJ.

CHARACTERS: 1 for each entry

CODES: **0** **No**
 1 **Yes**
 9 **Unknown** (V143AJ, V143RJ);

no System rehab admission (V143RJ) See note on page 98 regarding “no System rehab admission” for Form Is entered after 03/31/2005.

Blank (for non day-1 admissions only)

COMMENTS: All operative procedures performed after the patient is admitted to System rehab must be recorded as having been performed “during rehab” (even if the patient returns to the acute medical/surgical unit for the surgery).

“Other orthosis” refers to other hard braces intended for spinal column stabilization only (e.g., Minerva, Philadelphia, etc.) Soft collars are excluded from this variable.

QC: See pages [65](#) and [67](#).

FORM I and FORM II

VARIABLE NAME: Closure of Decubitus Ulcer(s)

DESCRIPTION: Document pedicle or flap graft surgery performed:

Form I (V143K):

- 1) **during acute (or subacute) medical/surgical care (for day-1 admissions only)** - V143AK and
- 2) **during inpatient acute (or subacute) rehab (for day-1 admissions only)** -V143RK;

Form I (V222A):

during the anniversary year being reported (V222A).

CHARACTERS: 1 for each entry

- CODES:
- 0** No closure but, patient did have ulcer(s)
 - 1** Yes
 - 8** Not applicable, no decubitus ulcers in the period being reported
 - 9** Unknown (V143AK, V143RK, V222A);
- no System rehab admission (V143RK)** *See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005.*

Blank (on Form I - for non day-1 admissions only)

Blank (on Form II - only if V201 = "5")

COMMENTS: All operative procedures performed after the patient is admitted to System rehab must be recorded as having been performed "during rehab" (even if the patient returns to the acute medical/surgical unit for the surgery).

QC: See pages [65](#) and [67](#).
 If variable 140A = "00" (*No ulcers*) then, V143AK must = "8".
 If variable 140R = "00" (*No ulcers*) then, V143RK must = "8".
 If V107 = "88888888" - see [page 65](#).
 If V108 = "88888888" - see [page 67](#).

REVISIONS: October 2000: code "8" was changed from "not applicable, not admitted to rehab" to "not applicable, no decubitus ulcers". "Not admitted to inpatient rehab" was assigned to code "9".

This variable is now collected only on day-1 admits. In the old variable (V144K), the data collection period was "during acute and rehab" for the day-1 admits and, "during rehab only" for non day-1 admits.

FORM II

VARIABLE NAME: Calculus Removal

DESCRIPTION: Removal of abnormal concretion from the kidney, ureter, or bladder.

Document calculus removals performed:

during the anniversary year being reported.

CHARACTERS: 1

CODES:

- 0 No calculus**
- 1 Yes calculus, removed**
- 2 Yes calculus, passed spontaneously**
- 8 Yes calculus, calculus not removed**
- 9 Unknown**

Blank (*only if V201 = "5"*)

REVISIONS: January 1998: The Form I variable (V143L) was deleted and, the Form II variable (current #V222B) no longer documented methods and locations of calculus removal.

CONVERSION: January 1998: the following conversions were made:

| Code in old variable | Code in current variable |
|----------------------|--------------------------|
| 00 | 0 |
| 01 to 06, 08, 09 | 1 |
| 07 | 2 |
| 88 | 8 |
| 99 | 9 |

FORM II

VARIABLE NAME: Bladder Neck Resection

DESCRIPTION: Resection of the neck of the bladder

during the anniversary year being reported.

CHARACTERS: 1

CODES: **0** **No**
 1 **Yes**
 9 **Unknown**

Blank *(only if V201 = "5")*

COMMENTS: Includes TUR.

FORM II

VARIABLE NAME: External Sphincterotomy or Other Sphincter Opening Procedures

DESCRIPTION: Incision of the external sphincter or the use of stents or other devices to increase the opening of the external sphincter
during the anniversary year being reported.

CHARACTERS: 1

CODES: **0** **No**
 1 **Yes**
 9 **Unknown**
Blank *(only if V201 = "5")*

REVISIONS: August 1993: This variable was expanded from external sphincterotomy only.

 October 2000: Name changed from Sphincter Dilatation and Sphincter Opening Procedures to External Sphincterotomy or Other Sphincter Opening Procedures.

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Items A through M and T

DESCRIPTION: This variable assesses severity of disability through measurement of the most common and useful functional assessment items. Only the thirteen motor assessment items (A through M) and the Motor Subtotal Score (S) are documented.

Data are collected

- 1) **at the beginning of the first inpatient acute rehab phase** (V144AA through V144AM, V144AT);
- 2) **prior to discharge from the last inpatient acute rehab phase** in the System (V144DA through V144DM, V144DT);
- 3) **on the anniversary date being reported** (V227A through V227M, V227T).

CHARACTERS: 1 for each FIM item (V144AA through V144AM, V144DA through V144DM, V227A through V227M)

2 for each Total Motor Score (V144AT, V144DT, V227T)

CODES: **9 Unknown -**

no observer was available to rate the subject's performance; or
the observer's rating is not available; or

the assessments were not performed within 72 hours of admission to inpatient rehab or within one week of inpatient rehab discharge; or

the subject is under the age of 6; or

the subject was not admitted to System inpatient acute rehab See note on page 98 regarding "no System rehab admission" for Form Is entered after 03/31/2005. ; or

evaluation/interview not done (for the Form II FIM only); or

subject does not perform the activity and a helper does not perform the activity for the subject - for FIM items G & H (at admission) and items A to J, L and M (at discharge and on Form II).

INDEPENDENT (NO HELPER): Another person is not required for the activity.

7 Complete Independence – The subject safely performs all the tasks described as making up the activity within a reasonable amount of time, and does so without modification, assistive devices, or aids.

6 Modified Independence - One or more of the following may be true: the activity requires an assistive device, the activity takes more than reasonable time, or the activity involves safety (risk) considerations.

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Items A through M and T

CODES: **DEPENDENT (REQUIRES HELPER):** Subject requires another person for either supervision or physical assistance in order for the activity, or it is not performed.

MODIFIED DEPENDENCE - The subject expends half (50%) or more of the effort. The levels of assistance required are defined below:

5 Supervision or Setup – The subject requires no more help than standby, cueing or coaxing, without physical contact; alternately, the helper sets up needed items or applies orthoses or assistive/adaptive devices.

4 Minimal Contact Assistance – The subject requires no more help than touching, and expends 75% or more of the effort.

3 Moderate Assistance – The subject requires more help than touching, or expends between 50 and 75% of the effort.

COMPLETE DEPENDENCE - The subject expends less than half (less than 50%) of the effort. Maximal or total assistance is required. The levels of assistance required are defined below:

2 Maximal Assistance – The subject expends between 25 and 49% of the effort.

1 Total Assistance – The subject expends less than 25% of the effort or subject cannot be rated due to physical or cognitive limitations and a helper performs the activity for the patient

0 Activity Does Not Occur – Use code 0 for Self Care, Transfers and Locomotion items during the admission assessment only and, in Transfers (Tub and Shower) at admission and discharge. The subject does not perform the activity, and a helper does not perform the activity for the subject.

NOTE: Do *not* use this code:

- if the subject performs the activity without a clinician's observation. In such cases, consult other clinicians, the subject's medical record, the subject, and the subject's family members.
- if the clinician does not observe the subject performing the activity. In such cases, consult other clinicians, the subject's medical record, the subject, and the subject's family members to obtain information about the subject's functional status. If no information is available, use code 9.

Blank (on Form II - only if V201 = "5")

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Items A through M and T

COMMENTS: For all systems, the beginning of the inpatient rehabilitation phase is marked by the first admission to the System's inpatient acute rehabilitation hospital, transfer to the System's inpatient rehabilitation unit, or commencement of the inpatient rehabilitation program in a multipurpose unit in the System. This is the date coded in Variable 108 (Date of first System Inpatient Rehab Admission). Admission assessments should occur within 72 hours of this date.

The discharge assessment should occur as close as possible to discharge from the last System inpatient rehab phase. For subjects who are discharged from the System's inpatient rehab unit, this is the date coded in Variable 110. Discharge assessments should preferably occur within three days of this date. If the assessments are not performed within one week of discharge, the FIM scores should not be reported (i.e., the "unknown" codes should be used).

Note: for subjects with multiple System inpatient rehab phases, the admit and discharge FIMs will be from different inpatient rehab phases.

If the clinician does not observe the subject performing the activity, consult other clinicians, the subject's medical record, the subject, and the subject's family members to obtain information about the subject's functional status. Self-report is not acceptable when the patient fills out an interview form (either in the clinic or one sent in the mail). The admission assessments for bladder and bowel accidents include the 4 days prior to the rehab admission, as well as the first 3 days in the rehab unit.

Record the number which best describes the respondent's level of function for each FIM item on the coding form. If the subject does not perform an activity during the observation period due to physical or cognitive limitations (e.g., a cast or IV line) and, a helper performs the activity for the subject, use code "1". If the subject does not perform an activity during the observation period and, a helper does not perform the activity for the subject, use code "0" (when allowed) or, use code "9" (when "0" is not allowed).

In the event FIM items are rated higher during therapy than when the subject is observed on the nursing floor or in his/her room, record the lower score. The usual reason for this is the subject has not mastered the function or is too tired or not motivated enough to transfer the behavior out of the therapy setting. The lower score is recorded because it is what the subject actually does. There may be a need to resolve the question of what is "usual" by discussion between the therapist and nurse.

Use the Uniform Data System's (UDS) training materials to train the persons who document this information. Training manuals are available (for a fee) from the UDS for non-UDS subscribers. Also, use the UDS FIM Decision Tree (see Appendix A of this syllabus) to assist with Form II assessments conducted by telephone where the clinician was not able to directly observe the respondent's behavior.

If the subject is coded "lost" (V201 = "5") then, leave all variables after V202 blank.

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Items A through M and T

SOURCE: Uniform Data System for Medical Rehabilitation.

QC: See pages [65](#) and [67](#).

REVISIONS: Form I FIM data are to be collected on all subjects admitted to the rehab unit after 9/30/88 (i.e., V108 greater than 09/30/1988).

November 1995: The FIM on Form II was added to the database. Data for all FIM items, in all the Extended data years (i.e., years 1, 2, 5, 10, 15, 20, 25) were expected in Form IIs with Indates between 02/01/1996 and 01/31/98.

January 1998: The FIM required only in annual years 1 and 2 and, all Communication and Social Cognition items (items N, NM, O, OM, P, Q and R) were deleted.

July 1998: The FIM (motor items and total motor score only) required in all the Extended data years (i.e., years 1, 2, 5, 10, 15, 20, 25). Between January and July 1998 the FIM was not required after year 2. Therefore, many Form IIs entered during that time have unknown codes in the FIM.

October 2000: FIM on Form II no longer required in annual year 2.

January 2002: UDS changes on Form I were implemented for those patients who were discharged on or after January 1, 2002 and, on Form II for the interviews performed on or after March 1, 2002.

The following is a list of all items included in this variable:

SELF CARE

- A. Eating
- B. Grooming
- C. Bathing
- D. Dressing - Upper body
- E. Dressing - Lower body
- F. Toileting

SPHINCTER CONTROL

- G. Bladder Management
- H. Bowel Management

MOBILITY (TRANSFER)

- I. Bed, Chair, Wheelchair
- J. Toilet
- K. Tub, Shower

LOCOMOTION

- L. Walking or Wheelchair
- LM. Mode of Locomotion
- M. Stairs

TOTAL

- T. Total Motor Score

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Self Care: Eating

DESCRIPTION: Includes the ability to use suitable utensils to bring food to the mouth, as well as the ability to chew and swallow the food once the meal is presented in the customary manner on a table or tray. The subject performs this activity safely.

CHARACTERS: 1 for each entry

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

7 Complete independence – The subject eats from a dish while managing a variety of food consistencies, and drinks from a cup or glass with the meal presented in the customary manner on a table or tray. The subject opens containers, butters bread, cuts meat, pours liquids and uses a spoon or fork to bring food to the mouth, where it is chewed and swallowed. The subject performs this activity safely.

6 Modified independence – Performance of the activity involves safety considerations, or the subject requires an adaptive or assistive device such as a long straw, spork or rocking knife; requires more than a reasonable amount of time to eat; or requires modified food consistency or blenderized food. If the subject relies on other means of alimentation, such as parenteral or gastrostomy feedings, then (s)he self-administers the feedings.

HELPER

5 Supervision or setup – The subject requires supervision (e.g., standing by, cueing or coaxing) or setup (application of orthoses or assistive/adaptive devices), or another person is required to open containers, butter bread, cut meat, or pour liquids.

4 Minimal contact assistance – The subject performs 75% or more of eating tasks.

3 Moderate assistance – The subject performs 50% to 74% of eating tasks.

2 Maximal assistance – The subject performs 25% to 49% of eating tasks.

1 Total assistance – The subject performs less than 25% of eating tasks, or the subject relies on parenteral or gastrostomy feedings (either wholly or partially) and does not administer self-administer the feedings; or the subject cannot perform the task due to physical or cognitive limitations and a helper performs the activity for the subject.

0 Activity does not occur – Enter code 0 only for the admission assessment (use code 9 at discharge and on Form II). The subject does not eat *and* does not receive any parenteral/enteral nutrition *and* a helper does not perform the activity for the subject. Use of this code should be rare.

Blank (on Form II - only if V201 = "5")

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Self Care: Grooming

DESCRIPTION: Includes oral care, hair grooming (combing or brushing hair), washing the hands*, washing the face*, and either shaving the face or applying makeup. If the subject neither shaves nor applies make-up, Grooming includes only the first four tasks. The subject performs this activity safely.

CHARACTERS: 1 for each entry

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

7 Complete independence – The subject cleans teeth or dentures, combs or brushes hair, washes the hands*, washes the face, and either shaves the face or applies make-up, including all preparations. The subject performs this activity safely.

6 Modified independence - The subject requires specialized equipment (including prosthesis or orthosis) to perform grooming activities, or takes more than a reasonable amount of time, or there are safety considerations.

HELPER

5 Supervision or setup - The subject requires supervision (e.g., standing by, cueing or coaxing) or setup (application of orthoses or adapted/assistive devices, setting out grooming equipment, and initial preparation such as applying toothpaste to toothbrush and opening make-up containers).

4 Minimal contact assistance – The subject performs 75% or more of grooming tasks.

3 Moderate assistance - The subject performs 50% to 74% of grooming tasks.

2 Maximal assistance - The subject performs 25% to 49% of grooming tasks.

1 Total assistance - The subject performs less than 25% of grooming tasks or the subject cannot perform the task due to physical or cognitive limitations and a helper performs the activity for the subject.

0 Activity does not occur – Enter code 0 only for the admission assessment (use code 9 at discharge and on Form II). The subject does not perform any grooming activities (oral care, hair grooming, washing the hands, washing the face, and either shaving the face or applying make-up) and is not groomed by a helper. Use of this code should be rare.

Blank (on Form II - only if V201 = "5")

COMMENT: Assess only the activities listed in the definition. Grooming does not include flossing teeth, shampooing the hair, applying deodorant, or shaving legs. If the subject is bald or chooses not to shave or apply make-up, do not access those activities.

* including rinsing and drying.

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Self Care: Bathing

DESCRIPTION: Includes washing, rinsing and drying the body from the neck down (excluding the neck and back) in either a tub or shower or sponge/bed bath. The patient performs the activity safely.

CHARACTERS: 1 for each entry

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

7 Complete independence – The subject safely bathes (washes, rinses and dries) the body.

6 Modified independence – The subject requires specialized equipment (including prosthesis or orthosis) to bathe, or takes more than a reasonable amount of time, or there are safety considerations.

HELPER

5 Supervision or setup – The subject requires supervision (e.g., standing by, cueing or coaxing) or setup (application of assistive/adaptive devices, setting out bathing equipment, and initial preparation such as preparing the water or washing materials).

4 Minimal contact assistance - The subject performs 75% or more of bathing tasks.

3 Moderate assistance - The subject performs 50% to 74% of bathing tasks.

2 Maximal assistance - The subject performs 25% to 49% of bathing tasks.

1 Total assistance - The subject performs less than 25% of bathing tasks or the subject cannot perform the task due to physical or cognitive limitations and a helper performs the activity for the subject.

0 Activity does not occur - Enter code 0 only for the admission assessment (use code 9 at discharge and on Form II). The subject does not bathe self and is not bathed by a helper. Use of this code should be rare.

Blank (on Form II - only if V201 = "5")

COMMENTS: There are ten body parts included in this activity, each accounting for 10% of the total: chest, left arm, right arm, abdomen, perineal area, buttocks, left upper leg, right upper leg, left lower leg (including foot) and right lower leg (including foot).

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Self Care: Dressing, Upper Body

DESCRIPTION: Includes dressing and undressing above the waist, as well as applying and removing prosthesis or orthosis when applicable. The subject performs this activity safely.

CHARACTERS: 1 for each entry

CODES: 9 Unknown (*see [page 147](#) for details*)

NO HELPER

7 Complete independence - The subject dresses and undresses self. This includes obtaining clothes from their customary places (such as drawers and closets) and may include managing a bra, pullover garment, front-opening garment, zippers, buttons, or snaps, as well as the application and removal of a prosthesis or orthosis (which is not used as an assistive device for upper body dressing) when applicable. The subject performs this activity safely.

6 Modified independence - The subject requires special adaptive closure such as Velcro® Fastener, or an assistive device (including a prosthesis or orthosis) to dress, or takes more than a reasonable amount of time.

HELPER

5 Supervision or setup - The subject requires supervision (e.g., standing by, cueing or coaxing) or setup (application of an upper body or limb orthosis/prosthesis, application of an assistive/adaptive device, or setting out clothes or dressing equipment).

4 Minimal contact assistance - The subject performs 75% or more of dressing tasks.

3 Moderate assistance - The subject performs 50% to 74% of dressing tasks.

2 Maximal assistance - The subject performs 25% to 49% of dressing tasks.

1 Total assistance - The subject performs less than 25% of dressing tasks or the subject cannot perform the task due to physical or cognitive limitations and a helper performs the activity for the subject.

0 Activity does not occur - Enter code 0 only for the admission assessment (use code 9 at discharge and on Form II). The subject does not dress in clothing that is appropriate to wear in public and is not dressed by a helper.. The subject who wears only a hospital gown should be coded “0 – Activity does not occur”. Putting on and taking off scrubs may be appropriate for purposes of assessment. Use of this code should be rare.

Blank (*on Form II - only if V201 = “5”*)

COMMENT: When assessing dressing and undressing, the subject must use clothing that is appropriate to wear in public. If the subject wears only hospital gowns or nightgowns/pajamas, score as level 0 at admit (9 at discharge and on Form II).

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Self Care: Dressing, Lower Body

DESCRIPTION: Includes dressing and undressing from the waist down, as well as applying and removing a prosthesis or orthosis when applicable. The subject performs this activity safely.

CHARACTERS: 1 for each entry

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

7 Complete independence – The subject dresses and undresses safely. This includes obtaining clothes from their customary places (such as drawers and closets), and may also include managing underpants, slacks, skirt, belt, stockings, shoes, zippers, buttons, and snaps as well as the application and removal of a prosthesis or orthosis (which is not used as an assistive device for lower body dressing) when applicable.

6 Modified independence - The subject requires special adaptive closure such as Velcro® Fastener, or an assistive device (including a prosthesis or orthosis) to dress, or takes more than a reasonable amount of time.

HELPER

5 Supervision or setup - The subject requires supervision (e.g., standing by, cueing or coaxing) or setup (application of an lower body or limb orthosis/prosthesis, application of an assistive/adaptive device or setting out clothes or dressing equipment).

4 Minimal contact assistance - The subject performs 75% or more of dressing tasks.

3 Moderate assistance - The subject performs 50% to 74% of dressing tasks.

2 Maximal assistance - The subject performs 25% to 49% of dressing tasks.

1 Total assistance - The subject performs less than 25% of dressing tasks or the subject cannot perform the task due to physical or cognitive limitations and a helper performs the activity for the subject.

0 Activity does not occur - Enter code 0 only for the admission assessment (use code 9 at discharge and on Form II). The subject does not dress in clothing that is appropriate to wear in public and is not dressed by a helper. The subject who wears only a hospital gown and/or underpants and/or footwear should be coded “0 – Activity does not occur”. Putting on and taking off scrubs may be appropriate for purposes of assessment. Use of this code should be rare.

Blank (on Form II - only if V201 = “5”)

COMMENT: When assessing dressing and undressing, the subject must use clothing that is appropriate to wear in public. If the subject wears only hospital gowns or nightgowns/pajamas, score as level 0 at admit (9 at discharge and on Form II).

VARIABLES 144AF, 144DF and 227F
FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Self Care: Toileting

DESCRIPTION: Includes maintaining perineal hygiene and adjusting clothing before and after toilet, bedpan, or urinal. The subject performs this activity safely.

CHARACTERS: 1 for each entry

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

7 Complete independence – The subject safely cleanses self after voiding and bowel movements and safely adjusts clothing before and after using toilet or bedpan.

6 Modified independence - The subject requires specialized equipment (including prosthesis or orthosis) during toileting, or takes more than a reasonable amount of time, or there are safety considerations.

HELPER

5 Supervision or setup - The subject requires supervision (e.g., standing by, cueing or coaxing) or setup (application of adaptive devices or opening packages).

4 Minimal contact assistance - The subject performs 75% or more of toileting tasks.

3 Moderate assistance - The subject performs 50% to 74% of toileting tasks.

2 Maximal assistance - The subject performs 25% to 49% of toileting tasks.

1 Total assistance - The subject performs less than 25% of toileting tasks; or the subject cannot perform the task due to physical or cognitive limitations and a helper performs the activity for the subject.

0 Activity does not occur - Enter code 0 only for the admission assessment (use code 9 at discharge and on Form II). The subject does not perform *any* of the toileting tasks (perineal cleansing, clothing adjustment before and after toilet use, etc.), and a helper does not perform *any* of these activities for the subject. Use of this code should be rare.

Blank (on Form II - only if V201 = "5")

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Sphincter Control: Bladder Management

DESCRIPTION: Bladder Management consists of two function modifiers (*Level of Assistance* and *Frequency of Accidents*). After these two function modifiers are scored, the lower (more dependent) score is recorded in FIM item G.

FUNCTION

MODIFIER #1: Bladder Management - Level of Assistance

DESCRIPTION: This is the first function modifier used to determine Sphincter Control: Bladder Management. It includes the safe use of equipment or agents for bladder management.

CODES: **9 Unknown** (*see page 147 for details*)

NO HELPER

7 Complete independence – The subject controls bladder completely and intentionally without equipment or devices, and is *never incontinent* (no accidents).

6 Modified independence - The subject requires a urinal, bedpan, catheter, absorbent pad, diaper, urinary collecting device, or urinary diversion or uses medication for control. If catheter is used, the subject cleans, sterilizes, and sets up the equipment for irrigation without assistance. If the subject uses a device, (s)he assembles and applies an external catheter with drainage bags or an ileal appliance without assistance of another person; the subject also empties, puts on, removes, and cleans leg bag or empties and cleans ileal appliance bag. *The subject has no accidents.*

HELPER

5 Supervision or setup - The subject requires supervision (e.g., standing by, cueing or coaxing) or setup (placing or emptying) of equipment to maintain a satisfactory voiding pattern or an external device.

4 Minimal contact assistance - The subject requires minimal contact assistance to maintain an external device, and performs 75% or more of bladder management tasks.

3 Moderate assistance - The subject requires moderate assistance to maintain an external device, and performs 50% to 74% of bladder management tasks.

2 Maximal assistance - The subject performs 25% to 49% of bladder management tasks.

1 Total assistance - The subject performs less than 25% of bladder management tasks; or the subject cannot perform the task due to physical or cognitive limitations and a helper performs the activity for the subject.

Blank (*on Form II - only if V201 = "5"*)

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Sphincter Control: Bladder Management

FUNCTION

MODIFIER #1: Bladder Management - Level of Assistance

COMMENTS: The functional goal of bladder management is to open the urinary sphincter only when needed and to keep it closed the rest of the time. This may require devices, medications (agents), or assistance in some subjects. This item deals with the level of assistance required to complete bladder management tasks. If the subject does not void (e.g., subject has renal failure and is on hemodialysis), then code level 7 – Complete Independence).

A separate function modifier, *Bladder Management – Frequency of Accidents*, deals with the success of the bladder management program. This modifier is scored separately. After these two function modifiers are scored, the lower (more dependent) score is reported in FIM item G.

FUNCTION

MODIFIER #2: Bladder Management - Frequency of Accidents

DESCRIPTION: This is the second function modifier used to determine Sphincter Control: Bladder Management. It includes complete intentional control of urinary bladder and, if necessary, use of equipment or agents for bladder control. Bladder accidents refer to the act of wetting linen or clothing with urine, and includes bedpan and urinal spills. The admission assessment for bladder accidents includes the 4 days prior to the rehab admission as well as the first 3 days in the rehab facility.

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

- 7 No accidents** – The subject controls bladder completely and intentionally, and does not have any accidents.
- 6 No accidents; uses device such as a catheter** - The subject requires a urinal, bedpan, catheter, absorbent pad, diaper, urinary collecting device, or urinary diversion or uses medication for control. The subject cleans and maintains equipment without assistance of another person. *The subject has no accidents.*

HELPER

- 5 One (1) bladder accident**, including bedpan and urinal spills, in the past 7 days.
- 4 Two (2) bladder accidents**, including bedpan and urinal spills, in the past 7 days.
- 3 Three (3) bladder accidents**, including bedpan and urinal spills, in the past 7 days.
- 2 Four (4) bladder accidents**, including bedpan and urinal spills, in the past 7 days.
- 1 Five (5) bladder accidents**, including bedpan and urinal spills, in the past 7 days.

Blank (on Form II - only if V201 = "5")

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Sphincter Control: Bladder Management

COMMENTS: The functional goal of bladder management is to open the urinary sphincter only when needed and to keep it closed the rest of the time. This item deals with the frequency of accidents required to complete bladder management tasks. If the subject does not void (e.g., subject has renal failure and is on hemodialysis), then code level 7 – Complete Independence.

A separate function modifier, *Bladder Management – Level of Assistance*, deals with the level of assistance to complete the bladder management tasks. This modifier is scored separately. After these two function modifiers are scored, the lower (more dependent) score is reported in FIM item G.

blank page

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Sphincter Control: Bowel Management

DESCRIPTION: Bowel Management consists of two function modifiers (*Level of Assistance* and *Frequency of Accidents*). After these two function modifiers are scored, the lower (more dependent) score is recorded in this FIM item.

FUNCTION

MODIFIER #1: Bowel Management - Level of Assistance

DESCRIPTION: This is the first function modifier used to determine Sphincter Control: Bowel Management. It includes the use of equipment or agents for bowel management. The admission assessment for bowel accidents includes the 4 days prior to the rehab admission, as well as the first 3 days in the rehab facility.

CODES: **9 Unknown** (*see [page 147](#) for details*)

NO HELPER

7 Complete independence – The subject controls bowels completely and intentionally without equipment or devices, and does not have any bowel accidents.

6 Modified independence - The subject requires a bedpan, digital stimulation or stool softeners, suppositories, laxatives (other than natural laxatives like prunes), or enemas on a regular basis; alternately, the patient uses other medications for control. If the subject has a colostomy, (s)he maintains it. *The subject has no accidents.*

HELPER

5 Supervision or setup - The subject requires supervision (e.g., standing by, cueing or coaxing) or setup of equipment necessary for the subject to maintain either a satisfactory excretory pattern or an ostomy device.

4 Minimal contact assistance - The subject requires minimal contact assistance to maintain a satisfactory excretory pattern by using suppositories, enemas, or an external device. The subject performs 75% or more of bowel management tasks.

3 Moderate assistance - The subject requires moderate assistance to maintain a satisfactory excretory pattern by using suppositories, enemas, or an external device. The subject performs 50% to 74% of bowel management tasks.

2 Maximal assistance - The subject performs 25% to 49% of bowel management tasks.

1 Total assistance - The subject performs less than 25% of bowel management tasks; or the subject cannot perform the task due to physical or cognitive limitations and a helper performs the activity for the subject.

Blank (*on Form II - only if V201 = "5"*)

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Sphincter Control: Bowel Management

FUNCTION

MODIFIER #1: Bowel Management - Level of Assistance

COMMENTS: The functional goal of bowel management is to open the anal sphincter only when needed and to keep it closed the rest of the time. This may require devices, medications (agents), or assistance in some subjects. This item deals with the level of assistance required to complete bowel management tasks.

A separate function modifier, *Bowel Management – Frequency of Accidents*, deals with the success of the bowel management program. This modifier is scored separately. After these two function modifiers are scored, the lower (more dependent) score is reported in FIM item H.

FUNCTION

MODIFIER #2: Bowel Management - Frequency of Accidents

DESCRIPTION: This is the second function modifier used to determine Sphincter Control: Bowel Management. It includes complete intentional control of bowel movements and (if necessary) use of equipment/agents for bowel control. Bowel accidents refer to the act of soiling linen or clothing with stool, and includes bedpan spills.

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

7 No accidents – The subject controls bowel completely and intentionally without equipment or devices, and is *never incontinent* (no accidents).

6 No accidents; uses device such as ostomy - The subject requires a bedpan, digital stimulation or stool softeners, suppositories, laxatives (other than natural laxatives like prunes), or enemas on a regular basis; alternately, the patient uses other medications for control. *The subject has no accidents.*

HELPER

5 One (1) accident in the past 7 days.

4 Two (2) accidents in the past 7 days.

3 Three (3) accidents in the past 7 days.

2 Four (4) accidents in the past 7 days.

1 Five (5) accidents in the past 7 days.

Blank (on Form II - only if V201 = "5")

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Sphincter Control: Bowel Management

FUNCTION

MODIFIER #2: Bowel Management - Frequency of Accidents

COMMENTS: The functional goal of bowel management is to open the anal sphincter only when needed and to keep it closed the rest of the time. This item deals with the frequency of accidents required to complete bowel management tasks.

A separate function modifier, *Bowel Management – Level of Assistance*, deals with the level of assistance to complete the bowel management tasks. This modifier is scored separately. After these two function modifiers are scored, the lower (more dependent) score is reported in FIM item H.

blank page

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Mobility (Transfers): Bed, Chair, Wheelchair

DESCRIPTION: Includes all aspects of transferring to and from bed, chair and wheelchair or coming to a standing position if walking is the typical mode of locomotion. The subject performs this activity safely.

CHARACTERS: 1 for each entry

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

7 Complete independence -

If walking: The subject safely approaches, sits down on a regular chair, and gets up to a standing position from a regular chair. The subject also safely transfers from bed to chair.

If in a wheelchair: The subject approaches a bed or chair, locks brakes, lifts foot rests, removes arm rest if necessary, and performs either a standing pivot or sliding transfer (without a board) and returns. The subject performs this activity safely.

6 Modified independence – The subject requires adaptive or assistive device such as a sliding board, a lift, grab bars, or a special seat/chair/brace/crutches; or the activity takes more than a reasonable amount of time; or there are safety considerations. In this case, a prosthesis or orthosis is considered an assistive device if used for the transfer.

HELPER

5 Supervision or setup - Requires supervision (e.g., standing by, cueing or coaxing) or setup (positioning sliding board, moving foot rests, etc.).

4 Minimal contact assistance - The subject requires no more than touching and performs 75% or more of transferring tasks.

3 Moderate assistance - The subject requires more help than touching or performs 50% to 74% of transferring tasks.

2 Maximal assistance - The subject performs 25% to 49% of transferring tasks.

1 Total assistance - The subject performs less than 25% of transferring tasks; or the subject cannot perform the task due to physical or cognitive limitations and a helper performs the activity for the subject.

0 Activity does not occur - Enter code 0 only for the admission assessment (use code 9 at discharge and on Form II) . The subject does not transfer to or from the bed or a chair, and is not transferred to or from the bed or chair by a helper or lifting device. Use of this code should be rare.

Blank (on Form II - only if V201 = "5")

COMMENTS: When assessing bed to chair transfer, the subject begins and ends in the supine position.

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Mobility (Transfer): Toilet

DESCRIPTION: Includes getting on and off a toilet.

CHARACTERS: 1 for each entry

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

7 Complete independence -

If walking: The subject approaches, sits down on a standard toilet and gets up from a standard toilet. The subject performs this activity safely.

If in a wheelchair: The subject approaches toilet, locks brakes, lifts foot rests, removes arm rests if necessary and does either a standing pivot or sliding transfer (without a board) and returns. The subject performs this activity safely.

6 Modified independence - The subject requires an adaptive or assistive device such as a sliding board, a lift, grab bars, or special seat; or takes more than a reasonable amount of time to complete the activity; or there are safety considerations. In this case, a prosthesis or orthosis is considered an assistive device if used for the transfer.

HELPER

5 Supervision or setup – The subject requires supervision (e.g., standing by, cueing or coaxing) or setup (positioning sliding board, moving foot rests, etc.).

4 Minimal contact assistance - The subject requires no more than touching and performs 75% or more of transferring tasks.

3 Moderate assistance - The subject requires more help than touching or performs 50% to 74% of transferring tasks.

2 Maximal assistance - The subject performs 25% to 49% of transferring tasks.

1 Total assistance - The subject performs less than 25% of transferring tasks; or the subject cannot perform the task due to physical or cognitive limitations and a helper performs the activity for the subject.

0 Activity does not occur - Enter code 0 only for the admission assessment (use code 9 at discharge and on Form II). The subject does not transfer on or off the toilet/commode, and is not transferred on or off the toilet/commode by a helper or lifting device. For example, the subject uses only a bedpan and/or urinal. Use of this code should be rare.

Blank (on Form II - only if V201 = "5")

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Mobility (Transfer): Tub, Shower

DESCRIPTION: Mobility (Transfer): Tub, Shower consists of two function modifiers (*Transfers: Tub and Transfers: Shower*). After these two function modifiers are scored, the lower (more dependent) score is recorded in this FIM item.

FUNCTION

MODIFIER #1: Transfers: Tub

DESCRIPTION: Includes getting into and out of a tub. The subject performs this activity safely. This is the first of two function modifiers.

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

7 Complete independence -

If walking: The subject approaches a tub, and gets into and out of it. The subject performs this activity safely.

If in a wheelchair: The subject approaches a tub, locks brakes, lifts foot rests, removes arm rests if necessary, and does either a standing pivot or sliding transfer (without a board) and returns. The subject performs this activity safely.

6 Modified independence - The subject requires an adaptive or assistive device (including prosthesis or orthosis) such as a sliding board, a lift, grab bars, or special seat; takes more than a reasonable amount of time to complete the activity or there are safety considerations.

HELPER

5 Supervision or setup - The subject requires supervision (e.g., standing by, cueing or coaxing) or setup (positioning sliding board, moving foot rests, etc.).

4 Minimal contact assistance - The subject performs 75% or more of transferring tasks.

3 Moderate assistance - The subject requires no more than touching and performs 50% to 74% of transferring tasks.

2 Maximal assistance - The subject requires more help than touching or performs 25% to 49% of transferring tasks.

1 Total assistance - The subject performs less than 25% of transferring tasks; or the subject cannot perform the task due to physical or cognitive limitations and a helper performs the activity for the subject.

0 Activity does not occur - The subject does not transfer into and out of a tub and is not transferred by a helper. Use of this code should be rare. Code 0 may be used on admission, discharge and on Form II.

Blank (on Form II - only if V201 = "5")

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Mobility (Transfer): Tub, Shower

FUNCTION

MODIFIER #1: Transfers: Tub

COMMENT: There is a separate function modifier that addresses transfers into a shower stall. Score the function modifiers separately. If the patient uses only one mode, record this score in FIM item K. If the patient transfers into the tub and shower, record the lower score.

FUNCTION

MODIFIER #2: Transfers: Shower

DESCRIPTION: Includes getting into and out of a shower. The subject performs this activity safely. This is the second of two function modifiers.

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER**7 Complete independence -**

If walking: The subject approaches a shower stall, and gets into and out of it. The subject performs this activity safely.

If in a wheelchair: The subject approaches a shower stall, locks brakes, lifts foot rests, removes arm rests if necessary, and does either a standing pivot or sliding transfer (without a board) and returns. The subject performs this activity safely.

6 Modified independence – The subject requires an adaptive or assistive device (including prosthesis or orthosis) such as a sliding board, a lift, grab bars, or special seat; takes more than a reasonable amount of time to complete the activity or there are safety considerations.

HELPER

5 Supervision or setup – The subject requires supervision (e.g., standing by, cueing or coaxing) or setup (positioning sliding board, moving foot rests, etc.).

4 Minimal contact assistance - The subject performs 75% or more of transferring tasks.

3 Moderate assistance - The subject requires no more than touching and performs 50% to 74% of transferring tasks.

2 Maximal assistance - The subject requires more help than touching or performs 25% to 49% of transferring tasks.

1 Total assistance - The subject performs less than 25% of transferring tasks; or the subject cannot perform the task due to physical or cognitive limitations and a helper performs the activity for the subject.

0 Activity does not occur - The subject does not transfer into and out of a shower and is not transferred by a helper. Use of this code should be rare. Code 0 may be used on admission, discharge and on Form II.

Blank (on Form II - only if V201 = "5")

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Mobility (Transfer): Tub,
Shower

FUNCTION

MODIFIER #2: Transfers: Shower

COMMENT: There is a separate function modifier that addresses transfers into a tub. Score the function modifiers separately. If the patient uses only one mode, record this score in FIM item K. If the patient transfers into the tub and shower, record the lower score.

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Locomotion: Walking or Wheelchair

DESCRIPTION: Locomotion: Walking or Wheelchair consists of two function modifiers (*Locomotion: Walk and Locomotion: Wheelchair*). The score that matches the type of locomotion is recorded in this FIM item. If both modes are performed equally, and the scores for each mode are not equal, the lower (more dependent) score is recorded in this FIM item. If the subject changes the mode of locomotion between admission and discharge (usually from wheelchair to walking), record the admission mode and scores based on the *more frequent mode of locomotion at discharge*.

FUNCTION

MODIFIER #1: Locomotion: Walk

DESCRIPTION: Includes walking on a level surface once in a standing position. The subject performs this activity safely. This is the first of two locomotion function modifiers.

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

7 Complete independence – The subject walks a minimum of 150 feet (50 meters) without assistive devices. The subject performs this activity safely.

6 Modified independence - The subject walks a minimum of 150 feet (50 meters) but uses a brace (orthosis) or prosthesis on leg, special adaptive shoes, cane, crutches, or walkerette; or takes more than a reasonable amount of time to complete the activity; or there are safety considerations.

5 Exception (household locomotion) - The subject walks only short distances (a minimum of 50 feet or 17 meters) *independently* with or without a device. The activity takes more than a reasonable amount of time, or there are safety considerations.

HELPER

5 Supervision – The subject requires standby supervision, cueing or coaxing to go a minimum of 150 feet (50 meters).

4 Minimal contact assistance - The subject performs 75% or more of walking effort to go a minimum of 150 feet (50 meters).

3 Moderate assistance - The subject performs 50% to 74% of walking effort to go a minimum of 150 feet (50 meters).

2 Maximal assistance - The subject performs 25% to 49% of walking effort to go a minimum of 50 feet (17 meters) and requires assistance of one person only.

1 Total assistance - The subject performs less than 25% of effort, or requires the assistance of two people, or walks less than 50 feet (17 meters).

0 Activity does not occur - Enter code 0 only for the admission assessment (use code 9 at discharge and on Form II). The subject does not walk. For example, use 0 if the subject uses only a wheelchair for locomotion or the subject is on bed rest.

Blank (on Form II - only if V201 = "5")

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Locomotion: Walking or Wheelchair

FUNCTION MODIFIER #1: Locomotion: Walk

COMMENTS: If the patient requires an assistive device for locomotion (prosthesis, walker, cane, AFO, adaptive shoe, etc.), then the Locomotion: Walk score can never be higher than level 6.

There are two locomotion function modifiers. Score both function modifiers on admission and discharge. FIM item *Mode of Locomotion (Walk or Wheelchair)* must be the same on admission and discharge. Indicate the most frequent mode of locomotion (Walk or Wheelchair) in FIM item LM. If both are used about equally, code "Both".

FUNCTION MODIFIER #2: Locomotion: Wheelchair

DESCRIPTION: Includes using a wheelchair on a level surface once in a seated position. The subject performs this activity safely. This is the second of two locomotion function modifiers. If the subject changes the mode of locomotion between admission and discharge (usually from wheelchair to walking), record the admission mode and scores based on the *more frequent mode of locomotion at discharge*.

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

7 This score is not to be used if the patient uses a wheelchair for locomotion.

6 Modified independence - The subject operates a manual or motorized wheelchair independently for a minimum of walks a minimum of 150 feet (50 meters); turns around; maneuvers the chair to a table, bed, toilet; negotiates at least a 3 percent grade; and maneuvers on rugs and over door sills.

5 Exception (household locomotion) - The subject operates a manual or motorized wheelchair *independently* only short distances (a minimum of 50 feet of 17 meters).

HELPER

5 Supervision - The subject requires standby supervision, cueing or coaxing to go a minimum of 150 feet (50 meters) in a wheelchair.

4 Minimal contact assistance - The subject performs 75% or more of locomotion effort to go a minimum of 150 feet (50 meters).

3 Moderate assistance - The subject performs 50% to 74% of locomotion effort to go a minimum of 150 feet (50 meters).

2 Maximal assistance - The subject performs 25% to 49% of locomotion effort to go a minimum of 50 feet (17 meters) and requires the assistance of one person only.

1 Total assistance - The subject performs less than 25% of effort, or requires assistance of two people, or wheels less than 50 feet (17 meters).

0 Activity does not occur - Enter code 0 only for the admission assessment (use code 9 at discharge and on Form II). The subject does not use a wheelchair, and is not pushed in a wheelchair by a helper.

Blank (on Form II - only if V201 = "5")

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Locomotion: Walking or Wheelchair

FUNCTION

MODIFIER #2: Locomotion: Wheelchair

COMMENTS: There are two locomotion function modifiers. Score both function modifiers on admission and discharge. FIM item *Mode of Locomotion (Walk or Wheelchair)* must be the same on admission and discharge. Indicate the most frequent mode of locomotion (Walk or Wheelchair) in FIM item LM. If both are used about equally, code "Both".

blank page

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Locomotion: Mode (Walking and/or Wheelchair)

DESCRIPTION: This variable documents the more frequent mode of locomotion (for the level recorded in FIM item L). If the subject changes the mode of locomotion between admission and discharge (usually from wheelchair to walking), record the admission mode and scores based on the *more frequent mode of locomotion at discharge*.

CHARACTERS: 1 for each entry

CODES: **0 Walking**
1 Wheelchair
2 Both walking and wheelchair (use only if both are used about equally often)
9 Unknown

Blank (on Form II - only if V201 = "5")

COMMENTS: FIM item Mode of Locomotion (Walk or Wheelchair) must be the same on admission and discharge. Indicate the most frequent mode of locomotion (Walk or Wheelchair). If both are used about equally, code "Both".

QC: If variable 144L (Locomotion: Walking and Wheelchair) = "9" (Unknown), this variable must = "9" (Unknown).

If variable 227L (Locomotion: Walking and Wheelchair) = "9" (Unknown), this variable must = "9" (Unknown).

FORM I and FORM II

VARIABLE NAME: Functional Independence Measure (FIM) - Locomotion: Stairs

DESCRIPTION: Includes going up and down 12 to 14 stairs (one flight) indoors in a safe manner.

CHARACTERS: 1 for each entry

CODES: **9 Unknown** (see [page 147](#) for details)

NO HELPER

- 7 Complete independence** – The subject safely goes up and down at least one flight of stairs without depending on any type of handrail or support.
- 6 Modified independence** - The subject goes up and down at least one flight of stairs but requires a side support, handrail, cane, or portable supports; or the activity takes more than a reasonable amount of time; or there are safety considerations.
- 5 Exception (household ambulation)** – The subject goes up and down 4 to 6 stairs *independently*, with or without a device. The activity takes more than a reasonable amount of time, or there are safety considerations.

HELPER

- 5 Supervision** - The subject requires supervision (e.g., standing by, cueing or coaxing) to go up and down one flight of stairs.
- 4 Minimal contact assistance** - The subject performs 75% or more of effort to go up and down one flight of stairs.
- 3 Moderate assistance** - The subject performs 50% to 74% of the effort to go up and down one flight of stairs.
- 2 Maximal assistance** - The subject performs 25% to 49% of the effort to go up and down 4 to 6 stairs, and requires the assistance of one person only.
- 1 Total assistance** - The subject performs less than 25% of the effort; or requires the assistance of two people; or goes up and down fewer than 4 stairs; or the subject cannot perform the task due to physical or cognitive limitations and a helper carries the subject up or down stairs.
- 0 Activity does not occur** - Enter code 0 only for the admission assessment (use code 9 at discharge and on Form II). The subject does not go up or down stairs, and a helper does not carry the subject up or down stairs. Use of this code should be rare.

Blank (on Form II - only if V201 = "5")

FORM I and FORM II

- VARIABLE NAME:** Functional Independence Measure (FIM) – Total Motor Score
- DESCRIPTION:** This variable documents the total of the levels in FIM items A through M.
This variable can be calculated by the NSCISC’s software.
- CHARACTERS:** 2 for each entry
- CODES:** **13 - 91** **99** **Unknown**
Blank (*on Form II - only if V201 = “5”*)
- COMMENTS:** Each of the 13 motor items comprising the FIM has a maximum level score of 7. At Admission, all FIM items except Bladder Control and Bowel Control have a minimum level score of 0. At discharge, only Transfers: Tub, Shower has a minimum level score of 0. All other items have a minimum score of 1.

The highest total score is 91 and the lowest total score is 13.

Code "99" must be used when 1 or more items are coded "9" (Unknown).

Do not include in this total the code in the Mode of Locomotion (LM).
- SOFTWARE:** The software includes a function key to calculate this variable. To use: place the cursor on the variable to be calculated (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button. For calculation purposes only, zeros are converted to 1.
- QC:** If the score in any item of the FIM (i.e., A through M) = “9” (*Unknown*), this variable (T) must = “99” (*Unknown*).

If the subject’s current age is less than 006, then all FIM items must = “9” and the Total FIM score must = “99”.

Also, see [page 67](#).

FORM I and REGISTRY

VARIABLE NAME: Date of Death

DESCRIPTION: This variable specifies the patient's date of death.

CHARACTERS: 8

CODES: **Any valid date**
88888888 Not applicable, patient alive
99999999 Unknown

FORMAT: mmddyyyy

COMMENTS: Record the month, day and year. If the month or day is unknown, it should be coded "99"; if the year is unknown it should be coded "9999". An estimated year of death is allowed (and preferred). Avoid using code "99999999" unless there is absolutely no information.

This variable is to be used to document the date of death for any patient who dies either during initial hospitalization or during the follow-up period.

This variable cannot be stored in date format since non-valid dates and non-valid parts of a date are allowed.

See Appendix D for tips on tracking patients (from internet sources, etc.).

SOFTWARE: When the software creates a new Form I record, the default code for "alive" (88888888) is inserted in this variable. Update this variable if the patient dies during follow-up.

From the Process/Data Entry screen of the software, there is a short-cut key that brings up the Form I Death Information items. To Use: place the cursor on the patient's line and click on the Death Info box. The software will now bring up the Date of Death, Cause of Death and Autopsy fields from Form I. Enter your data, save the changes, and the data will be stored in the Form I record.

QC: If the patient dies during a System inpatient treatment phase, this date is the same as the Date of Discharge (variable 110).

FORM I

VARIABLE NAME: Cause(s) of Death

DESCRIPTION: This variable documents cause(s) of death by diagnosis.

Write out the diagnoses in the spaces provided and code each diagnosis according to a five-digit code required by The International Classification of Diseases, (ICD-9-CM).

CHARACTERS: 7 for the primary cause (V146_1)
6 for each of the 4 secondary causes (V146_2 through V146_5)

CODES: **Any valid ICD9 code**

_888.88 Not applicable, patient alive (in coding position #1 only)

_000.00 Unknown (in coding position #1 only)

Blank (in coding positions # 2 through #5 only)

COMMENTS: **The primary cause of death should be coded in the first position (1)** with other pathologic conditions contributing to the patient's demise listed as secondary diagnoses (positions 2 through 5).

The primary cause of death should reflect autopsy findings (if available). The use of E codes to document external causes of death (e.g., suicide, automobile accidents) is permitted in this variable only as a Primary Cause. However, see additional information in the syllabus section titled "Guidelines for Coding Primary Cause of Death" (starting on page 23).

This variable is to be used to document the Cause(s) of Death for any patient who dies either during initial hospitalization or during the follow-up period.

A code in coding position #1 is mandatory.

Codes 0000.00 and 8888.88 are allowed only in coding position #1. When one of these codes is entered in coding position #1, no codes are allowed in coding positions 2 to 5. The decimal point is stored in this variable.

REVISIONS: October 1990: converted from ICDA8 codes to ICD9CM codes.

SOFTWARE: When the software creates a new Form I record, the default code for "alive" (8888.88) is inserted in this variable. Update this variable if the patient dies during follow-up.

When code 0000.00 (or code 8888.88) is entered, the software advances the user to the next variable.

EXAMPLE: 146. Cause(s) of Death..... 0 3 8 . 9 0 1. Sepsis
Primary Cause
4 8 6 . 0 0 2. Pneumonia
_ _ _ . _ _ 3.
_ _ _ . _ _ 4.
_ _ _ . _ _ 5.

FORM I

VARIABLE NAME: Autopsy

DESCRIPTION: This variable documents whether the patient's reported primary cause of death was confirmed by autopsy findings.

CHARACTERS: 1

CODES: **0 Autopsy not performed**
1 Autopsy results confirm primary cause of death
2 Autopsy performed, results unknown
8 Not applicable, patient alive
9 Unknown if an autopsy was performed

SOFTWARE: When the software creates a new Form I the default code for "alive" (8) is inserted in this variable. Update this variable if the patient dies during follow-up.

REVISIONS: October 1986: this variable was added to the database.

FORM I

The Treatment Phase variables document (track) all phases of treatment the patient receives (for SCI) **from the time of injury to the End of the Last Inpatient Treatment Phase**. These include treatments received in the Model System (*System*) and outside the Model System (*non-System*). A phase is a component of the services trajectory from injury to discharge back to the community with rehabilitation completed. Each phase is distinguished by the *nature* of the activities that the patient undergoes/undertakes, and/or the identity of the *entity* that provides the services. A new phase starts whenever the nature of the activities changes (from those described in one code of V148 to those described by another code), and/or when the entity responsible for delivering those services changes.

Five types of phases of treatment are reported:

- 1) Acute Medical/Surgical Hospitalization
- 2) Nursing Home
- 3) Inpatient Acute Rehabilitation
- 4) Inpatient Subacute Medical/Surgical Care
- 5) Inpatient Subacute Rehabilitation

Once a patient is receiving outpatient rehab, all med-surg (sub)acute and inpatient Rehab hospitalizations are considered Rehospitalizations (not additional Treatment Phases). Such rehospitalizations should be documented in the Rehospitalization variables (V217, V218 and V219).

All rehospitalizations (med-surg or rehab) while a patient is in a Nursing Home treatment phase are considered Treatment Phases (not rehospitalizations) since the Nursing Home Treatment Phase is a temporary interlude between other treatment phases in the sequence from injury through death/completion of rehabilitation.

Record each treatment phase separately, in sequence by date of admission (or start date).

Document all the following items for each phase:

| Variable # | Variable Name | Syllabus Page # |
|------------|---|-----------------|
| 148 | Treatment Phase Type for SCI | 173 |
| 149 | System or Non-system | 178 |
| 150 | Date of Admission (or Start of Phase) | 179 |
| 151 | Date of Discharge (or End of Phase) | 180 |
| 152 | Number of Short-term Discharge Days | 181 |
| 153 | Number of Days in Treatment Phase (<i>computer-generated</i>) | 183 |
| 154 | Charges (<i>System only</i>) | 184 |
| 155 | Charges Reliability Code (<i>System only</i>) | 185 |

- If there is a delay in obtaining some information (e.g., hospitalization charges), submit the Form I when 80% or more of the information is available and code the missing items “unknown”. Then, update the Form I when the missing data are available.
- Data in Variables 154 and 155 are required only for System phases. If V149 = “0”, leave variables V154 and V155 blank.

FORM I

VARIABLE NAME: Treatment Phase Type for SCI

DESCRIPTION: This variable documents 5 treatment phase types (for SCI) occurring from the time of injury through the completion of initial inpatient System rehab:

Acute Medical/Surgical Hospitalization, Nursing Home, Inpatient Acute Rehab, Inpatient Subacute Medical/Surgical Care, Inpatient Subacute Rehab.

CHARACTERS: 1 for each entry, up to 12 entries

CODES:

- 1 Acute Medical/Surgical Hospitalization** – The first inpatient hospitalization following spinal cord injury and any subsequent inpatient hospitalization that takes place for **continuing** medical or surgical care, or the treatment of a secondary medical complication, until the end of the rehabilitation program or the patient's death, whichever comes earlier. The facility should be licensed as a hospital where an inpatient bed is assigned to the patient. This includes intensive care unit (ICU) and non-ICU beds and SCI specialty unit beds.

Once a patient is receiving outpatient rehab, all med-surg (sub)acute and inpatient Rehab hospitalizations are considered Rehospitalizations (not additional Treatment Phases). Such rehospitalizations should be documented in the Rehospitalization variables (V217, V218 and V219).

- 2 Nursing Home**– A facility licensed as a nursing home where a patient bed is assigned to the patient, and no rehabilitation services are provided (or rehabilitation is a very minor part of ongoing care). A nursing home unit, separately licensed as a nursing home, may be physically part of a hospital, with permanent or swing beds. Skilled Nursing Facilities (SNF) are also included in this category. Nursing home stays are considered as a treatment phase only if the patient is there on a **temporary** basis between other treatment phases in the sequence from injury through death/completion of rehabilitation. If the patient is discharged from inpatient rehabilitation (or some other inpatient stay) to a nursing home on a temporary basis, (e.g. awaiting completion of modifications to make the home accessible, or to receive nursing care for some medical problem that cannot be treated at home) then, this nursing home stay is to be reported as a phase.

If rehabilitation is finished and the nursing home is the **permanent** residence, then code the Nursing Home days in variable 220 (not as a treatment phase) and code “nursing home” (code 03) for Place of Residence (V120D).

- 3 Inpatient Acute Rehabilitation** – A facility licensed as a hospital (either a rehabilitation unit within a hospital or a free-standing rehabilitation hospital) where an inpatient bed is assigned to the patient. The primary purpose of the hospitalization is for rehabilitation, including some combination of physical therapy, occupational therapy, speech therapy, recreational therapy, patient and family education, and rehabilitation psychology, medicine and nursing care. The goal of inpatient acute rehabilitation is to provide 3 or more hours of occupational and/or physical therapy per day, plus other therapies as indicated (Medicare 3-hour rule).

FORM I

VARIABLE NAME: Treatment Phase Type

- 4 Inpatient Subacute Medical/Surgical Care** – A licensed facility where an inpatient bed that is specifically designated as a subacute bed is assigned to the patient. A Subacute medical/surgical care unit may be part of a hospital or of a nursing home; the designation of the unit as subacute is crucial. Limited or no rehabilitation services are provided. Typically, these are patients who have continuing medical problems and are not yet ready for a full rehabilitation program, or have completed their rehabilitation and are awaiting resolution of continuing medical problems before discharge to a more permanent location.
- 5 Inpatient Subacute Rehabilitation** - A licensed facility (typically part of a hospital or nursing home) where an inpatient bed that is specifically designated as a subacute rehab bed is assigned to the patient.
However, unlike Inpatient Subacute Medical/Surgical Care (code 4), the goal is to provide rehabilitation services of at least 1 hour per day of either physical or occupational therapy plus other therapies as indicated and tolerated.
- 6 Day Hospital Rehabilitation Services** *This is NOT a valid code in Form Is with Indates after 03/31/2005*
- 7 Outpatient Rehabilitation** *This is NOT a valid code in Form Is with Indates after 03/31/2005*
- 8 Home Rehabilitation** *This is NOT a valid code in Form Is with Indates after 03/31/2005*
- 9 Unknown** - *This is a CONVERSION CODE ONLY for non day-1 patients only (phases 1 and 2 only). Data collectors may not use this code.*
- Blank** *(in coding positions # 2 through #12 only)*

See the **Summary Information on the Treatment Phases** table (page 175) for a comparison of the treatment phase types.

FORM I

VARIABLE NAME: Treatment Phase Type for SCI

| Summary Information on the Treatment Phases | | |
|---|---|---|
| Treatment Phase | Description of Treatment Facility | Treatment Time Period, Minimal Amount of Services |
| Acute Medical/Surgical Code 1 | <ul style="list-style-type: none"> ▪ A licensed hospital where an inpatient bed is assigned to the patient. ▪ includes intensive care unit (ICU) and non-ICU beds and SCI specialty unit beds. ▪ for continuing medical or surgical care, or the treatment of a secondary medical complication until the end of the rehabilitation program or the patient's death, whichever comes earlier. | <ul style="list-style-type: none"> ▪ The initial inpatient hospitalization following injury ▪ any subsequent inpatient hospitalization from injury through death/completion of rehabilitation that does NOT occur during a Day Hospital, Outpatient Rehab or Home Rehab phase |
| Nursing Home Code 2 | <ul style="list-style-type: none"> ▪ A facility licensed as a nursing home where a patient bed is assigned to the patient. ▪ A nursing home unit, separately licensed as a nursing home. ▪ May be physically part of a hospital, with permanent or swing beds. ▪ Skilled Nursing Facilities (SNF) are also included in this category. | <ul style="list-style-type: none"> ▪ a temporary stay between other treatment phases in the sequence from injury through death/completion of rehabilitation ▪ a short-term stay awaiting return to the permanent residence ▪ No rehabilitation services are provided or ▪ rehabilitation is a very minor part of ongoing care |
| Inpatient Acute Rehabilitation Code 3 | <ul style="list-style-type: none"> ▪ A facility licensed as a hospital where an inpatient bed is assigned to the patient. ▪ Either a rehabilitation unit within a hospital or a free-standing rehabilitation hospital | <ul style="list-style-type: none"> ▪ a combination of rehab services ▪ 3 or more hours of therapy per day planned |
| Inpatient Subacute Medical/Surgical Care Code 4 | <ul style="list-style-type: none"> ▪ A licensed facility where an inpatient bed that is specifically designated as a subacute bed is assigned to the patient. ▪ typically located in a hospital or nursing home | <ul style="list-style-type: none"> ▪ Limited or no rehabilitation services ▪ For patients who have continuing medical problems and are not yet ready for a full rehabilitation program or ▪ For patients who are awaiting resolution of medical problems before discharge to (sub)acute rehab or to a permanent residence location. |
| Inpatient Subacute Rehabilitation Code 5 | <ul style="list-style-type: none"> ▪ A licensed facility where an inpatient bed that is specifically designated as a subacute bed is assigned to the patient. ▪ typically located in a hospital or nursing home | <ul style="list-style-type: none"> ▪ physical or occupational therapy plus other therapies as indicated or tolerated ▪ at least 1 hour per day planned |

FORM I

VARIABLE NAME: Treatment Phase Type for SCI

COMMENTS: Code each phase in sequence, by date. Code up to 12 treatment phases. At least 1 treatment phase must be coded; coding positions #2 through #12 may be blank.

Dates cannot overlap. A patient can be in only 1 treatment phase at a time (i.e., a patient cannot be in an acute medical/surgical bed and in a rehab bed on the same day but, the discharge date of one can be the admit date for the next).

See page 211 for instructions on coding rehospitalizations that occur after discharge from an inpatient facility and before the completion of initial rehab.

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

January 2005: data are no longer collected on any outpatient treatment phases. Therefore, codes 5, 6 and 7 are not valid in V148 for any Form Is with Indate1 after 03/31/2005.

EXAMPLE 1: John was injured on May 12, 2000. The EMS took him from the site of the injury to the Model System hospital emergency department. After a number of hours, he was admitted to the SCI unit, where he stayed until May 31. That day he was transferred to the System's acute rehabilitation unit, where he spent a month. He was discharged home on July 1 with a planned readmission for more inpatient rehabilitation later. On August 20th he was admitted for more inpatient rehab and, on August 30th he was discharged home. The attending physician and the team members decided at this time that his treatment had been successful and all goals accomplished.

| | Treatment Phase # | <u>1</u> | <u>2</u> |
|-----|---------------------------------------|-----------------|-----------------|
| 148 | Treatment Phase | 1 | 3 |
| 149 | System or Non-system | 1 | 1 |
| 150 | Date of Admission (or Start of Phase) | 5/12/2000 | 05/31/2000 |
| 151 | Date of Discharge (or End of Phase) | 5/31/2000 | 08/30/2000 |
| 152 | Number of Short-term Discharge Days | 000 | 050 |

FORM I

VARIABLE NAME: Treatment Phase Type for SCI

EXAMPLE 2: Mary was injured on November 12, 2000 and she was immediately brought to the emergency department of a large tertiary care facility, not part of the Model System. She was admitted to the surgical ICU on November 13. At the insistence of her insurance carrier, she was moved to the model system SCI ICU on November 15. She was transferred to a non-ICU surgical bed on December 12 and was ready for rehabilitation on January 4, 2001. Her physician had wanted to admit her to the SCI unit of the System's rehabilitation facility, but the carrier intervened, sending her instead to a small, newly opened freestanding rehabilitation hospital. She was discharged home on March 12, 2001.

| Treatment Phase # | | <u>1</u> | <u>2</u> | <u>3</u> |
|--------------------------|---------------------------------------|-----------------|-----------------|-----------------|
| 148 | Treatment Phase | 1 | 1 | 3 |
| 149 | System or Non-system | 0 | 1 | 0 |
| 150 | Date of Admission (or Start of Phase) | 11/12/2000 | 11/15/2000 | 01/04/2001 |
| 151 | Date of Discharge (or End of Phase) | 11/15/2000 | 01/04/2001 | 03/12/2001 |

EXAMPLE 3: Andrew was injured on April 17, 2000, admitted to a community hospital, and transferred to the Model System's acute medical facility on the 21st. His medical program was completed on the 29th, but because of a halo brace, he could not start rehabilitation services. He was admitted to a nursing home bed in a nursing home affiliated with the System, and from there to the acute rehabilitation program on May 27. He was discharged home on June 17, 2000.

| Treatment Phase # | | <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> |
|--------------------------|---------------------------------------|-----------------|-----------------|-----------------|-----------------|
| 148 | Treatment Phase | 1 | 1 | 2 | 3 |
| 149 | System or Non-system | 0 | 1 | 1 | 1 |
| 150 | Date of Admission (or Start of Phase) | 04/17/2000 | 04/21/2000 | 04/29/2000 | 05/27/2000 |
| 151 | Date of Discharge (or End of Phase) | 04/21/2000 | 04/29/2000 | 05/27/2000 | 06/17/2000 |

EXAMPLE 4: Carol was injured on February 12, 2000 and admitted to the System's spinal injury intensive care unit. She was transferred to a non-ICU bed on February 18, and to the rehabilitation unit on March 13. However, on March 17 she developed high fever and was transferred back to a medical unit, until March 22. Her doctors decided that she would do better in a subacute rehabilitation program, and she was admitted to a subacute unit in a nursing home affiliated with the System. In this rehabilitation unit, her course was smooth, and she was discharged home on April 23.

| | | |
|-----|--|-----------|
| 107 | Date of First System Admission | 2/12/2000 |
| 108 | Date of First System Inpatient Rehab Admission | 3/13/2000 |
| 110 | Date of Discharge from the Last System Inpatient Phase | 4/23/2000 |

| Treatment Phase # | | <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> |
|--------------------------|---------------------------------------|-----------------|-----------------|-----------------|-----------------|
| 148 | Treatment Phase | 1 | 3 | 1 | 5 |
| 149 | System or Non-system | 1 | 1 | 1 | 1 |
| 150 | Date of Admission (or Start of Phase) | 2/12/2000 | 3/13/2000 | 3/17/2000 | 3/22/2000 |
| 151 | Date of Discharge (or End of Phase) | 3/13/2000 | 3/17/2000 | 3/22/2000 | 4/23/2000 |

NOTE: all complications and operative procedures performed after rehab admission (i.e., after March 13th) are to be recorded as having occurred "during rehab" (including the complication for which she was sent back to the acute medical unit on March 17th).

FORM I

VARIABLE NAME: Treatment Phase Type for SCI

COMMENTS: For a complete overview of phases, the *entire* sequence of inpatient services and entities providing them, from injury to a *permanent* residence in the community, needs to be investigated and reported. A permanent residence is generally a private residence, but it may be a nursing home or a long-term hospital, if that is where the patient is discharged to as the permanent residence. If the patient is discharged to a nursing home on a *temporary* basis, e.g. to await making the own home accessible, then the nursing home stay is to be reported as the (last) phase of the sequence.

If a patient dies before the completion of inpatient rehabilitation the discharge date of the last phase reported should be the same as the day of death.

The first phase generally will be an acute med surg admission (code 1). It cannot be a rehab admission (code 3 or 5), and code 2 or 4 are also very unlikely if not impossible. If the first phase(s) is/are *before* the patient receives model system services, it is/they are to be reported. The admit date of the first phase will generally be the same as the date of injury, in some circumstances the next day.

Note: in multihospital systems, there probably is only one legal entity, but each hospital is *licensed* separately. The separate licensing should be considered as creating two phases if the patient moves between hospitals within a system. If a hospital has two buildings, but they are licensed together as *one* hospital, a change of the patient's bed from one building to another is not the start of a new phase – as long as the nature of the *services* does not change such that a different V148 code is needed.

Both the type of services and who provides them are to be considered in deciding whether a phase is to be reported. Examples of special situations:

- Within XYZ general hospital, the patient moves from acute med surg (code 1) to inpatient acute rehab (code 3) = two phases
- Within XYZ general hospital, patient moves from acute med surg unit A (code 1) to acute med surg unit B (code 1) = one phase (starting with admission to A, and ending with discharge from B)
- Patient moves from acute med surg unit in XYZ general hospital (code 1) to acute med surg unit in DFG hospital (code 1) = two phases (two hospitals are involved).
- Patient is admitted to the SCI unit of hospital ABC, and first receives acute care (code 1) and then rehab care (code 3) = 2 phases. The decision by the physician/project director as to what is the last acute day, and what is the first day of rehabilitation determines the admission and discharge dates of the phases.

blank page

FORM I

VARIABLE NAME: System or Non-system

DESCRIPTION: This variable documents if the treatment phase occurred in a Model System facility or in a non Model System facility.

CHARACTERS: 1 for each entry; up to 12 entries

CODES: **0 Non-system**

1 System

Blank (in coding positions # 2 through #12 only if corresponding V148 = blank)

COMMENTS: Provide this information for each treatment phase documented in variable 148. Unknowns are not allowed in this variable.

“Model System” refers to the fact that the Project Director and other Model System senior staff have some degree of control over the nature, quality, and quantity of services offered; and, that services, admission, and discharge are coordinated with other Model System components. The organization that is the Model System grant recipient does not need to own the hospital, nursing home, outpatient rehab facility in which services are offered.

When a person continues the initial rehab process at another currently funded Model System the treatment phase at the subsequent system is considered “in System”. The system that first treated the patient is responsible for submitting the Form I and all Form IIs for that patient.

QC: If V149 = “0” then, leave variables 154 and 155 blank.

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

EXAMPLES: See pages 176 to 177A.

FORM I

VARIABLE NAME: Date of Admission to the Treatment Phase

DESCRIPTION: This variable identifies the date of admission to the treatment phase being documented. Treatment phases may occur in or out of the System.

Document each admission date to Acute Medical/Surgical Hospitalization, Nursing Home, Inpatient Acute Rehab and Inpatient Subacute Medical/Surgical Care, Inpatient Subacute Rehab.

Code all treatment phases in sequence by admission date. Code up to 12 treatment phases.

CHARACTERS: 8 for each entry, up to 12 entries

FORMAT: mmddyyyy

CODES: **Any valid date**

Blank (in coding positions # 2 through #12 only if corresponding V148 = blank)

99 Unknown month or day

9999 Unknown year

99999999 Entire date unknown

Unknowns are allowed only for non-System phases.

COMMENTS: Provide this information for each treatment phase documented in variable 148. The end of a phase is when all services end (even though they may have dropped below the minimum level specified in the phase criteria at an earlier date). See pages 176 to 177A for more information.

Record the month, day and year. Unknowns are allowed in this variable only for non-system treatment phases.

This variable cannot be stored in date format since non-valid dates and non-valid parts of a date are allowed.

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

EXAMPLES: See pages 177A to 177E.

FORM I

VARIABLE NAME: Date of Discharge from the Treatment Phase

DESCRIPTION: This variable identifies the date of discharge from the treatment phase being documented. Treatment phases may occur in or out of the System.

Document each discharge date from Acute Medical/Surgical Hospitalization, Nursing Home, Inpatient Acute Rehab, Inpatient Subacute Medical/Surgical Care and Inpatient Subacute Rehab.

Code up to 12 treatment phases.

CHARACTERS: 8 for each entry, up to 12 entries

FORMAT: mmddyyyy

CODES: **Any valid date**

99 **Unknown month or day**

9999 **Unknown year**

99999999 **Entire date unknown**

Unknowns are allowed only for non-System phases.

Blank *(in coding positions # 2 through #12 only if corresponding VI48 = blank)*

COMMENTS: Provide this information for each treatment phase documented in variable 148. The end of a phase is when all services end (even though they may have dropped below the minimum level specified in the phase criteria at an earlier date). See pages 176 to 177A for more information.

Record the month, day and year. Unknowns are allowed in this variable only for non-system treatment phases.

This variable cannot be stored in date format since non-valid dates and non-valid parts of a date are allowed.

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

EXAMPLES: See pages 176 to 177A.

FORM I

VARIABLE NAME: Number of Short-term Discharge Days during the Treatment Phases

DESCRIPTION: This variable documents the actual number of days spent out of the hospital or nursing home (system or non-system) on short-term discharge(s) during an inpatient type treatment phase. **These are days for which hospitalization charges are not incurred.**

Short-term discharges are, for example, for the purpose of home adjustment or interruptions in the inpatient rehabilitation process due to the stabilization process (for body jackets, halos, etc.). There is intent to return for additional inpatient services and, the patient spends the time in a private residence. If, during this period of time, the patient is in a nursing home, subacute medical/surgical unit, etc. report this as a separate phase (since charges are incurred). Short-term discharge days always occur DURING a phase – never between phases.

Document short-term discharges occurring during Acute Medical/Surgical Hospitalization, during Nursing Home admissions, during Inpatient Acute Rehab, during Inpatient Subacute Medical/Surgical Care and during Inpatient Subacute Rehab. These days are not included in the lengths of stay for any of these phases.

Code this item for each treatment phase (codes “1”, “2”, “3”, “4” or “5”) that is recorded in variable 148.

FORM I

VARIABLE NAME: Number of Short-term Discharge Days

CHARACTERS: 3 for each entry, up to 12 entries

CODES: **000 None**

000 - 887 Valid range

888 Yes short-term discharge days, number unknown

Note: the use of code **888** to indicate *Not applicable, outpatient treatment phase* was valid in Form Is with Indates up to 03/31/2005 when the corresponding V148 = 6, 7 or 8.

Blank (in coding positions # 2 through #12 only if corresponding V148 = blank)

999 Unknown if there were any short-term discharge days

Code 999 is allowed

- for all non-system admissions, in all inpatient phase types (Acute Medical/Surgical Hospitalization, Nursing Home, Inpatient Acute Rehab, Inpatient Subacute Medical/Surgical Care and Inpatient Subacute Rehab);
- for system admissions: only for Nursing Home admissions, Inpatient Subacute Medical/Surgical Care admissions and Inpatient Subacute Rehab admissions in records with in-dates prior to 11/1/2000;
- for system admissions, in the Acute Medical/Surgical Hospitalization and Inpatient Acute Rehab phases, as a conversion code only in records with in-dates prior to 2/1/1996.

COMMENTS: This variable cannot be computed by the NSCISC's software.

REVISIONS: In November 1995 the old Number of Short-term Discharge Days variable (pre Nov. 1995 variable #125) was separated into 2 variables: Number of Short-term Discharge Days During Acute Care (pre Oct. 2000 variable 106A) and During Inpatient Rehab (pre Oct. 2000 variable 106B).

October 2000: Number of Short-term Discharge Days during Nursing Home admissions, Inpatient Subacute Medical Care and Inpatient Subacute Rehab were added to the database. Data are required for patients admitted to the System after 10/31/2000.

January 2004: Code 888 may be used if there were short-term discharge days but the number of days is not known (for phase type codes 1 through 5).

EXAMPLES: See page 186.

FORM I

VARIABLE NAME: Number of Days in Treatment Phase

DESCRIPTION: This is the number of days between admission to and discharge from
 Acute Medical/Surgical Hospitalization, Nursing Home, Inpatient
 Acute Rehab and Inpatient Subacute Medical/Surgical Care, Inpatient
 Subacute Rehab (minus the short-term discharge days).

These days do not include short-term discharge days.

Code this item for each treatment phase documented in variable 148. This variable can be calculated by the NSCISC's software.

CHARACTERS: 4 for each entry, up to 12 entries

CODES: **1 to 9998 Valid range**

Blank (in coding positions # 2 through #12 only if corresponding V148 = blank)

9999 Unknown

Code 9999 is allowed

- for all non-system inpatient treatment phase types;
- for system admissions only for Nursing Home admissions, Inpatient Subacute Medical/Surgical Care admissions and Inpatient Subacute Rehab admissions in records with in-dates prior to 11/1/2000;
- for system admissions, in the Acute Medical/Surgical Hospitalization and Inpatient Acute Rehab phases, as a conversion code only in records with in-dates prior to 2/1/1996.

REVISIONS: November 1995: the old Number of Days Hospitalized in System variable (pre-11/95 variable #127) was separated into 2 variables: Number of Days Hospitalized in Acute Care (pre- Oct. 2000 variable V109A) and in Inpatient Rehab (pre- Oct. 2000 variable V109B).

October 2000: Number of Days in Day Hospital, Outpatient Rehab and Home Rehab were added to the database.

SOFTWARE: During the PROCESS function, the computer calculates variable 153 using the dates in variable 150 and variable 151 minus the number of days in variable 152. To use: place the cursor on the variable to be calculated (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button. If V152 = 999 then, this variable = 9999.

EXAMPLES: See page 186.

FORM I

VARIABLE NAME: Charges

DESCRIPTION: This variable documents the charges incurred during each System inpatient treatment phase. Leave this variable blank for all non-System inpatient treatment phases. Document the charges for each treatment phase coded in variable 148 and received at a System facility during each phase of Acute Medical/Surgical Hospitalization, Nursing Home, Inpatient Acute Rehab, Inpatient Subacute Medical/Surgical Care, Inpatient Subacute Rehab. Charges include room and board, X-ray, laboratory, pharmacy, inpatient rehabilitation medicine (occupational therapy, physical therapy, respiratory therapy, neurological program), central supply, intensive care unit, operating room, recovery room, anesthesia, nuclear medicine and all other costs associated with the treatment phase. Physician fees may or may not be included (as coded in V155).

CHARACTERS: 7 for each entry, up to 12 entries

CODES: **0000000** *Conversion code only (data collectors are not allowed to use this code)*
0 to 9999998 **Valid range**
9999999 **Unknown** *(and, use code 9 in V155)*
Blank *(for all non-system treatment phases, in all coding positions)*
Blank *(in coding positions # 2 through #12 for system and non-system phases if corresponding V148 = blank)*

COMMENTS: This variable is collected only for system inpatient treatments. If the treatment phase occurs at a non-system facility leave this variable blank. Document the charge to the nearest dollar but do not round up. In the corresponding variable 155, document the data reliability (actual or estimated) and whether or not these charges include physicians' fees. Use code 9999999 for the indigent patient. Some Systems have access only to the Total Charges and will not be able to divide charges into the individual treatment phases. In this case,

- Code this Charges variable (V154) "9999999" and code V155 (Reliability code) "9".
- Then, enter the Total in the Total Charges variable (V164) and the applicable Reliability Code for Total Charges in variable 165.
 - When you do this, do NOT use the software's calculation function to calculate variable 164. If you do use the software function, the results in V164 will be "9999999".

QC: See page 178.

REVISIONS: 2001: The code for Unknown was changed from "0000000" to "9999999". The remaining zeros are in records of patients for whom acute and rehab lengths of stay could not be differentiated. In these cases, all charges were attributed to the rehab length of stay.

EXAMPLES: See page 186.

FORM I

VARIABLE NAME: Reliability Codes for Charges

DESCRIPTION: This variable documents (1) the reliability of the charges coded in variable 154 and (2) whether or not these charges include physicians' fees.

Document the reliability of charges for each phase coded in variable 148 that was received at a System facility. Leave this variable blank for all non-System treatment phases.

CHARACTERS: 1 for each entry, up to 12 entries

CODES: **Actual charges**

1 Includes physicians' fees

2 Does not include physicians' fees

5 Inclusion of physicians' fees unknown

Estimated charges

3 Includes physicians' fees

4 Does not include physicians' fees

6 Inclusion of physicians' fees unknown

9 Unknown (*V154 must = "999999" and vice versa*)

Blank (*for all non-system treatment phases, in all coding positions*)

Blank (*in coding positions # 2 through #12 for system and non-system phases if corresponding V148 = blank*)

COMMENTS: This variable is collected only for system treatments. If the treatment phase occurs at a non-system facility leave this variable blank.

A reliability code of "9" is not allowed with a known dollar amount in the corresponding V154.

QC: See page 178.

REVISIONS: November 1995: The change in the reporting policy to allow charges that include physicians' fees was implemented in 1995. This change was made to accommodate those systems for whom itemized charges were not available and, therefore, it was impossible to exclude the physicians' fees. Codes "5" or "6" were used to convert existing data.

October 2000: Codes "5" and "6" are allowed in any record.

FORM I

VARIABLE NAME: Reliability Codes for Charges

EXAMPLE: The patient was first admitted to a non-System acute unit during October 2000 (the exact day of the month is not known). He was discharged from this unit on October 15, 2000. Number of short-term discharge days is unknown.

The same patient was admitted to a Model System acute unit on October 15, 2000 and discharged on October 20, 2000. The charges for this phase were \$16, 800. Physician fees were included in some, but not all charges.

On October 20, 2000 the patient was admitted to the system’s inpatient acute rehab unit and discharged from there on November 12, 2000. The actual charge (with no physicians’ fees) for this phase was \$29,808. There were no short-term discharge days in phases 2 and 3.

| Treatment Phase # | | <u>1</u> | <u>2</u> | <u>3</u> |
|--------------------------|---------------------------------------|-----------------|-----------------|-----------------|
| 148 | Treatment Phase Type for SCI | 1 | 1 | 3 |
| 149 | System or Non-system | 0 | 1 | 1 |
| 150 | Date of Admission (or Start of Phase) | 10/99/2000 | 10/15/2000 | 10/20/2000 |
| 151 | Date of Discharge (or End of Phase) | 10/15/2000 | 10/20/2000 | 11/12/2000 |
| 152 | Number of Short-term Discharge Days | 999 | 000 | 000 |
| 153 | Number of Days in Treatment Phase | 9999 | 0005 | 0023 |
| 154 | Charges | | 16800 | 29808 |
| 155 | Charges Reliability Code | | 5 | 2 |

FORM I

VARIABLE NAME: Hours of Physical Therapy

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

December 2004: variable was deleted.

FORM I

VARIABLE NAME: Hours of Occupational Therapy

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

December 2004: variable was deleted.

FORM I

VARIABLE NAME: Hours of Recreational Therapy

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

| December 2004: variable was deleted.

FORM I

VARIABLE NAME: Hours of Vocational Rehab

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

| December 2004: variable was deleted.

FORM I

VARIABLE NAME: Hours of Psychological Counseling

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

December 2004: variable was deleted.

FORM I

VARIABLE NAME: Hours of Social Worker Services

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

| December 2004: variable was deleted.

FORM I

VARIABLE NAME: Hours of Other Therapy

REVISIONS: October 2000: this variable was added to the database. Data are required for patients admitted to the System after 10/31/2000.

| December 2004: variable was deleted.

FORM I

VARIABLE NAME: Hours of Other Therapy

| December 2004: variable was deleted.

FORM I

VARIABLE NAME: Total Number of Days Hospitalized in the System's Acute (and Subacute) Medical/Surgical Care Unit and Total Days Hospitalized in the System's Inpatient Acute (and Subacute) Rehabilitation Unit

DESCRIPTION: These variables document:

- 1) **total length of stay in the System's acute (and subacute) medical/surgical care unit** (Variable 163A) and
- 2) **total length of stay in the System's inpatient acute (and subacute) rehab unit to discharge from the last inpatient rehab phase** (Variable 163R).

These variables can be calculated by the NSCISC's software.

CHARACTERS: 4 for each entry, 2 entries

CODES: **1-8888 Valid range**

8888 Not applicable not admitted to the System's Acute (or Subacute) Medical/Surgical Care Unit (V163A)

8888 Not applicable, not admitted to System inpatient rehab unit (V163R)

NOT a valid code in Form Is with Indates after 03/31/2005 unless the patient expired, achieved complete recovery or minimal deficit status during System acute care

9999 Unknown (not allowed in records with in-dates after 2/1/1996)

COMMENTS: If the patient was never admitted to the System inpatient rehab unit, code variable 163R "8888".

Persons with minimal neurologic impairment on admission into the system who complete inpatient rehab in the system's acute care unit may continue to be included in the database if they are hospitalized in the system more than 1 week.

Data in these variables are required of patients who are admitted to the system on or after December 1, 1995.

REVISIONS: November 1995: the old Number of Days Hospitalized in System variable (old variable #127) was separated into 2 variables: Number of Days Hospitalized in Acute Care (V109A) and in Inpatient Rehab (V109R). The unknown code ("9999") is not allowed in records with indates after 2/1/1996.

SOFTWARE: During the PROCESS function, the software calculates V163A by summing the values in variables 153_1 through V153_12 IF V148=1 (or 4) and V149=1. The software calculates V163R by summing the values in variables 153_1 through V153_12 IF V148=3 (or 5) and V149=1. To use: place the cursor on the variable to be calculated (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

QC: See pages 65 and 67 and, IF <Indate1> > 03/31/2005 and [(<V110> <> <V145>) and (V131D not equal 3 or 6 or 7)] THEN V163R cannot = 8888.

FORM I

VARIABLE NAME: Total System Hospitalization Charges

DESCRIPTION: This variable documents the total charges incurred during the initial System inpatient hospitalization period. This variable is the sum of the amounts in 154_1 through V154_12, for system hospitalizations, **for the acute (and sub-acute) medical and inpatient acute (and sub-acute) rehab treatment phases only, for day-1 admissions only.**

Charges include room and board, X-ray, laboratory, pharmacy, inpatient rehabilitation medicine (occupational therapy, physical therapy, respiratory therapy, neurological program), central supply, intensive care unit, operating room, recovery room, anesthesia, nuclear medicine and all other costs associated with the treatment phase. Physician fees may or may not be included.

CHARACTERS: 7

CODES: **1 to 9999998** Valid range
8888888 Not applicable [*System treatment phase(s) were all out-patient only; (code V165 "8")*]
NOT a valid code in Form Is with Indates after 03/31/2005
9999999 Unknown (*code V165 "9"*)
Blank For non-day-1 admissions

COMMENTS: This variable is the sum of the amounts in 154_1 through V154_12, for System acute medical and System inpatient acute rehab treatment phases (i.e., V148 = "1", "3", "4" or "5" AND V149 = "1"), for day-1 admissions only. The charges for treatment phases in the Nursing Home are not included in this variable.

SOFTWARE: The software calculates this variable by adding the amounts in V154_1 through V154_12 IF the corresponding V149=1 AND the corresponding V148=1, 3, 4 or 5 and V109A = 001. To use: place the cursor on the variable to be calculated (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

FORM I

VARIABLE NAME: Reliability Codes for Total System Hospitalization Charges

DESCRIPTION: This variable documents (1) the reliability of the Total Charges coded in variable 164 and (2) whether or not these charges include physicians' fees (for day-1 admissions only).

CHARACTERS: 1

CODES: Actual charges

- 1 Includes physicians' fees**
- 2 Does not include physicians' fees**
- 5 Inclusion of physicians' fees unknown**

Estimated charges

- 3 Includes physicians' fees**
- 4 Does not include physicians' fees**
- 6 Inclusion of physicians' fees unknown**

- 8 Not applicable** [*System treatment phase(s) were all out-patient only; (code V164 "888888")*]
NOT a valid code in Form Is with Indates after 03/31/2005

- 9 Unknown** (V164 must = "999999")

Blank For non-day-1 admissions

COMMENTS: This variable is to **document only system acute (and sub-acute) medial and System inpatient acute (and sub-acute) rehab treatment phases, for day-1 admissions only.** See page 196 for more information.

A reliability code of "9" is not allowed with a known dollar amount in V164.

SOFTWARE: The software calculates this variable by using the codes in V155_1 through V155_12 IF the corresponding V149=1 AND the corresponding V148=1, 3, 4 or 5. To use: place the cursor on the variable to be calculated (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

The formula is:

If any V155 = 9 then V165 = 9.

Else: if any V155 = 6, then V165 = 6.

Else: If any V155 = 4, then V165 = 4.

Else: If any V155 = 3, then V165 = 3.

Else: If any V155 = 5, then V165 = 5.

Else: If any V155 = 2, then V165 = 2.

Else: If any V155 = 1, then V165 = 1.

Else: If any V155 = blank, then V165 = blank.

REVISIONS: November 1995: The change in the reporting policy to allow charges that include physicians' fees was implemented in 1995. This change was made to accommodate those systems for whom itemized charges were not available and, therefore, it was impossible to exclude the physicians' fees. Codes "5" or "6" were used to convert existing data.

October 2000: Codes "5" and "6" are allowed in any record.

FORM II

VARIABLE NAME: Post-injury/Anniversary Year

DESCRIPTION: This variable documents the post-injury year being reported. When Form IIs are required, they should be submitted as soon as possible following the annual anniversary date of the patient's injury. Form II data submission is required of all patients in post-injury years 1, 5, 10, 15, 20, 25 and 30. Data submission in other years is permitted, but not required.

CHARACTERS: 2

COMMENTS: Do not submit any Form IIs until after the patient has been discharged from the initial hospitalization period. If a patient is still in the initial hospitalization period on his first anniversary, do not submit a Year 1 Form II. Document all the events occurring through discharge from the initial hospitalization on Form I.

The first Form II will document only the events occurring in the interval between discharge from the last System inpatient phase and the first anniversary date of the patient's spinal cord injury. This is often an incomplete year; however, subsequent Form IIs will contain data for complete follow-up years. See page 16 for information on patients who are still in the initial hospitalization period past their first anniversary.

EXAMPLE 1: The patient was injured on 06/18/77 and discharged on 09/02/77.

| <u>Data Collection Form</u> | <u>Time Period Covered</u> |
|-----------------------------|--|
| FORM I: | 06/18/77 through 09/02/77 |
| FORM II, Year 1: | 09/03/77 through 06/17/78 |
| Year 2: | 06/18/78 through 06/17/79 <i>(not a required form)</i> |
| Year 5: | 06/18/81 through 06/17/82 |

EXAMPLE 2: The patient was injured on 06/18/77, still hospitalized on his first anniversary, and discharged on 07/18/78.

| <u>Data Collection Form</u> | <u>Time Period Covered</u> |
|-----------------------------|--|
| FORM I: | 06/18/77 through 07/18/78 |
| FORM II, Year 1: | NO FORM II |
| Year 2: | 07/19/78 through 06/17/79 <i>(not a required form)</i> |
| Year 5: | 06/18/81 through 06/17/82 |

FORM II

VARIABLE NAME: Category of Follow-up Care Provided by the Model SCI System
DESCRIPTION: This variable describes the type of medical care being provided to the patient by the System **on the anniversary date being reported.**

CHARACTERS: 1

CODES: **1 Primary or Major Consulting Care:** Patient does not have an identified health care provider (physician/institution) outside the System and receives all medical care through the System OR the patient has an identified health care provider (physician/institution) outside the System but receives some SCI related medical care that may include annual evaluations through the System. All variables on Form II must be completed when this code is used.

4 Data Collection Only: Follow-up data collection requires telephone/correspondence contact. No scheduled patient contact for medical care during the follow-up year (the patient is still in the original System or, the patient's primary or major consulting care has been transferred to another federally-designated System). After transfer, the System that originally submitted the Form I remains responsible for obtaining and submitting follow-up data.

All interview variables on Form II must be completed and the annual exam variables (V211-V213) and neurological exam variables (V244-V249) must be coded "*Unknown, not done*" when this code is used. (*see QC pg 200*)

5 Lost to System: Patient's whereabouts are unknown; or patient refuses; or patient is not allowed to participate in data collection; or a third party refuses access to the patient (e.g. prison authorities); or patient does not return the interview form; or the patient refuses to sign the current consent form. The System is unable to obtain data for the entire follow-up year.

When this code is used, it is necessary to complete only variables 201 and 202. Provide the "Reason for Lost" in V202. Variables 203 through 249 should be blank.

Once a patient has been reported "lost to system" in a follow-up year, consecutive "lost" Form IIs should not be submitted. The patient still remains eligible for future follow-up but future Form IIs should not be submitted unless the patient's Category of Follow-up Care changes from "lost".

8 Not Applicable: During the follow-up year being reported, the patient's neurologic status was "normal" or "minimal deficit". No further data collection will be required. This category supersedes category of care codes 1, 4 and 6. All variables on Form II must be completed when this code is used.

When a patient's neurologic status changes to normal or minimal deficit, a Form II for the year in which the change occurred should be submitted (even if the year is not a required data submission year). This ensures that the recovery will be reported in the proper year and that future follow-up will not be required after that year.

9 Unknown

FORM II

VARIABLE NAME: Category of Follow-up Care Provided by the Model SCI System

REVISIONS: January 1998: V203A (Reason for Lost) was added.

October 2000: For “Transferred” patients, continued follow-up data are required from the System that submitted the Form I.

June 2001: Code “6” (Transferred) was deleted. Transferred patients were moved to code “4” (Data Collection Only).

CONVERSIONS: January 1985: The "Deceased" category (old code 7) was deleted. Records using old code "7" were changed to code "9".

November 1995: codes 1 and 2 were combined into 1 category and the restriction of only 3 consecutive years of Data Collection Only was removed.

June 2001: records with code 6 were changed to code 4.

COMMENTS: If, after 3 months following a patient's anniversary date, there is absolutely no hope of obtaining data on a patient, a Form II should be submitted declaring the patient *lost to system*. An update can always be submitted if information becomes available in the future.

If the patient is coded “lost” (V201 = “5”) then, leave all variables after V202 blank.

For telephone interview: if your IRB allows, you may get a verbal consent (with a witness?). If both the patient and the witness agree, you may proceed with the interview. If a patient transfers to another currently-funded Model System and the IRBs from both systems agree to a telephone waiver, this allows both systems to share data on the transferred patient.

QC: See [page 101](#) for coding instructions for patients with *minimal deficit* or *normal neurologic* status.

If Variable 201 = “4” (*Data collection only*) then:

variables 211 through 213 and variables 244 through 249 must be coded *Unknown, not done*.

If Variable 201 = “5” (*Lost*) then:

variable 202 cannot be coded “8” (*Not applicable, not lost*) and all variables from V203 through V249 must = blank.

FORM II

| | |
|----------------|--|
| VARIABLE NAME: | Reason for Lost |
| DESCRIPTION: | This variable documents the reason the patient is currently coded "lost" in the Category of Care variable (V201). |
| CHARACTERS: | 1 |
| CODES: | <p>1 Patient refused/withdrew consent</p> <p>2 Patient incarcerated and not available</p> <p>3 Unable to contact after all attempts recommended by the Tracking Committee* have failed or patient agreed to complete the interview form but did not return the form</p> <p>4 Other</p> <p>8 Not applicable, patient not coded "5" in V201 (<i>use this code if V201= "1", "4", "8" or "9"</i>)</p> <p>9 Unknown - This is a <u>CONVERSION CODE ONLY</u>. Data collectors may NOT use this code. This information is provided for data analyses purposes only.</p> |
| COMMENTS: | <p>*These are the Follow-up Tracking Committee's conditions for which you may use code 3:</p> <p>A) There should be more than one attempt to schedule a patient for follow-up evaluations in the clinic.</p> <p>B) After obtaining the most current, valid, phone number, there should be at least six attempts to contact a person. These attempts should be made at different times during the day, evening and weekends.</p> <p>C) If unable to contact by telephone, a survey requesting the data should be mailed to the patient's home.</p> <p>Once you have made all these attempts to find a patient, you do not need to repeat the process for the next required data submission year.</p> <p>If the patient is coded "lost" (V201 = "5") then, leave all variables after V202 blank.</p> <p>See Appendix D for follow-up tips.</p> |
| REVISIONS: | <p>January 1998: This variable was added and the information will be used by the Follow-up Tracking Committee to delete some "lost" patients from their tracking reports. Data are required in records newly entered into the database after 2/1/98 and optional in "lost" records present in the database prior to 2/1/98. <u>However, it is in the system's best interests to complete this variable for all patients who are currently coded <i>lost</i>. It is STRONGLY suggested that all systems provide data in this variable for patients whose last Form II = <i>lost</i>.</u></p> |
| CONVERSION: | <p>January 1998: for all Form IIs in the database at this time and coded lost in V201, code "9" (<i>unknown</i>) was inserted in this variable.</p> |
| QC: | <p>If this variable = "8" (<i>not applicable</i>) then: V201 must NOT be coded "5".</p> |

FORM II

VARIABLE NAME: Change in Marital Status

DESCRIPTION: This variable documents change in marital status between the current Form II and the last Form II with known marital status data. When coding the year 1 Form II, this variable documents the change in marital status between injury and the year 1 anniversary.

CHARACTERS: 1

- CODES:
- 0 No change**
 - 1 Divorce**
 - 2 Marriage**
 - 3 Widowed**
 - 4 Divorce + marriage** (*in either order*)
 - 5 Widowed + marriage** (*in either order*)
 - 6 Divorce, marriage + widowed** (*in any order: DMW, MDW, WMD*)
 - 7 Other**
 - 9 Unknown**

Blank (*only if V201 = "5"*)

COMMENTS: When asking the patient this question, the interviewer will need to cue the patient concerning the appropriate time period. For example, if data are being collected for year 10 and the patient has Form IIs for years 5 and 1 but marital status was unknown in year 5, the interviewer should ask for the changes that occurred since year 1. Ignore separations whether temporary or permanent.

EXAMPLE 1: At the time of injury, the patient was single. The patient married shortly after being discharged and was still married at the time of his first anniversary of injury.

| Form I V121 Marital Status | Form II, year 01 | |
|----------------------------------|------------------------|----------------------------------|
| | V204 Marital Status | V209 Change in Marital Status |
| 1 | 2 | 2 |

EXAMPLE 2: The patient is being interviewed for his year 01 anniversary. He was married at the time of injury but is now separated.

| Form I V121 Marital Status | Form II, year 01 | |
|----------------------------------|------------------------|----------------------------------|
| | V204 Marital Status | V209 Change in Marital Status |
| 2 | 4 | 0 |

There was no legal change in marital status since the patient was only separated (not legally divorced).

FORM II

VARIABLE NAME: Change in Marital Status

EXAMPLE 2: At the time of injury, the patient was married to his first wife. The patient was “lost” during year 01. During year 03 the patient divorced and in year 04, he married his second wife. At his 5th anniversary, the patient was still married to his second wife.

| Form I V121 Marital Status | Form II, year 01 V204 Marital Status | Form II, year 05 | |
|----------------------------------|--|------------------------|----------------------------------|
| | | V204 Marital Status | V209 Change in Marital Status |
| 2 | blank | 2 | 4 |

EXAMPLE 3: The patient was single at the time of her first anniversary and her marital status on her year 05 Form II was unknown.

These are the pre-interview codes in the patient’s Form II records:

| Year 01 V204 Marital Status | Year 05 V204 Marital Status |
|-----------------------------------|-----------------------------------|
| 1 | 9 |

Her status on the 10th anniversary was married. Since marital status on her 5th anniversary was unknown, the interviewer asked her for all changes in marital status since her first anniversary. She said that she married 2 years after her injury and her first husband died in her 6th anniversary year. She remarried 7 years after her injury.

These are the post-interview codes (if the data collector does not update the year 05 Form II):

| Year 01 V204 Marital Status | Year 05 V204 Marital Status | V204 Marital Status | Year 10 V209 Change in Marital Status |
|-----------------------------------|-----------------------------------|------------------------|---|
| 1 | 9 | 2 | 5 |

However, if the data collector chooses to update the year 05 data, these are the post-interview codes:

| Year 01 V204 Marital Status | Year 05 V204 Marital Status | V204 Marital Status | Year 10 V209 Change in Marital Status |
|-----------------------------------|-----------------------------------|------------------------|---|
| 1 | 2 | 2 | 5 |

NOTE: data collectors are encouraged to update records whenever new data are available.

FORM II

VARIABLE NAME: Date of the Annual Examination

DESCRIPTION: This variable specifies the date on which the annual physical examination (i.e., history and physical by a physician) was performed.

CHARACTERS: 8

CODES: **Any valid date**

88888888 Not applicable, no annual examination

99999999 Unknown

Blank (only if V201 = "5")

FORMAT: mmddyyyy

COMMENTS: Code the month, day and year of the examination. Partial unknown dates (i.e., unknown in the month, day or year) are not allowed in this variable. Use the Unknown code (99999999) if it is not known whether or not the patient had an annual exam.

When data for an annual examination are collected during a system rehospitalization, the date of the exam should be the day on which data for most of the variables are available. When there are multiple exams during a year, use the date on which data for most of the variables are available or, if the data are equally available, use the exam that was done closest to the anniversary date. **For the first (or second see [page 16](#) for details) anniversary, it is extremely important to obtain data as close as possible to the anniversary date.**

This variable cannot be stored in date format since non-valid date codes (88888888 and 99999999) are allowed.

The following variables are all to be collected on the date coded in this variable:

| Variable Number | Variable Name | Syllabus Page |
|-----------------|--|---------------|
| 212 | Grade of Worst Pressure Ulcer | 207 |
| 213 | Number of Pressure Ulcers | 120 |
| 244* | Neurologic Impairment | 100 |
| 245* | ASIA Impairment Scale | 102 |
| 246* | ASIA Motor Index Score | 104 |
| 247* | Sensory Level | 107 |
| 248* | Motor Level | 108 |
| 249* | Level of Preserved Neurologic Function | 110 |

* Required for the year 1 physical exam and optional in subsequent years

FORM II

VARIABLE NAME: Date of the Annual Examination

COMMENTS: The annual examination for any anniversary year may be performed 6 months (182 days) prior to and up to 6 months (182 days) after the anniversary date. For the first anniversary, it is extremely important to obtain data as close as possible to the anniversary date.

Example: if the patient was injured on 05/19/1973 and his discharge was on 10/22/1973, the windows of time (for the required data submission years) are listed under the “during the annual exam” columns.

Exam and Interview Dates

Patient ID: B 000001 V106 = 05/19/1973 V151 = 10/22/1973

| Anniversary Year Number [V200] | Anniversary Date | Windows Of Time For Variables Collected | | | | | |
|--------------------------------|------------------|---|------------|------------------------|------------|----------------------|------------|
| | | during the anniversary year | | during the annual exam | | during the interview | |
| | | Beginning | End | Beginning | End | Beginning | End |
| ▶ 1 | 05/19/1974 | 10/23/1973 | 05/18/1974 | 11/18/1973 | 11/17/1974 | 11/18/1973 | 11/17/1974 |
| 5 | 05/19/1978 | 05/19/1977 | 05/18/1978 | 11/18/1977 | 11/17/1978 | 11/18/1977 | 05/18/1979 |
| 10 | 05/19/1983 | 05/19/1982 | 05/18/1983 | 11/18/1982 | 11/17/1983 | 11/18/1982 | 05/18/1984 |
| 15 | 05/19/1988 | 05/19/1987 | 05/18/1988 | 11/18/1987 | 11/17/1988 | 11/18/1987 | 05/18/1989 |
| 20 | 05/19/1993 | 05/19/1992 | 05/18/1993 | 11/18/1992 | 11/17/1993 | 11/18/1992 | 05/18/1994 |
| 25 | 05/19/1998 | 05/19/1997 | 05/18/1998 | 11/18/1997 | 11/17/1998 | 11/18/1997 | 05/18/1999 |
| 30 | 05/19/2003 | 05/19/2002 | 05/18/2003 | 11/18/2002 | 11/17/2003 | 11/18/2002 | 05/18/2004 |
| 35 | 05/19/2008 | 05/19/2007 | 05/18/2008 | 11/18/2007 | 11/17/2008 | 11/18/2007 | 05/18/2009 |

Back

* The start of the first anniversary year begins the day after discharge; subsequent anniversary years begin on the anniversary of the date of injury.

QC: See [page 200](#) for information on patients whose Category of Follow-up Care is "Data Collection Only".

SOFTWARE: The software includes functions to (1) calculate the correct anniversary year for an annual exam date and (2) provide the acceptable range of dates for the annual exam if the anniversary year is known. To Use: move the cursor to the patient’s line in the PROCESS/Data Entry screen and click on the “Exam Date” button.

FORM II

VARIABLE NAME: Date of the Annual Examination

REVISIONS: October 1986: The Date of the Annual Exam was added. Locations and Grades of Pressure Ulcers and Number of Pressure Ulcers were changed from those occurring during the anniversary year to those present at the time of the annual examination. The ASIA Motor Index Score was added to this exam.

November 1995: The remaining neurologic exam variables (Neuro Impairment, Levels, ZPP and ASIA Impairment Scale) were added to the annual exam.

Data for these 1995 items are expected in Form IIs with Dates of Annual Examination on or after January 1, 1996 (i.e., V213 equal to or greater than 01/01/1996).

January 1998: Pressure Ulcers Present at the Time of the Annual Exam was changed to Worst Pressure Ulcer Present at the Time of the Annual Exam and the neurologic exam variables (Neuro Impairment, Levels, ZPPs, ASIA Impairment Scale and ASIA Motor Index Score) are required only in annual years 1 and 2.

October 2000: Motor ZPP and Sensory ZPP items were deleted. The Neuro exam items are collected in year 01 only. Other Annual Exam items are collected in year 1 and every 5th anniversary.

CONVERSION: Data from the old neurologic variables (i.e., old variable numbers 211, 212, 212A, 212B, 212C, 212D and 213) and the old Mechanical Ventilation variable (V219) were retained. The Date of the Annual Exam can be used to distinguish these records from those in which these data are acquired during the Annual Exam (i.e., if the Annual Exam is on or after 1/1/96, these data were obtained on that date).

FORM II

VARIABLE NAME: Grade of the Worst Pressure Ulcer Present at the Time of the Annual Exam

DESCRIPTION: This variable documents the grade of the worst sore present, upon visual examination, during the annual physical examination.

CHARACTERS: 1

CODES:

| | |
|--------------|--|
| 0 | No pressure ulcers present at the time of the annual exam |
| 1 | Grade 1 |
| 2 | Grade 2 |
| 3 | Grade 3 |
| 4 | Grade 4 |
| 8 | Pressure ulcer present, grade unknown* |
| 9 | Unknown, exam not done |
| Blank | <i>(only if V201 = "5")</i> |

* When there are multiple ulcers AND at least one ulcer is "8" (grade unknown):

if one of the ulcers is a grade "4", code this variable "4"

otherwise, code this variable "8".

COMMENTS: Document the worst ulcer present on the date specified in Variable 211 (Date of Annual Examination).

REVISIONS: October 1986: the Form II Pressure Ulcer variable was changed (from ulcers developing during the entire follow-up year) to documenting only those ulcers present upon visual inspection at the time of the annual examination.

January 1998: This variable was changed from Location(s) and Grade(s) of Pressure Ulcer(s) Present at the Time of the Annual Exam to Grade of the Worst Pressure Ulcer Present at the Time of the Annual Exam.

CONVERSION: January 1998: the following conversions were made:

If code "4" is found anywhere from old V218_1 through V218_27 then,
current Grade of Worst Sore variable = "4".

If no code "4" and no code "9" found anywhere from old V218_1 through V218_27 then,

current Grade of Worst Sore variable = highest grade ("0", "1", "2", "3" or "8") found in old V218_1 through V218_27.

If at least one code "9" and a sore present (code "1", "2", "3" or "8") in another location in old V218_1 through V218_27 then,

current Grade of Worst Sore variable = "8".

Otherwise current Grade of Worst Sore variable = "9".

QC: If variable 212 is coded "0", then variable 213 must be coded "00".

If variable 212 is coded "9", then variable 213 must be coded "99".

FORM II

VARIABLE NAME: Rehospitalizations – Number of Days Rehospitalized and Primary Reason for Rehospitalization

DESCRIPTION: This variable documents

- 1) the number of days rehospitalized for each rehospitalization (**V217D_1 through V217D_8**) and
- 2) the primary reason for each rehospitalization (**V217R_1 through V217R_8**)

during the anniversary year being reported.

Document all rehospitalizations in all hospitals (i.e., system and non-system) **during the anniversary year being reported.**

For the year 01 Form II only:

- ❖ the year 01 Form II documents only rehospitalizations occurring in the interval between the discharge from the last System inpatient treatment phase to the first anniversary date of the patient's injury.

All Form IIs after year 01 document rehospitalizations occurring during the entire follow-up year being reported.

Do not include the initial System hospitalization or hospitalizations preceding the initial admission into the System.

Do not record any custodial admissions as rehospitalizations in this variable. These days should be reported as days in a nursing home in variable 220.

If more than 7 rehospitalizations occur, then add the days for all rehospitalizations over #7 and report those days in V217D_8 and report the primary reason for the longest of the rehospitalizations over #7 in V217R_8.

FORM II

VARIABLE NAME: Rehospitalizations – Number of Days Rehospitalized and Primary Reason for Rehospitalization

CHARACTERS: 3 for each Number of Days (up to 8 entries, V217D_1 through V217D_8)
2 for each Reason (up to 8 entries, V217R_1 through V217R_8)

CODES: **Number of Days (V217D):**
000 None (*Valid only in coding position #1 only*)
1-887 Valid range
888 Yes, number of days unknown
999 Unknown (*Valid in coding position #1 only*)
Blank (*only if V201 = "5"*)

| Primary Reason for Rehospitalization (V217R) | | ICD9 Code |
|---|---|-----------|
| 01 | Infectious and parasitic diseases, including AIDS | 0-139 |
| 02 | Cancer | 140-239 |
| 03 | Endocrine, nutritional and metabolic diseases and immunity disorders | 240-279 |
| 04 | Diseases of blood and blood-forming organs | 280-289 |
| 05 | Mental disorders, including alcohol and drug-related problems | 290-319 |
| 06 | Disease of nervous system and sense organs | 320-389 |
| 07 | Diseases of the circulatory system, including heart disease, hypertension, pulmonary embolus, cerebrovascular disease, and diseases of arteries and veins | 390-459 |
| 08 | Diseases of respiratory system | 460-519 |
| 09 | Disease of digestive system, including oral cavity, salivary glands, esophagus, stomach, duodenum, appendicitis, abdominal hernia, noninfectious enteritis and colitis, other disease of the intestine, peritoneum, liver and gall bladder | 520-579 |
| 10 | Diseases of genitourinary system, including renal, urethral, ureteral, and bladder stones and conditions, urinary tract infections, diseases of the prostate, orchitis/epididymitis, disorders of genital organs, disorders of the breast and female pelvic organs | 580-629 |
| 11 | Uncomplicated childbirth or complications of pregnancy, childbirth and the puerperium | 630-676 |
| 12 | Diseases of skin and subcutaneous tissue, including pressure sores | 680-709 |
| 13 | Diseases of musculoskeletal system and connective tissue, including arthropathies, arthritis, ankylosing spondylitis, intervertebral disc disorders, rheumatism, osteopathies and acquired musculoskeletal deformities | 710-739 |
| 14 | Congenital anomalies | 740-759 |
| 15 | Symptoms and ill-defined conditions, includes cases for which no specific diagnosis can be made; transient symptoms of undetermined nature or symptoms that point with equal suspicion to two or more disease or body systems without final determination being made. | 780-799 |
| 16 | Injuries and poisoning, regardless of intention (can be accidental or attempted suicide or homicide), including complications of surgical and medical care and any external cause such as temperature, drowning, radiation, toxic products or environment, fire or trauma | 800-999 |
| 17 | Other unclassified (e.g. baclofen pump) | |
| 18 | Inpatient rehab services only | |
| 88 | Not applicable, no rehospitalizations (<i>Valid only in coding position #1</i>) | |
| 99 | Unknown | |
| Blank | <i>(only if V201 = "5")</i> | |

FORM II

VARIABLE NAME: Rehospitalizations – Number of Days Rehospitalized and Primary Reason for Rehospitalization

COMMENTS: It is mandatory to enter a code in coding position #1. When code 000 (for days) and code 88 (for reason) are entered in coding position #1, no codes are allowed in coding positions #2 through #8.

The interviewer must ask the patient for this information. If the patient has been rehospitalized, it is recommended that hospital records be obtained to verify the number of days rehospitalized, the dates of admission and discharge, and the reasons for rehospitalization.

If, during a follow-up year, the patient remains rehospitalized past his anniversary date:

- > For those variables to be documented "at the time of the annual physical examination", code the information obtained on the date of the annual physical examination.
- > Those variables to be documented "on the anniversary date being reported" should reflect the patient's status as it was on the anniversary date.

However,

- > All variables documenting events occurring "during the anniversary year being reported" should include all events up until the completion of the rehospitalization. Variable 219 may be greater than 365 days.

If there are multiple reasons for a hospitalization, code the first reason for the admission.

SOFTWARE: When code 000 is entered in V217D and code 88 is entered in V217R, the software advances the user to variable 220.

REVISIONS: October 2000: these variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

EXAMPLE 1: The subject was not hospitalized at all during the follow-up year being reported.

| | | | | | | | | | |
|------|--------------------------------------|-----|--|--|--|--|--|--|--|
| 217. | Rehospitalizations | #1 | #2 | #3 | #4 | #5 | #6 | #7 | 8+ |
| | D. Number of Days | 000 | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |
| | R. Reason | 88 | <input type="checkbox"/> <input type="checkbox"/> |
| 218. | Number of Rehospitalization(s) | 0 | | | | | | | |
| 219. | Number of Days Rehospitalized..... | 000 | | | | | | | |

EXAMPLE 2: The subject was hospitalized 3 times during the follow-up year being reported. The first hospitalization was for drug abuse problems and lasted 30 days. The second hospitalization was for 5 days due to hypertension and the third hospitalization was for 3 days for renal stones.

| | | | | | | | | | |
|------|--------------------------------------|-----|-----|-----|--|--|--|--|--|
| 217. | Rehospitalizations | #1 | #2 | #3 | #4 | #5 | #6 | #7 | 8+ |
| | D. Number of Days | 030 | 005 | 003 | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |
| | R. Reason | 05 | 07 | 10 | <input type="checkbox"/> <input type="checkbox"/> |
| 218. | Number of Rehospitalization(s) | 3 | | | | | | | |
| 219. | Number of Days Rehospitalized..... | 038 | | | | | | | |

FORM II

VARIABLE NAME: Number of Rehospitalizations

DESCRIPTION: This variable documents the number of planned and unplanned, system and non-system hospital admissions occurring **during the anniversary year being reported.**

For the year 01 Form II only:

- ❖ the year 01 Form II documents only rehospitalizations occurring in the interval between the discharge from the last System inpatient treatment phase to the first anniversary date of the patient's injury.

All subsequent Form IIs document rehospitalizations occurring during the year being reported.

Do not include the initial System hospitalization or hospitalizations preceding the initial admission into the System.

Do not record any custodial admissions as rehospitalizations in this variable. These days should be reported as days in a nursing home in variable 220.

This variable can be calculated by the NSCISC's software.

CHARACTERS:

1

CODES:

- 0 None**
- 1 One**
- 2 Two**
- 3 Three**
- 4 Four**
- 5 Five**
- 6 Six**
- 7 More than six**
- 8 Rehospitalized, number unknown**
- 9 Unknown**
- Blank** (*only if V201 = "5"*)

FORM II

VARIABLE NAME: Number of Rehospitalizations

COMMENTS: If, during a follow-up year, the patient remains rehospitalized past his anniversary date:

- > For those variables to be documented "at the time of the annual physical examination", code the information obtained on the date of the annual physical examination.
- > Those variables to be documented "on the anniversary date being reported" should reflect the patient's status as it was on the anniversary date.

However,

- > All variables documenting events occurring "during the anniversary year being reported" should include all events up until the completion of the rehospitalization. Variable 219 may be greater than 365 days.

SOFTWARE: The software calculates this variable by adding the number of positions coded in V217. If more than 6 positions are coded in V217, then V219 = "7". To use: place the cursor on the variable to be calculated (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

FORM II

VARIABLE NAME: Number of Days Rehospitalized During Reporting Period

DESCRIPTION: This variable records the total days rehospitalized (planned and unplanned days) in all hospitals (i.e., system and non-system) **during the anniversary year being reported.**

For the year 01 Form II only:

- ❖ the year 01 Form II documents only rehospitalizations occurring in the interval between the discharge from the last System inpatient treatment phase to the first anniversary date of the patient's injury.

All subsequent Form IIs document rehospitalizations occurring during the year being reported. This variable can be calculated by the NSCISC's software.

CHARACTERS: 3

CODES: **000** **None**
 000 - 887 **Valid range**
 888 **Yes, number of days unknown**
 999 **Unknown**
 Blank *(only if V201 = "5")*

COMMENTS: If, during a follow-up year, the patient remains rehospitalized past his anniversary date:

- > For those variables to be documented "at the time of the annual physical examination", code the information obtained on the date of the annual physical examination.
- > Those variables to be documented "on the anniversary date being reported" should reflect the patient's status as it was on the anniversary date.

However,

- > All variables documenting events occurring "during the anniversary year being reported" should include all events up until the completion of the rehospitalization. Variable 219 may be greater than 365 days.

SOFTWARE: The software calculates this variable by adding the values in V217D_1 through V217D_8. To use: place the cursor on the variable to be calculated (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button. Note: in order to retain the data converted from the old Rehospitalization Days variable, this function is disabled for Form IIs with an Indate prior to 10/01/2001.

FORM II

VARIABLE NAME: Number of Days in Nursing Home

DESCRIPTION: This variable records the number of days the patient has spent in a nursing home **during the anniversary year being reported.**

The term "nursing home" applies to all other custodial medical facilities such as extended care facilities, long-term care facilities, etc.

The Form II for the first post-injury year will document only the total days in nursing home(s) after discharge from the last System inpatient treatment phase to the first anniversary date of the patient's injury. All subsequent annual reports will document the total days in nursing home(s) during the annual year being reported.

CHARACTERS: 3

CODES: **000 - 366 Valid range**
888 Yes, number of days unknown
999 Unknown
Blank (*only if V201 = "5"*)

COMMENTS: The maximum number of days for this variable is 366. Report all temporary and permanent nursing home admissions. However, on the year 01 Form II, report only those nursing home admissions occurring after discharge from the initial hospitalization period.

QC: V220 in year 01 must be less than 366.

FORM II

VARIABLE NAME: Date of the Interview

DESCRIPTION: This variable records the date on which all or most of the interview items were obtained. Interviews may be conducted in person, by mail or by phone. Data for all variables (except variables 211 to 213 and variables 244 to 249) may be collected by interview.

CHARACTERS: 8

CODES: **Any valid date**

88888888 Interview not done

99999999 Unknown - This is a CONVERSION CODE ONLY. Data collectors may NOT use this code. This information is provided for data analyses purposes only.

Blank (only if V201 = "5")

COMMENTS: Unknowns are not allowed in this variable (except as a conversion code). Data in this variable are required in records entered into the database after October 31, 2000.

If the interview is done by telephone, this is the date of the phone call. If the interview was done by mail, this is the date the subject completed the interview form. If the interviewer knows the respondent's responses are not reliable, code the interview "not done" and code all the interview items unknown. It is better to encourage an unknown response rather than an inaccurate response.

This variable cannot be stored in date format since non-valid date codes (88888888 and 99999999) are allowed. Data for "**Window variables**" may be collected from up to 182 days before the anniversary date to 365 days after the anniversary date. The window of time for the year 01 (or year 02) Form II is limited to 182 days after the anniversary. "Window" variables are V211 to V213, 223 to 239 and 244 to 249. Window variables are marked with an ! on the Form II data collection form.

For the first (or second see details on page 16) anniversary, it is extremely important to obtain data as close as possible to the anniversary date.

If the patient is coded "lost" (V201 = "5") then, leave all variables after V202 blank.

REVISIONS: October 2000: this variable was added. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 223 = "88888888", then variable 224 must = "8" and variables 225 to 239 must all = *Unknown*.

SOFTWARE: The NSCISC's software contains functions to calculate (1) the correct post-injury year for an exam (or interview) date; (2) the range of dates for an anniversary year; and (3) the range of dates for the "window" variables. See the Software Users' Manual for complete instructions.

EXAMPLE: See the table on [page 205](#). The range of dates for the interview are in the "during the interview" column.

FORM II

VARIABLE NAME: How was the interview conducted?

DESCRIPTION: This variable documents if the interview was conducted in person, by phone and/or by mail.

Data for all variables (except variables 211 to 213 and variables 244 to 249) may be collected by interview.

CHARACTERS: 1

CODES:

- 1 Interview in person**
- 2 Interview by phone**
- 3 Self-administered (by mail or in the clinic)**
- 4 Combination of in person, by phone and/or by mail**
- 8 Not applicable, no interview**
- 8 Not applicable, respondent's current age is less than 18**
- 9 Unknown**

Blank (*only if V201 = "5"*)

COMMENTS: The Psycho/Social committee has established a list of priorities for each interview. All systems should structure the Psycho/Social variables in their interviews in this order:

| Interview Items | Variable Numbers |
|----------------------|------------------|
| Diener | 228 |
| Pain | 238, 239 |
| Self-report Health | 225, 226 |
| CHIEF | 230 |
| BHQ | 231 |
| CHART | 229 |
| Assistive Technology | 250A to 267 |
| Drug/Alcohol/CAGE | 232 to 237 |
| FIM | 227 |

An Interview Form (in English and Spanish) containing all the interview items begins on page 16 of Appendix B.

QC: See [page 215](#).

REVISIONS: February 1996: this variable was added to the database.

FORM II

VARIABLE NAME: Self-perceived Health Status

DESCRIPTION: The following question is asked: *In General, Would You Say That Your Health Is Excellent, Very Good, Good, Fair or Poor?*

This item is question 1 from the Short Form Health Survey (SF-36).

CHARACTERS: 1

CODES:

- 1 Excellent**
- 2 Very good**
- 3 Good**
- 4 Fair**
- 5 Poor**
- 6 Don't know**
- 7 Refuses**
- 9 Unknown, interview not done, or respondent's current age is less than 18**

Blank (*only if V201 = "5"*)

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

SOURCE: SF-36 Physical and Mental Health Summary Scales. John E. Ware, Jr. Ph.D., Mark Kosinski, M.A., Susan D. Keller, Ph.D. The Health Institute, New England Medical Center, Boston, Massachusetts.

QC: See [page 215](#).

REVISIONS: November 1995: this variable was added to the database.

May 1997: the minimum age rule added.

October 2000: code "8" (Not applicable, respondent's current age is less than 18) was deleted. Coding rule changed to: code "9" should be used for respondents whose current age is less than 18.

FORM II

VARIABLE NAME: Compared to 1 year ago, how would you rate your health in general now?

DESCRIPTION: This item is question 2 from the Short Form Health Survey (SF-36).

When doing the year 01 interview, ask *Compared to the time of discharge, how would you rate your health in general now?*

CHARACTERS: 1

CODES:

- 1 Much better now than one year ago**
- 2 Somewhat better now than one year ago**
- 3 About the same as one year ago**
- 4 Somewhat worse now than one year ago**
- 5 Much worse now than one year ago**
- 6 Don't know**
- 7 Refuses**
- 9 Unknown, interview not done, or respondent's current age is less than 18**

Blank (only if V201 = "5")

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

SOURCE: SF-36 Physical and Mental Health Summary Scales. John E. Ware, Jr. Ph.D., Mark Kosinski, M.A., Susan D. Keller, Ph.D. The Health Institute, New England Medical Center, Boston, Massachusetts.

QC: See [page 215](#).

REVISIONS: May 1998: this variable was added to the database.

October 2000: code "8" (Not applicable, respondent's current age is less than 18) was deleted. Coding rule changed to: code "9" should be used for respondents whose current age is less than 18.

FORM II

VARIABLE NAME: Satisfaction With Life Scale

DESCRIPTION: This variable measures the concept of life satisfaction based on the **patient's responses** to these five statements.

1. In most ways my life is close to my ideal. (V228_1)
2. The conditions of my life are excellent. (V228_2)
3. I am satisfied with my life. (V228_3)
4. So far I have gotten the important things I want in life. (V228_4)
5. If I could live my life over, I would change almost nothing (V228_5.)

Responses to each of the five statements and the total score (V228T) are recorded in this variable.

CHARACTERS: 1 for each statement, 5 statements (V228_1 to V228_5)
2 for the total (V228T)

CODES: **Statements (V228_1 to V228_5)**

1 Strongly disagree

2 Disagree

3 Slightly disagree

4 Neither agree nor disagree

5 Slightly agree

6 Agree

7 Strongly agree

9 Unknown, interview not done, or respondent's current age is less than 18

Blank (*only if V201 = "5"*)

Total (V228)

05-35 Valid range

99 Unknown, interview not done, or respondent's current age is less than 18

Blank (*only if V201 = "5"*)

FORM II

VARIABLE NAME: Satisfaction With Life Scale

COMMENTS: Instructions for administering the scale are:

Ask the patient if he agrees or disagrees with each of the five statements. Use the 1-7 scale to indicate his agreement with each item. Instruct the patient to be open and honest with his responses.

Ask all questions; record each response and the total score. If the patient does not respond to a question, code that question "9" and code the total score "99".

Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

Use the unknown code if the patient's current age is less than 18.

SOURCE: The Satisfaction with Life Scale, E. Diener, R.A. Emmons, R.J. Larsen and S. Griffin.

REVISIONS: November 1995: Total Score was added to the database.

February 1996: individual statements were added to the database.

September 1996: the minimum age rule was added.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The Craig Handicap Assessment and Reporting Technique, Short Form (CHART-SF)

DESCRIPTION: The Craig Handicap Assessment and Reporting Technique (CHART) is a widely used questionnaire useful in measuring societal participation for persons with disabilities. The goal of CHART-SF (Short Form) was to develop a shorter questionnaire that would reproduce all the CHART subscales with at least 90% accuracy. CHART-SF includes 17 items from the original 37 question CHART, and the addition of three summary variables in the Social Integration sub-scale.

In addition to the 20 individual items, the CHART-SF includes 6 dimensions of handicap: 1) physical independence, 2) cognitive independence, 3) mobility, 4) occupation, 5) social integration, and 6) economic self-sufficiency. A Total CHART score is also documented.

The NSCISC's software calculates the dimension totals and the total score.

COMMENTS: This is a "Window variable" (see rules on page 215).

The 2-page CHART interview sheet (see Appendix A) may be used.

Use the unknown code in all CHART items if the respondent's current age is less than 18 or if the interview was not done.

If the patient is coded "lost" (V201 = "5") then, leave all variables after V202 blank.

SOURCE: Guide for the Use of CHART, the Craig Hospital Research Department, Englewood, Colorado 1999. See <ftp://www.craighospital.org/generalftp/chart>.

SOFTWARE: The NSCISC's software calculates the 6 dimension totals (variables 229_20 to 229_25 as well as the Total CHART Score (V229T). To use: place the cursor on the variable to be calculated (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

REVISIONS: November 1995: this variable was added to the database.

September 1996: rule for the minimum age was added.

October 2000: changed to the Short Form and the Cognitive Independence items were added.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Physical Independence - Number of Hours of Assistance Per Day

DESCRIPTION: The following question is asked:

How many hours in a typical 24-hour day do you have someone with you to provide assistance for personal care activities such as eating, bathing, dressing, toileting and mobility?

Document:

- A. Number of hours of paid assistance and
- B. Number of hours of unpaid assistance (family, others)

CHARACTERS: 2 for each entry

CODES: **00 No assistance**

00 to 24 Valid range

99 Unknown, interview not done, or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: If a person has a disability that would typically result in a high level of dependency, and indicates no attendant care is used, probe this a bit further. The respondent may not understand that assistance with dressing grooming, bowel and bladder care, etc. is to be considered attendant care.

If an individual has various hours of assistance on different days of the week ask the respondent to estimate the total number of hours of assistance per week, then divide that number by 7 to come up with a daily estimate.

See [page 17](#) for the rules for rounding fractions of an hour.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Cognitive Independence –

DESCRIPTION: The following question is asked:

How much time is someone with you in your home to assist you with activities that require remembering, decision making, or judgment?

CHARACTERS: 1

CODES:

- 1** Someone else is always with me to observe or supervise
- 2** Someone else is always around, but they only check on me now and then
- 3** Sometimes I am left alone for an hour or two
- 4** Sometimes I am left alone for most of the day
- 5** I have been left alone all day and all night, but someone checks in on me
- 6** I am left alone without anyone checking on me
- 9** Unknown, interview not done, or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: If the person is independent, and doesn't need supervision or assistance to any degree, use code 6.

QC: See [page 215](#).

REVISIONS: October 2000: variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

FORM II

VARIABLE NAME: The CHART: Cognitive Independence –

DESCRIPTION: The following question is asked:

How much of the time is someone with you to help you with remembering, decision making, or judgment when you go away from your home?

CHARACTERS: 1

CODES:

- 1 I am restricted from leaving, even with someone else**
- 2 Someone is always with me to help with remembering, decision making or judgment when I go anywhere.**
- 3 I go to places on my own as long as they are familiar**
- 4 I do not need help going anywhere**
- 9 Unknown, interview not done, or respondent's current age is less than 18**

Blank (only if V201 = "5")

COMMENTS: If the person is independent, and doesn't need supervision or assistance to any degree, use code 4.

QC: See [page 215](#).

REVISIONS: October 2000: variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

FORM II

VARIABLE NAME: The CHART: Mobility - Number of Hours Out of Bed Per Day, Are You Up and About Regularly?

DESCRIPTION: The following question is asked:

On a typical day, how many hours are you out of bed?

CHARACTERS: 2

CODES: **0 to 24** Valid range

99 Unknown, interview not done, or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: See [page 17](#) for the rules for rounding fractions of an hour.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Mobility - Are You Up and About Regularly?

DESCRIPTION: The following question is asked:

In a typical week, how many days do you get out of your house and go somewhere?

CHARACTERS: 1

CODES: **0 to 7** Valid range

9 Unknown, interview not done, or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: The responses to this question may vary according to season, weather, etc. For example, many people are out daily in the summer, but only one or two days a week in the winter. Ask the respondent to use his/her judgment, based on the climate in which he/she lives, to estimate the average number of days out per week throughout the year.

Being out of the house and going somewhere means that the person leaves his/her own "property". Being out in the garden or yard does not qualify as "going somewhere".

See [page 17](#) for the rules for rounding fractions of an hour.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Mobility - Are You Up and About Regularly?

DESCRIPTION: The following question is asked:

In the last year, how many nights have you spent away from your home (excluding hospitalizations)?

CHARACTERS: 1

CODES:

- 0** None
- 1** 1-2 nights
- 3** 3-4 nights
- 5** 5 or more nights
- 9** Unknown, interview not done, or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: Any night spent away from a person's usual sleeping environment is considered a night away from home. Visiting family or friends and spending the night at someone else's house, therefore, is a night away from home.

For the year 1 interview, ask "*Since discharge, how many nights have you spent away from your home (excluding hospitalizations)?*"

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Occupation - How Do You Spend Your Time?

DESCRIPTION: The following question is asked:

How many hours per week do you spend working in a job for which you get paid?

CHARACTERS: 2

CODES: **00 to 98** Valid range

99 Unknown, interview not done, or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: Respondents must be working in jobs for which they are paid in order to get points for this question. If a person is working but not getting paid, consider this voluntary activity and do not include in this variable.

See [page 17](#) for the rules for rounding fractions of an hour.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Occupation - How Do You Spend Your Time?

DESCRIPTION: The following question is asked:

How many hours per week do you spend in school working toward a degree or in an accredited technical training program? (including hours in class and studying)

CHARACTERS: 2

CODES: 00 to 98 Valid range

99 Unknown, interview not done, or respondent's current age is less than 18

Blank (only if V201 = "5")

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Occupation - How Do You Spend Your Time?

DESCRIPTION: The following question is asked:

How many hours per week do you spend in active homemaking including parenting, housekeeping, and food preparation?

CHARACTERS: 2

CODES: **00 to 98** Valid range

99 Unknown, interview not done, or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: Active homemaking, parenting, housekeeping, etc. is exactly what it means. Being at home with the children at night with everyone asleep is not considered "active" parenting. Helping children with homework, playing with them or supervising their play, however, are considered "active" parenting.

In addition "active" can imply supervising housework and food preparation. If someone is developing the household menus, arranging for housework to be done, or overseeing other individuals performing those activities, there is active involvement; therefore, count the time spent in these planning/supervising activities. However, don't credit someone with doing (for example) eight hours of yard work, if his/her only "active" involvement was arranging and instructing the work needing to be done. This "active" role might, in fact, take an hour, so credit for 1 hour is appropriate.

For variables 229_9 through 229_11, do not duplicate responses in categories. For example, if someone "plays" with the children and considers it sports or exercise, as well as active parenting, that individual can only receive credit in one category. In another example, a person who gardens as a hobby may describe spending 20 hours a week in home maintenance, then states that gardening is a hobby. When in doubt, allow the respondent to choose the category which best describes an activity.

COMMENTS: See [page 17](#) for the rules for rounding fractions of an hour.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Occupation - How Do You Spend Your Time?

DESCRIPTION: The following question is asked:

How many hours per week do you spend in home maintenance activities such as gardening, house repairs or home improvement?

CHARACTERS: 2

CODES: **00 to 98** Valid range

99 Unknown, interview not done, or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: Hours spent in active home maintenance may vary with season and with weather. Use same logic employed in variable 229_5 in estimating hours.

COMMENTS: See [page 17](#) for the rules for rounding fractions of an hour.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Occupation - How Do You Spend Your Time?

DESCRIPTION: The following question is asked:

How many hours per week do you spend in recreational activities such as sports, exercise, playing cards, or going to movies?

Please do not include time spent watching TV or listening to the radio.

CHARACTERS: 2

CODES: **00 to 98 Valid range**

99 Unknown, interview not done, or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: See [page 17](#) for the rules for rounding fractions of an hour.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Social Integration – With Whom Do You Spend Your Time?

DESCRIPTION: The following question is asked:

How many people do you live with?

CHARACTERS: 2

CODES: **00 None, lives alone**

00 to 87 Valid range

99 Unknown, interview not done, or respondent's current age is less than 18

Blank (*only if V201 = "5"*)

COMMENTS: "Live with" applies to the sharing of "private spaces" (e.g., a bedroom, kitchen, etc.).

If the subject lives in a group home (e.g., nursing home, dormitory, etc.), ask: "How many roommates do you share your room with?"

QC: If variable 229_12 = "00" (*lives alone*) then, 229_13 should = "8" (*lives alone*) and variable 229_14 should = "88" (*lives alone*).

See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Social Integration – With Whom Do You Spend Your Time?

DESCRIPTION: The following question is asked:

Of the people you live with, is one of them your spouse or significant other/partner?

CHARACTERS: 1

CODES:

- 0** No (does not live with significant other/partner or unrelated roommate or attendant)
- 1** Lives with a spouse or significant other/partner
- 2** Lives with unrelated roommate and/or attendant
- 8** Not applicable, lives alone (Use this code if V229_12 = “00”)
- 9** Unknown, interview not done, or respondent’s current age is less than 18

Blank (only if V201 = “5”)

QC: If variable 229_12 = “00” (*lives alone*) then, 229_13 should = “8” (*lives alone*) and variable 229_14 should = “88” (*lives alone*).

See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Social Integration – With Whom Do You Spend Your Time?

DESCRIPTION: The following question is asked:

Of the people you live with how many (others) are relatives?

CHARACTERS: 2

CODES: **00 None are relatives**

00 to 87 Valid range

88 Not applicable, lives alone

99 Unknown, interview not done, or respondent's current age is less than 18

Blank (*only if V201 = "5"*)

COMMENTS: "Live with" applies to the sharing of "private spaces" (e.g., a bedroom, kitchen, etc.). Do not include the person counted in variable 229_13.

In-laws and parents of a significant other are considered relatives (especially if the respondent considers them as such)

QC: If variable 229_12 = "00" (*lives alone*) then, 229_13 should = "8" (*lives alone*) and variable 229_14 should = "88" (*lives alone*).

See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Social Integration – With Whom Do You Spend Your Time?

DESCRIPTION: The following question is asked:

How many business or organizational associates do you visit, phone, or write to at least once a month?

CHARACTERS: 2

CODES: **00** **None**

01 to 09 **One to nine**

10 **Ten or more**

99 **Unknown, interview not done, or respondent's current age is less than 18**

Blank *(only if V201 = "5")*

COMMENTS: In Variables 238_15 through 238_17, remember to count the number of people contacted, not the actual number of times a person is contacted. For example, someone may talk with a particular business associate on a daily basis -- that is considered one contact, not five (typical working day of the week).

Emailing counts as "writing".

Don't worry about getting exact counts of business associates if a person indicates "lots" or "dozens" of people are contacted.

Again, be careful that you don't double count people in different categories.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Social Integration – With Whom Do You Spend Your Time?

DESCRIPTION: The following question is asked:

How many friends (non-relatives contacted outside business or organizational settings) do you visit, phone, or write to at least once a month?

CHARACTERS: 1

CODES: **0** **None**

0 to 5 **Valid range**

5 **Five or more**

9 **Unknown, interview not done, or respondent's current age is less than 18**

Blank *(only if V201 = "5")*

COMMENTS: See [page 236](#) for additional instructions.

Emailing counts as "writing".

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Social Integration – With Whom Do You Spend Your Time?

DESCRIPTION: The following question is asked:

With how many strangers have you initiated a conversation in the last month (for example to ask information or place an order)?

CHARACTERS: 1

CODES: **0** **None**

1 **1-2**

3 **3-5**

6 **6 or more**

9 **Unknown, interview not done, or respondent's current age is less than 18**

Blank *(only if V201 = "5")*

COMMENTS: See [page 236](#) for additional instructions.

Emailing counts as “initiating a conversation”.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Economic Self-sufficiency – Combined Annual Family Income

DESCRIPTION: The following question is asked:

Approximately what was the combined annual income, in the last year, of all family members in your household?

Consider all sources including wages and earnings, disability benefits, pensions and retirement income, income from court settlements, investments and trust funds, child support and alimony, contributions from relatives, and any other sources (that are available to the subject).

CHARACTERS: 1

CODES:

| | |
|--------------|--|
| 1 | Less than \$10,000 |
| 2 | \$10,000 to \$14,999 |
| 3 | \$15,000 to \$19,999 |
| 4 | \$20,000 to \$24,999 |
| 5 | \$25,000 to \$34,999 |
| 6 | \$35,000 to \$49,999 |
| 7 | \$50,000 to \$74,999 |
| 8 | \$75,000 or more |
| 9 | Unknown, interview not done or respondent's current age is less than 18 |
| Blank | <i>(only if V201 = "5")</i> |

COMMENTS: Some people may indicate there is no household income from any source. Probe this, because there must be money from somewhere, whether it is from a charitable source, government funds, other family support or something else.

The intent of this variable is to determine the amount of the respondent's financial resources compared to the national poverty level.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Economic Self-sufficiency – Unreimbursed Medical Care Expenses

DESCRIPTION: The following question is asked:

Approximately how much did you pay last year for medical care expenses?

Consider any amounts paid by yourself or the family members in your household and **not reimbursed** by insurance or benefits.

CHARACTERS: 1

CODES:

| | |
|----------|--|
| 1 | Less than \$1,000 |
| 2 | \$1,000 to \$2,499 |
| 3 | \$2,500 to \$4,999 |
| 4 | \$5,000 to \$9,999 |
| 5 | \$10,000 or more |
| 9 | Unknown, interview not done or respondent's current age is less than 18 |

Blank (only if V201 = "5")

COMMENTS: Items include (but are not limited to) medical insurance premiums, co-payments, supplies, etc. Provide a reasonable estimate of unreimbursed medical care expenses.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Physical Independence Total

DESCRIPTION: This variable is computed using the data in variables 229_1A and 229_1B. The NSCISC's software computes this variable.

CHARACTERS: 3

CODES: **000 to 100 Valid range**

999 Unknown, interview not done or respondent's current age is less than 18

Blank (*only if V201 = "5"*)

COMMENTS: A score of 100 indicates no handicap in an individual's ability to sustain a customarily effective independent existence. The need for regular or periodic assistance for activities, which used to be performed independently, is indicative of some degree of handicap.

SOFTWARE: The software calculates this variable. To calculate: place the cursor on variable 229_20 and click on the Calculate button.

The formula used is:

$$V229_20 = 100 - 4*(V229_1A + V229_1B)$$

If $4*(V229_1A + V229_1B)$ greater than 100, then $V229_20 = 0$

If $V229_1A = 99$ or $V229_1B = 99$, then $V229_20 = 999$

If $V229_1A = \text{blank}$ or $V229_1B = \text{blank}$, then $V229_20 = \text{blank}$.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Cognitive Independence Total

DESCRIPTION: This variable is computed using the data in variables 229_2 and 229_3. The NSCISC's software computes this variable.

CHARACTERS: 3

CODES: **000 to 100 Valid range**

999 Unknown, interview not done or respondent's current age is less than 18

Blank (*only if V201 = "5"*)

SOFTWARE: The software calculates this variable. To calculate: place the cursor on variable 229_21 and click on the Calculate button.

The formula is:

$$V229_21 = 11*(V229_2 - 1) + 15*(V229_3 - 1)$$

If $[11*(V229_2 - 1) + 15*(V229_3 - 1)]$ greater than 100, then
 $V229_21 = 100$

If $V229_2 = 9$ or $V229_3 = 9$, then $V229_21 = 999$

If $V229_2 = \text{blank}$ or $V229_3 = \text{blank}$, then $V229_21 = \text{blank}$

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Mobility Total

DESCRIPTION: This variable is computed using the data in variables 229_4, 229_5 and 229_6. The NSCISC's software computes this variable.

CHARACTERS: 3

CODES: **000 to 100 Valid range**
999 Unknown, interview not done or respondent's current age is less than 18
Blank (*only if V201 = "5"*)

COMMENTS: A score of 100 indicates no handicap in an individual's ability to move about effectively in his/her surroundings.

SOFTWARE: The software calculates this variable. To calculate: place the cursor on variable 229_22 and click on the Calculate button.

The formula is:

If V229_6 = 0, then $V229_22 = 3*(V229_4) + 7*(V229_5)$

If V229_6 = 1, then $V229_22 = 10 + 3*(V229_4) + 7*(V229_5)$

If V229_6 = 3, then $V229_22 = 15 + 3*(V229_4) + 7*(V229_5)$

If V229_6 = 5, then $V229_22 = 20 + 3*(V229_4) + 7*(V229_5)$

If V229_22 greater than 100, then V229_22 = 100

If V229_4 = 99 or V229_5 = 9 or V229_6 = 9, then

V229_22 = 999

If V229_4 = blank or V229_5 = blank or V229_6 = blank then,
V229_22 = blank

QC: See [page 215](#)

FORM II

VARIABLE NAME: The CHART: Occupation Total

DESCRIPTION: This variable is computed using the data in variables 229_7 through 229_11. The NSCISC's software computes this variable.

CHARACTERS: 3

CODES: **000 to 100 Valid range**

999 Unknown, interview not done or respondent's current age is less than 18

Blank (*only if V201 = "5"*)

COMMENTS: A score of 100 indicates no handicap in an individual's ability to occupy time in the manner customary to that person's sex, age and culture.

SOFTWARE: The software calculates this variable. To calculate: place the cursor on variable 229_23 and click on the Calculate button.

The formula is:

$$V229_23 = 2.5*(V229_7 + V229_8 + V229_9 + V229_10) + 1.25*(V229_11)$$

If $[2.5*(V229_7 + V229_8 + V229_9 + V229_10) + 1.25*(V229_11)]$ greater than 100, then $V229_23 = 100$

If $V229_7 = 99$ or $V229_8 = 99$ or $V229_9 = 99$ or $V229_10 = 99$, or $V229_11 = 99$, then $V229_23 = 999$

If $V229_7 = \text{blank}$ or $V229_8 = \text{blank}$ or $V229_9 = \text{blank}$ or $V229_10 = \text{blank}$ or $V229_11 = \text{blank}$ then, $V229_23 = \text{blank}$

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Social Integration Total

DESCRIPTION: This variable is computed using the data in variables 229_13 through 229_17. The NSCISC's software computes this variable.

CHARACTERS: 3

CODES: **000 to 100 Valid range**

999 Unknown, interview not done or respondent's current age is less than 18

Blank (*only if V201 = "5"*)

COMMENTS: A score of 100 indicates no handicap in an individual's ability to participate in and maintain customary social relationships.

SOFTWARE: The software calculates this variable. To calculate: place the cursor on variable 229_24 and click on the Calculate button.

The formula is:

$V229_{24} = A + B + C + D + E$, where

A = 0

Else: If $V229_{13} = 1$, then A = 38

Else: If $V229_{13} = 2$, then A = 25

B = $6 * (V229_{14})$

Else: If $V229_{14} = 88$, then B = 0

C = 0

Else: If $V229_{17} = 1$, then C = 15

Else: If $V229_{17} = 3$, then C = 23

Else: If $V229_{17} = 6$, then C = 30

D = $2.5 * (V229_{15})$

Else: If $2.5 * (V229_{15})$ greater than 25, then D = 25

E = $13 * (V229_{16})$

Else: If $13 * (V229_{16})$ greater than 65, then E = 65

Else: If A + B + C + D + E greater than 100, then $V229_{24} = 100$

Else: If $V229_{13} = 9$ or $V229_{14} = 99$ or $V229_{15} = 99$ or

$V229_{16} = 9$ or $V229_{17} = 9$, then $V229_{24} = 999$

Else: If $V229_{13} = \text{blank}$ or $V229_{14} = \text{blank}$ or $V229_{15} = \text{blank}$ or $V229_{16} = \text{blank}$ or $V229_{17} = \text{blank}$ then, $V229_{24} = \text{blank}$.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Economic Self-sufficiency Total
DESCRIPTION: This variable is computed using the data in variables 229_18 and 229_19. The NSCISC's software computes this variable.
CHARACTERS: 3
CODES: **000 to 100** Valid range
999 Unknown, interview not done or respondent's current age is less than 18
Blank (only if V201 = "5")
COMMENTS: A score of 100 indicates no handicap in an individual's ability to sustain customary socio-economic activity and independence.
SOFTWARE: The software calculates this variable. To calculate: place the cursor on variable 229_25 and click on the Calculate button. Data entry is disabled on all CHART items in records with in-dates prior to 1993.

The formula is:

$V229_25 = 50 * [(A-B)/C]$, where

A = 5000

Else: If V229_18 = 2, then A = 12500

Else: If V229_18 = 3, then A = 17500

Else: If V229_18 = 4, then A = 22500

Else: If V229_18 = 5, then A = 30000

Else: If V229_18 = 6, then A = 42500

Else: If V229_18 = 7, then A = 62500

Else: If V229_18 = 8, then A = 80000

B = 500

Else: If V229_19 = 2, then B = 1750

Else: If V229_19 = 3, then B = 3750

Else: If V229_19 = 4, then B = 7500

Else: If V229_19 = 5, then B = 15000

C = appropriate value from the following table:

Indate (year only)

| V229_12 | 1993 | 1994 | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 |
|---------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|
| 0 | 7143 | 7363 | 7547 | 7763 | 7995 | 8178 | 8310 | 8500 | 8787 | 9044 | 9182 | 9573 | 9827 |
| 1 | 9137 | 9414 | 9661 | 9933 | 10233 | 10468 | 10636 | 10869 | 11234 | 11559 | 11752 | 12321 | 12649 |
| 2 | 11186 | 11522 | 11821 | 12158 | 12516 | 12803 | 13001 | 13290 | 13737 | 14129 | 14351 | 14393 | 14776 |
| 3 | 14335 | 14763 | 15141 | 15569 | 16036 | 16404 | 16655 | 17028 | 17601 | 18104 | 18390 | 18979 | 19484 |
| 4 | 16952 | 17449 | 17900 | 18408 | 18952 | 19387 | 19682 | 20115 | 20804 | 21411 | 21743 | 22887 | 23497 |
| 5 | 19137 | 19718 | 20235 | 20804 | 21389 | 21880 | 22227 | 22719 | 23491 | 24197 | 24578 | 26324 | 27025 |
| 6 | 21594 | 22383 | 22923 | 23552 | 24268 | 24825 | 25188 | 25815 | 26783 | 27514 | 27952 | 30289 | 31096 |
| 7 | 24053 | 24838 | 25427 | 26237 | 27091 | 27713 | 28023 | 28788 | 29941 | 30546 | 31111 | 33876 | 34778 |
| 8 | 28745 | 29529 | 30300 | 31280 | 31971 | 32705 | 33073 | 34075 | 35574 | 36058 | 36860 | 40751 | 41836 |

Else: If V229_12 greater than 8 and V229_12 less than 99,
then use row 8 from the above table

Else: If (A-B)/C greater than 2, then V229_25 = 100

Else: If (A-B)/C less than 0, then V229_25 = 0

Else: If V229_18 = 9 or V229_19 = 9 or V229_12 = 99,
Then V229_25 = 999

Else: If V229_18 = blank or V229_19 = blank or V229_12 = blank, then V229_25 = blank.

Note: V229_25 and V229T are calculated using the Federal Poverty Level data which is not released until February or March of the current year. When the current year's statistics are released, the Data Center will release a database updater that will insert the correct statistics into the CHART table and recalculate the values for all patients entered in the current year who have data in variables V229_25 and V229T.

QC: See [page 215](#).

FORM II

VARIABLE NAME: The CHART: Total Score

DESCRIPTION: This variable is computed using the data in variables 229_20 through 229_25. The NSCISC's software computes this variable.

CHARACTERS: 3

CODES: **000 to 600** Valid range
999 Unknown, interview not done or respondent's current age is less than 18
Blank (only if V201 = "5")

COMMENTS: A score of 600 indicates no handicap.

SOFTWARE: The software calculates this variable. To calculate: place the cursor on variable 229_T and click on the Calculate button.

The following formula is used:

$$V229T = V229_20 + V229_21 + V229_22 + V229_23 + V229_24 + V229_25$$

Else: If [V229_20 + V229_21 + V229_22 + V229_23 + V229_24 + V229_25] greater than 600, then V229T = 999

Else: If V229_20 = blank or V229_21 = blank or V229_22 = blank or V229_23 = blank or V229_24 = blank or V229_25 = blank, then V229T = blank.

Note: V229_25 and V229T are calculated using the Federal Poverty Level data which is not released until February or March of the current year. When the current year's statistics are released, the Data Center will release a database updater that will insert the correct statistics into the CHART table and recalculate the values for all patients entered in the current year who have data in variables V229_25 and V229T.

QC: See [page 215](#).

FORM II

| | |
|----------------|---|
| VARIABLE NAME: | The Craig Hospital Inventory of Environmental Factors – Short Form |
| DESCRIPTION: | The Craig Hospital Inventory of Environmental Factors (CHIEF) is designed to assess the frequency and magnitude of perceived physical, attitudinal, and policy barriers that keep people with disabilities from doing what they want or need to do. It is designed to be a short inventory of environmental barriers that can be utilized in large-scale surveys and surveillance systems, and be valid for both individuals with and without disabilities. |
| COMMENTS: | <p>The NSCISC's software calculates the subscales and the total score.</p> <p>The CHIEF has demonstrated that compared with non-disabled people, people with disabilities encounter more frequent and more problematic environmental barriers. Moreover, the CHIEF has demonstrated that the impact of barriers are associated with the type and severity of the disability.</p> <p>The focus of CHIEF is the quantification of barriers experienced in broad categories of environmental items. Respondents rate the frequency with which they encounter barriers (daily, weekly, monthly, less than monthly, or never) on 12 items of the CHIEF Short Form reflecting elements of the physical, attitudinal, and policy environments. When respondents indicate that they encounter environmental barriers at any frequency other than never, a follow-up question is asked about whether they consider the barrier to be a big or a little problem. Scoring of each CHIEF item is the product of the frequency score (from never=0 to daily=4) and the magnitude of impact score (little problem=1 and big problem=2) to produce an item score that ranges from 0-8.</p> <p>The CHIEF items are “Window variables” (see rules on page 215). Obtain the data as close as possible to the anniversary date. When asking the questions during the year 1 interview, ask <i>Since discharge....</i> (rather than “<i>during the past 12 months...</i>”). The 2-page CHIEF interview sheet (see Appendix A) may be used.</p> <p>Use the unknown code in all CHIEF items if the respondent's current age is less than 18. If the patient is coded “lost” (V201 = “5”) then, leave all variables after V202 blank.</p> <p>Note to interviewers: once it has been determined that the respondent is not working and not in school, do not ask CHIEF questions 7 and 9.</p> |
| SOURCE: | Guide for the Use of CHIEF, the Craig Hospital Research Department, Englewood, Colorado 2000. See ftp://www.craighospital.org/generalftp/chief . |
| SOFTWARE: | The NSCISC's software calculates the 5 subscales (variables 230_13 to 230_17) as well as the Total CHIEF Score (V230T). To use: place the cursor on the variable to be calculated (in the data entry box), the software will then ask <i>Calculate this variable?</i> Place the cursor on <i>Yes</i> and <i>click once</i> with the left mouse button. |
| REVISIONS: | October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001. |
| QC: | See page 215 . |

FORM II

VARIABLE NAME: The CHIEF: Question 1

DESCRIPTION: The following question is asked:

In the past 12 months, how often has the availability of transportation been a problem for you? (V230_1)

Followed by this question:

When this problem occurs has it been a big problem or a little problem? (V230_1A)

CHARACTERS: 1 for each entry, 2 entries

CODES: Frequency (V230_1)

0 **Never** (code Magnitude 0)

1 **Less than monthly**

2 **Monthly**

3 **Weekly**

4 **Daily**

9 **Unknown, interview not done or respondent's current age is less than 18** (code magnitude 9)

Blank (only if V201 = "5")

Magnitude (V230_1A)

0 **No problem** (code Frequency 0)

1 **Little problem**

2 **Big problem**

9 **Unknown, interview not done or respondent's current age is less than 18**

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

For the year 1 (or year 2) interview, ask "*Since discharge, how often has the availability of transportation been a problem for you?*"

REVISIONS: October 2000: variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 230_1 is coded 0 then, variable 230_1A must be coded 0.

See [page 215](#).

FORM II

VARIABLE NAME: The CHIEF: Question 2.

DESCRIPTION: The following question is asked:

In the past 12 months, how often has the natural environment – temperature, terrain, climate - made it difficult to do what you want or need to do? (V230_2)

Followed by this question:

When this problem occurs has it been a big problem or a little problem? (V230_2A)

CHARACTERS: 1 for each entry, 2 entries

CODES: Frequency (V230_2)

0 **Never** (code Magnitude 0)

1 **Less than monthly**

2 **Monthly**

3 **Weekly**

4 **Daily**

9 **Unknown, interview not done or respondent's current age is less than 18** (code magnitude 9)

Blank (only if V201 = "5")

Magnitude (V230_2A)

0 **No problem** (code Frequency 0)

1 **Little problem**

2 **Big problem**

9 **Unknown, interview not done or respondent's current age is less than 18**

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

For the year 1 (or year 2) interview, ask "*Since discharge, how often has the natural environment- temperature, terrain, climate - made it difficult to do what you want or need to do?*"

REVISIONS: October 2000: variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 230_2 is coded 0 then, variable 230_2A must be coded 0.

See [page 215](#).

FORM II

VARIABLE NAME: The CHIEF: Question 3.

DESCRIPTION: The following question is asked:

In the past 12 months, how often have other aspects of your surroundings – lighting, noise, crowds, etc – made it difficult to do what you want or need to do? (V230_3)

Followed by this question:

When this problem occurs has it been a big problem or a little problem? (V230_3A)

CHARACTERS: 1 for each entry, 2 entries

CODES: Frequency (V230_3)

0 Never (code Magnitude 0)

1 Less than monthly

2 Monthly

3 Weekly

4 Daily

9 Unknown, interview not done or respondent's current age is less than 18 (code magnitude 9)

Blank (only if V201 = "5")

Magnitude (V230_3A)

0 No problem (code Frequency 0)

1 Little problem

2 Big problem

9 Unknown, interview not done or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

For the year 1 (or year 2) interview, ask "*Since discharge, how often have other aspects of your surroundings – lighting, noise, crowds, etc – made it difficult to do what you want or need to do?*"

REVISIONS: October 2000: variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 230_3 is coded 0 then, variable 230_3A must be coded 0.

See [page 215](#).

FORM II

VARIABLE NAME: The CHIEF: Question 4

DESCRIPTION: The following question is asked:

In the past 12 months, how often has the information you wanted or needed not been available in a format you can use or understand?
(V230_4)

Followed by this question:

When this problem occurs has it been a big problem or a little problem? (V230_4A)

CHARACTERS: 1 for each entry, 2 entries

CODES: Frequency (V230_4)

0 Never (code Magnitude 0)

1 Less than monthly

2 Monthly

3 Weekly

4 Daily

9 Unknown, interview not done or respondent's current age is less than 18 (code Magnitude 9)

Blank (only if V201 = "5")

Magnitude (V230_4A)

0 No problem (code Frequency 0)

1 Little problem

2 Big problem

9 Unknown, interview not done or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

For the year 1 (or year 2) interview, ask "Since discharge, how often has the information you wanted or needed not been available in a format you can use or understand?"

REVISIONS: October 2000: variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 230_4 is coded 0 then, variable 230_4A must be coded 0.

See [page 215](#).

FORM II

VARIABLE NAME: The CHIEF: Question 5

DESCRIPTION: The following question is asked:

In the past 12 months, how often has the availability of health care services and medical care been a problem for you? (V230_5)

Followed by this question:

When this problem occurs has it been a big problem or a little problem? (V230_5A)

CHARACTERS: 1 for each entry, 2 entries

CODES: Frequency (V230_5)

0 **Never** (code Magnitude 0)

1 **Less than monthly**

2 **Monthly**

3 **Weekly**

4 **Daily**

9 **Unknown, interview not done or respondent's current age is less than 18** (code Magnitude 9)

Blank (only if V201 = "5")

Magnitude (V230_5A)

0 **No problem** (code Frequency 0)

1 **Little problem**

2 **Big problem**

9 **Unknown, interview not done or respondent's current age is less than 18**

Blank (only if V201 = "5")

COMMENTS: If health care/medical care services are not needed, code Frequency "0" and code Magnitude "0".

This is a "Window variable" (see rules on page 215).

For the year 1 (or year 2) interview, ask "*Since discharge, how often has the availability of health care services and medical care been a problem for you?*"

REVISIONS: October 2000: variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 230_5 is coded 0 then, variable 230_5A must be coded 0.

See [page 215](#).

FORM II

VARIABLE NAME: The CHIEF: Question 6

DESCRIPTION: The following question is asked:

In the past 12 months, how often did you need someone else's help in your home and could not get it easily? (V230_6)

Followed by this question:

When this problem occurs has it been a big problem or a little problem? (V230_6A)

CHARACTERS: 1 for each entry, 2 entries

CODES: Frequency (V230_6)

0 **Never** (code Magnitude 0)

1 **Less than monthly**

2 **Monthly**

3 **Weekly**

4 **Daily**

9 **Unknown, interview not done or respondent's current age is less than 18** (code Magnitude 9)

Blank (only if V201 = "5")

Magnitude (V230_6A)

0 **No problem** (code Frequency 0)

1 **Little problem**

2 **Big problem**

9 **Unknown, interview not done or respondent's current age is less than 18**

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

For the year 1 (or year 2) interview, ask "Since discharge, often did you need someone else's help in your home and could not get it easily?"

REVISIONS: October 2000: variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 230_6 is coded 0 then, variable 230_6A must be coded 0.

See [page 215](#).

FORM II

VARIABLE NAME: The CHIEF: Question 7

DESCRIPTION: The following question is asked:

In the past 12 months, how often did you need someone else's help at school or work and could not get it easily? (V230_7)

Followed by this question:

When this problem occurs has it been a big problem or a little problem? (V230_7A)

CHARACTERS: 1 for each entry, 2 entries

CODES: Frequency (V230_7)

0 **Never** (code Magnitude 0)

1 **Less than monthly**

2 **Monthly**

3 **Weekly**

4 **Daily**

8 **Not applicable, person not working and not in school** (code Magnitude 8)

9 **Unknown, interview not done or respondent's current age is less than 18** (code Magnitude 9)

Blank (only if V201 = "5")

Magnitude (V230_7A)

0 **No problem** (code Frequency 0)

1 **Little problem**

2 **Big problem**

8 **Not applicable, person not working and not in school** (code Frequency 8)

9 **Unknown, interview not done or respondent's current age is less than 18**

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

For the year 1 (or year 2) interview, ask "*Since discharge, how often did you need someone else's help at school or work and could not get it easily?*"

Note to interviewers: once it has been determined that the respondent is not working and not in school, do not ask CHIEF questions 7 and 9.

REVISIONS: October 2000: variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 230_7 is coded 0 then, variable 230_7A must be coded 0.

If variable 230_7 is coded 8 then, variable 230_7A must be coded 8.

See [page 215](#).

FORM II

VARIABLE NAME: The CHIEF: Question 8

DESCRIPTION: The following question is asked:

In the past 12 months, how often have other people's attitudes toward you been a problem at home? (V230_8)

Followed by this question:

When this problem occurs has it been a big problem or a little problem? (V230_8A)

CHARACTERS: 1 for each entry, 2 entries

CODES: Frequency (V230_8)

0 Never (code Magnitude 0)

1 Less than monthly

2 Monthly

3 Weekly

4 Daily

9 Unknown, interview not done or respondent's current age is less than 18 (code Magnitude 9)

Blank (only if V201 = "5")

Magnitude (V230_8A)

0 No problem (code Frequency 0)

1 Little problem

2 Big problem

9 Unknown, interview not done or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

For the year 1 (or year 2) interview, ask "Since discharge, how often have other people's attitudes toward you been a problem at home?"

If the person lives alone, this question must still be asked and coded accordingly. If the person lives alone and other people's attitudes toward him have not been a problem in his home, code this variable 0.

REVISIONS: October 2000: variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 230_8 is coded 0 then, variable 230_8A must be coded 0.

See [page 215](#).

FORM II

VARIABLE NAME: The CHIEF: Question 9

DESCRIPTION: The following question is asked:

In the past 12 months, how often have other people's attitudes toward you been a problem at school or work? (V230_9)

Followed by this question:

When this problem occurs has it been a big problem or a little problem? (V230_9A)

CHARACTERS: 1 for each entry, 2 entries

CODES: Frequency (V230_9)

0 Never (code Magnitude 0)

1 Less than monthly

2 Monthly

3 Weekly

4 Daily

8 Not applicable, person not working or not in school (code Magnitude 8)

9 Unknown, interview not done or respondent's current age is less than 18 (code Magnitude 9)

Blank (only if V201 = "5")

Magnitude (V230_9A)

0 No problem (code Frequency 0)

1 Little problem

2 Big problem

8 Not applicable, person not working or not in school (code Frequency 8)

9 Unknown, interview not done or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

For the year 1 (or year 2) interview, ask "Since discharge, how often have other people's attitudes toward you been a problem at school or work?"

Note to interviewers: once it has been determined that the respondent is not working and not in school, do not ask CHIEF questions 7 and 9.

REVISIONS: October 2000: variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 230_9 is coded 0 then, variable 230_9A must be coded 0.

If variable 230_9 is coded 8 then, variable 230_9A must be coded 8.

See [page 215](#).

FORM II

VARIABLE NAME: The CHIEF: Question 10

DESCRIPTION: The following question is asked:

In the past 12 months, how often did you experience prejudice or discrimination? (V230_10)

Followed by this question:

When this problem occurs has it been a big problem or a little problem? (V230_10A)

CHARACTERS: 1 for each entry, 2 entries

CODES: Frequency (V230_10)

0 Never (code Magnitude 0)

1 Less than monthly

2 Monthly

3 Weekly

4 Daily

9 Unknown, interview not done or respondent's current age is less than 18 (code Magnitude 9)

Blank (only if V201 = "5")

Magnitude (V230_10A)

0 No problem (code Frequency 0)

1 Little problem

2 Big problem

9 Unknown, interview not done or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

For the year 1 (or year 2) interview, ask "*Since discharge, how often did you experience prejudice or discrimination?*" This variable does include racial prejudice.

REVISIONS: October 2000: variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 230_10 is coded 0 then, variable 230_10A must be coded 0. See [page 215](#).

FORM II

VARIABLE NAME: The CHIEF: Question 11

DESCRIPTION: The following question is asked:

In the past 12 months, how often did the policies and rules of businesses and organizations make problems for you? (V230_11)

Followed by this question:

When this problem occurs has it been a big problem or a little problem? (V230_11A)

CHARACTERS: 1 for each entry, 2 entries

CODES: Frequency (V230_11)

0 Never (code Magnitude 0)

1 Less than monthly

2 Monthly

3 Weekly

4 Daily

9 Unknown, interview not done or respondent's current age is less than 18 (code Magnitude 9)

Blank (only if V201 = "5")

Magnitude (V230_11A)

0 No problem (code Frequency 0)

1 Little problem

2 Big problem

9 Unknown, interview not done or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

For the year 1 (or year 2) interview, ask "*Since discharge, how often did the policies and rules of businesses and organizations make problems for you?*"

REVISIONS: October 2000: variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 230_11 is coded 0 then, variable 230_11A must be coded 0.

See [page 215](#).

FORM II

VARIABLE NAME: The CHIEF: Question 12

DESCRIPTION: The following question is asked:

In the past 12 months, how often did government programs and policies make it difficult to do what you want or need to do?
(V230_12)

Followed by this question:

When this problem occurs has it been a big problem or a little problem? (V230_12A)

CHARACTERS: 1 for each entry, 2 entries

CODES: Frequency (V230_12)

0 **Never** (code Magnitude 0)

1 **Less than monthly**

2 **Monthly**

3 **Weekly**

4 **Daily**

9 **Unknown, interview not done or respondent's current age is less than 18** (code magnitude 9)

Blank (only if V201 = "5")

Magnitude (V230_12A)

0 **None** (code Frequency 0)

1 **Little problem**

2 **Big problem**

9 **Unknown, interview not done or respondent's current age is less than 18**

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

For the year 1 (or year 2) interview, ask "*Since discharge, how often did government programs and policies make it difficult to do what you want or need to do?*"

REVISIONS: October 2000: variables were added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 230_12 is coded 0 then, variable 230_12A must be coded 0. See [page 215](#).

FORM II

VARIABLE NAME: The CHIEF: Policies Subscale

DESCRIPTION: This variable is the mean of the product scores for variables 230_11 and 230_12. This variable is calculated by the NSCISC's software.

The product score = item frequency x item magnitude.

CHARACTERS: 4

CODES: **0.00 to 8.00** Valid range

9.99 Unknown, interview not done or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

March 2001: Unknown code changed from 9.00 to 9.99 and characters changed from 3 to 4 (to store the decimal point).

QC: If variable 230_11 = "9" or variable 230_12 = "9" then, this variable should = "9.99".

See [page 215](#).

SOFTWARE: The software includes a function to calculate this variable. To use: place the cursor on V230_13 (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

FORM II

VARIABLE NAME: The CHIEF: Physical/Structural Subscale

DESCRIPTION: This variable is the mean of the product scores for variables 230_2 and 230_3. This variable is calculated by the NSCISC's software.

The product score = item frequency x item magnitude.

CHARACTERS: 4

CODES: **0.00 to 8.00** Valid range

9.99 Unknown, interview not done or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

March 2001: Unknown code changed from 9.00 to 9.99 and characters changed from 3 to 4 (to store the decimal point).

QC: If variable 230_2 = "9" or variable 230_3 = "9" then, this variable should = "9.99".

See [page 215](#).

SOFTWARE: The software includes a function to calculate this variable. To use: place the cursor on V230_14 (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

FORM II

VARIABLE NAME: The CHIEF: Work/School Subscale.

DESCRIPTION: This variable is the mean of the product scores for variables 230_7 and 230_9. This variable is calculated by the NSCISC's software.

The product score = item frequency x item magnitude.

CHARACTERS: 4

CODES: **0.00 to 8.00** Valid range

8.88 Not applicable, person not working or not in school

9.99 Unknown, interview not done or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

March 2001: Unknown code changed from 9.00 to 9.99 and characters changed from 3 to 4 (to store the decimal point).

QC: If variable 230_7 = "9" or variable 230_9 = "9" then, this variable should = "9.99".

If variable 230_7 = "8" or variable 230_9 = "8" then, this variable should = "8.88".

See [page 215](#).

SOFTWARE: The software includes a function to calculate this variable. To use: place the cursor on V230_13 (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

FORM II

VARIABLE NAME: The CHIEF: Attitudes/Support Subscale.

DESCRIPTION: This variable is the mean of the product scores for variables 230_8 and 230_10. This variable is calculated by the NSCISC's software.

The product score = item frequency x item magnitude.

CHARACTERS: 4

CODES: **0.00 to 8.00** Valid range

9.99 Unknown, interview not done or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

March 2001: Unknown code changed from 9.00 to 9.99 and characters changed from 3 to 4 (to store the decimal point).

QC: If variable 230_8 = "9" or variable 230_10 = "9" then, this variable should = "9.99".

See [page 215](#).

SOFTWARE: The software includes a function to calculate this variable. To use: place the cursor on V230_16 (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

FORM II

VARIABLE NAME: The CHIEF: Services/Assistance Subscale.

DESCRIPTION: This variable is the mean of the product scores for variables 230_1, 230_4, 230_5 and 230_6. This variable is calculated by the NSCISC's software.

The product score = item frequency x item magnitude.

CHARACTERS: 4

CODES: **0.00 to 8.00** Valid range

9.99 Unknown, interview not done or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

March 2001: Unknown code changed from 9.00 to 9.99 and characters changed from 3 to 4 (to store the decimal point).

QC: If variable 230_1 = "9" or variable 230_4 = "9" or variable 230_5 = "9" or variable 230_6 = "9" then, this variable should = "9.99".

See [page 215](#).

SOFTWARE: The software includes a function to calculate this variable. To use: place the cursor on V230_17 (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

FORM II

VARIABLE NAME: The CHIEF: Total

DESCRIPTION: This variable is the mean of the product scores for all variables 230_1 through 230_12. This variable is calculated by the NSCISC's software.

The product scores for 230_7 and 230_9 are excluded from the CHIEF Total if V230_7, V230_7A, V230_9 and V230_9A are coded "8".

The product scores for all CHIEF items are excluded from the CHIEF Total if 1 or more items are coded "9".

CHARACTERS: 4

CODES: **0.00 to 8.00** Valid range

9.99 Unknown, interview not done or respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

March 2001: Unknown code changed from 9.00 to 9.99 and characters changed from 3 to 4 (to store the decimal point).

QC: If the Frequency of any variable from 230_1 through 230_12 is coded "9", then this variable = "9.99".

See [page 215](#).

SOFTWARE: The software includes a function to calculate this variable. To use: place the cursor on V230T (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

FORM II

VARIABLE NAME: The Patient Health Questionnaire (Brief Version): Question 1

DESCRIPTION: The following question is asked:

Over the last 2 weeks, how often have you been bothered by little interest or pleasure in doing things?

CHARACTERS: 1

CODES:

- 0 Not at all**
- 1 Several days**
- 2 More than half the days**
- 3 Nearly every day**
- 9 Unknown, interview not done, respondent's current age is less than 18**

Blank (*only if V201 = "5"*)

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

SOURCE: Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc.

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If the patient's current age is less than 18 then, this variable must be coded "9".

See [page 215](#).

FORM II

VARIABLE NAME: The Patient Health Questionnaire (Brief Version) : Question 2

DESCRIPTION: The following question is asked:

Over the last 2 weeks, how often have you been bothered by feeling down, depressed, or hopeless?

CHARACTERS: 1

CODES:

- 0 Not at all**
- 1 Several days**
- 2 More than half the days**
- 3 Nearly every day**
- 9 Unknown, interview not done, respondent's current age is less than 18**

Blank (*only if V201 = "5"*)

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If the patient's current age is less than 18 then, this variable must be coded "9".

See [page 215](#).

FORM II

VARIABLE NAME: The Patient Health Questionnaire (Brief Version): Question 3

DESCRIPTION: The following question is asked:

Over the last 2 weeks, how often have you been bothered by trouble falling or staying asleep, or sleeping too much?

CHARACTERS: 1

CODES:

- 0 Not at all**
- 1 Several days**
- 2 More than half the days**
- 3 Nearly every day**
- 9 Unknown, interview not done, respondent's current age is less than 18**

Blank (*only if V201 = "5"*)

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If the patient's current age is less than 18 then, this variable must be coded "9".

See [page 215](#).

FORM II

VARIABLE NAME: The Patient Health Questionnaire (Brief Version) : Question 4

DESCRIPTION: The following question is asked:

Over the last 2 weeks, how often have you been bothered by feeling tired or having little energy?

CHARACTERS: 1

CODES:

- 0 Not at all**
- 1 Several days**
- 2 More than half the days**
- 3 Nearly every day**
- 9 Unknown, interview not done, respondent's current age is less than 18**

Blank (*only if V201 = "5"*)

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If the patient's current age is less than 18 then, this variable must be coded "9".

See [page 215](#).

FORM II

VARIABLE NAME: The Patient Health Questionnaire (Brief Version) : Question 5

DESCRIPTION: The following question is asked:

Over the last 2 weeks, how often have you been bothered by poor appetite or overeating?

CHARACTERS: 1

CODES:

- 0 Not at all**
- 1 Several days**
- 2 More than half the days**
- 3 Nearly every day**
- 9 Unknown, interview not done, respondent's current age is less than 18**

Blank (*only if V201 = "5"*)

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If the patient's current age is less than 18 then, this variable must be coded "9".

See [page 215](#)

FORM II

VARIABLE NAME: The Patient Health Questionnaire (Brief Version) : Question 6

DESCRIPTION: The following question is asked:

Over the last 2 weeks, how often have you been bothered by feeling bad about yourself – or that you are a failure or have let yourself or your family down?

CHARACTERS: 1

CODES:

- 0 Not at all**
- 1 Several days**
- 2 More than half the days**
- 3 Nearly every day**
- 9 Unknown, interview not done, respondent's current age is less than 18**

Blank (*only if V201 = "5"*)

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If the patient's current age is less than 18 then, this variable must be coded "9".

See [page 215](#).

FORM II

VARIABLE NAME: The Patient Health Questionnaire (Brief Version): Question 7

DESCRIPTION: The following question is asked:

Over the last 2 weeks, how often have you been bothered by trouble concentrating on things, such as reading the newspaper or watching television?

CHARACTERS: 1

CODES:

- 0 Not at all**
- 1 Several days**
- 2 More than half the days**
- 3 Nearly every day**
- 9 Unknown, interview not done, respondent's current age is less than 18**

Blank (*only if V201 = "5"*)

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If the patient's current age is less than 18 then, this variable must be coded "9".

See [page 215](#).

FORM II

VARIABLE NAME: The Patient Health Questionnaire (Brief Version) : Question 8

DESCRIPTION: The following question is asked:

Over the last 2 weeks, how often have you been bothered by moving or speaking so slowly that other people could have noticed?

Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual?

CHARACTERS: 1

CODES:

- 0 Not at all**
- 1 Several days**
- 2 More than half the days**
- 3 Nearly every day**
- 9 Unknown, interview not done, respondent's current age is less than 18**

Blank (only if V201 = "5")

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If the patient's current age is less than 18 then, this variable must be coded "9".

See [page 215](#).

FORM II

VARIABLE NAME: The Patient Health Questionnaire (Brief Version) : Question 9

DESCRIPTION: The following question is asked:

Over the last 2 weeks, how often have you been bothered by thoughts that you would be better off dead or of hurting yourself in some way?

CHARACTERS: 1

CODES:

- 0 Not at all**
- 1 Several days**
- 2 More than half the days**
- 3 Nearly every day**
- 9 Unknown, interview not done, respondent's current age is less than 18**

Blank (*only if V201 = "5"*)

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

Each system should develop their own response procedures if the participant responds "yes" to this question. Copies of the protocols used at the Denver and Seattle systems are available from the NSCISC.

One system's consent form already has some wording that states confidentiality is not absolute.

The attorney at another system advised them that they do not have a duty to report since there is not a "patient-doctor" relationship inherent in the data collection process. He advised that it would be sufficient to provide appropriate referral information if the patient requests it.

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If the patient's current age is less than 18 then, this variable must be coded "9".

See [page 215](#).

FORM II

VARIABLE NAME: The Patient Health Questionnaire (Brief Version): Question 10

DESCRIPTION: The following question is asked:

If you had any of the problems I asked about in questions 1 through 9, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

CHARACTERS: 1

CODES:

- 0 Not difficult at all**
- 1 Somewhat difficult**
- 2 Very difficult**
- 3 Extremely difficult**
- 8 Not applicable, did not have any of the problems in questions 1 through 9**
- 9 Unknown, interview not done, respondent's current age is less than 18**

Blank (*only if V201 = "5"*)

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variables 231_1 through 231_9 are coded "0" then, this variable must be coded "8".

If the patient's current age is less than 18 then, this variable must be coded "9".

See [page 215](#).

FORM II

VARIABLE NAME: Major Depressive Syndrome

DESCRIPTION: This variable is calculated using the responses in variables 231_1 through 231_9.

This variable is generated by the NSCISC's software.

CHARACTERS: 1

CODES: **0 No depressive syndrome**
 1 Major depressive syndrome
 2 Other depressive syndrome
 9 Unknown, interview not done, respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

If this variable = "1" or "2", notify the clinical staff at your Model System.

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If variable 231_10 = "8", then V231_1 through V231_9 must = "0" and V231M must = "0".

See [page 215](#).

SOFTWARE: The software includes a function key to calculate this variable. These are the specifications for the calculation:

V231M = 0.

If (V231_1 = 2 or 3 OR V231_2 = 2 or 3) AND
 5 or more of V231_1 through V231_9 = 2 or 3 (count V231_9 if coded 1, 2, or 3)
 then, V231M = 1.

If (V231_1 = 2 or 3 OR V231_2 = 2 or 3) AND
 2, 3 or 4 of V231_1 through V231_9 = 2 or 3 (count V231_9 if coded 1, 2, or 3)
 then, V231M = 2.

Else: if (V231_1 = 9 or V231_2 = 9 or V231_3 = 9 or V231_4 = 9 or V231_5 = 9 or V231_6 = 9
 or V231_7 = 9 or V231_8 = 9 or V231_9 = 9) AND

[(V231_1 = 2 or 3 OR V231_2 = 2 or 3) AND 5 or more of V231_1 through V231_9
 = 2 or 3 (count V231_9 if coded 1, 2, or 3) = NOT TRUE]
 then, V231M = 9.

Once the minimal score for major depression is attained then, unknown codes in some elements don't matter.

Else: if (V231_1 = blank or V231_2 = blank or V231_3 = blank or V231_4 = blank or V231_5 = blank or V231_6 = blank or V231_7 = blank or V231_8 = blank or V231_9 = blank) AND
 [(V231_1 = 2 or 3 OR V231_2 = 2 or 3) AND 5 or more of V231_1 through V231_9 = 2 or 3
 (count V231_9 if coded 1, 2, or 3) = NOT TRUE]
 then, V231M = blank.

The logic is that, once the minimal score for major depression is attained then, blanks in some elements don't matter.

FORM II

VARIABLE NAME: Severity of Depression

DESCRIPTION: This variable is the sum of the responses in variables 231_1 through 231_9.

This variable can be generated by the NSCISC's software.

CHARACTERS: 2

CODES: **00 to 27** Valid range

99 Unknown, interview not done, respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: The checks utilize the formula below and the info on [page 215](#).

SOFTWARE: The software includes a function key to calculate this variable. To use: place the cursor on V231S (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

Formula used:

If <V231_1> = blank or <V231_2> = blank or <V231_3> = blank or <V231_4> = blank or <V231_5> = blank or <V231_6> = blank or <V231_7> = blank or <V231_8> = blank or <V231_9> = blank then, <V231M> = blank.

If <V231_1> = 9 or <V231_2> = 9 or <V231_3> = 9 or <V231_4> = 9 or <V231_5> = 9 or <V231_6> = 9 or <V231_7> = 9 or <V231_8> = 9 or <V231_9> = 9 then, <V231M> = 99.

Else <V231M> = sum <V231_1> + <V231_2> + <V231_3> + <V231_4> + <V231_5> + <V231_6> + <V231_7> + <V231_8> + <V231_9>.

FORM II

VARIABLE NAME: Alcohol Use

DESCRIPTION: The following question is asked:

Do you drink any alcoholic beverages (such as beer, wine, wine coolers or liquor)?

CHARACTERS: 1

CODES: **0** No, never ever drank alcohol
 1 Yes, currently drinks or did drink in the past
 9 Unknown, interview not done, respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If V233 = "0" then,
 V234, V237_1, V237_2, V237_3, V237_4 and V237T must = "8" and V235 and V236 must = "88".

If the patient's current age is less than 18 then,

V234, V237_1, V237_2, V237_3, V237_4 and V237T must = "9" and V235 and V236 must = "99".

See [page 215](#).

FORM II

VARIABLE NAME: Alcohol Use: Number of Days Per Week

DESCRIPTION: The following question is asked:

During the past month, how many days per week did you drink any alcoholic beverages such as beer, wine, wine coolers or liquor, on the average?

CHARACTERS: 1

CODES: **0 None**

1 to 7 Valid range

8 Drinks alcohol but number of days unknown

8 Not applicable, never drank alcohol (use this code if V233 = 0)

9 Unknown, interview not done, respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: See pages [215](#) and [280](#).

FORM II

VARIABLE NAME: Alcohol Use: Number of Drinks

DESCRIPTION: The following question is asked:

On the days you drank (during the past month), about how many drinks did you drink, on the average?

CHARACTERS: 2

CODES: **00 None**

00 to 87 Valid range

88 Drinks alcohol but number of drinks unknown

88 Not applicable, never drank alcohol (*use this code if V233 = 0*)

99 Unknown, interview not done, respondent's current age is less than 18

Blank (*only if V201 = "5"*)

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: See pages [215](#) and [280](#).

FORM II

VARIABLE NAME: Alcohol Use: Frequency During the Past Month

DESCRIPTION: The following question is asked:

Considering all types of alcoholic beverages, how many times during the past month did you have five (5) or more drinks on an occasion?

CHARACTERS: 2

CODES: **00 None**

00 to 31 Valid range

88 Drinks alcohol but frequency unknown

88 Not applicable, never drank alcohol (*use this code if V233 = 0*)

99 Unknown, interview not done, respondent's current age is less than 18

Blank (*only if V201 = "5"*)

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: See pages [215](#) and [280](#).

FORM II

VARIABLE NAME: The CAGE – Question 1

DESCRIPTION: The following question is asked:

During the past year: have you ever felt you should cut down on your drinking?

CHARACTERS: 1

CODES: **0** No

1 Yes

8 Not applicable, never ever drank alcohol *(use this code if V233 = 0)*

9 Unknown, interview not done, respondent's current age is less than 18

Blank *(only if V201 = "5")*

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

February 2002: The "during the past year" time period was implemented in interviews done after February 2002. Prior to that, participants were asked "did you ever...".

QC: See pages [215](#) and [280](#).

FORM II

VARIABLE NAME: The CAGE – Question 2

DESCRIPTION: The following question is asked:

During the past year: have people annoyed you by criticizing your drinking?

CHARACTERS: 1

CODES: **0** No

1 Yes

8 Not applicable, never ever drank alcohol (use this code if V233 = 0)

9 Unknown, interview not done, respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

February 2002: The "during the past year" time period was implemented in interviews done after February 2002. Prior to that, participants were asked "did you ever...".

QC: See pages [215](#) and [280](#).

FORM II

VARIABLE NAME: The CAGE – Question 3

DESCRIPTION: The following question is asked:

During the past year: have you ever felt bad or guilty about your drinking?

CHARACTERS: 1

CODES: **0** No

1 Yes

8 Not applicable, never ever drank alcohol (use this code if V233 = 0)

9 Unknown, interview not done, respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

February 2002: The "during the past year" time period was implemented in interviews done after February 2002. Prior to that, participants were asked "did you ever...".

QC: See pages [215](#) and [280](#).

FORM II

VARIABLE NAME: The CAGE – Question 4

DESCRIPTION: The following question is asked:

During the past year: have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover (eye-opener)?

CHARACTERS: 1

CODES: **0** No

1 Yes

8 Not applicable, never ever drank alcohol (use this code if V233 = 0)

9 Unknown, interview not done, respondent's current age is less than 18

Blank (only if V201 = "5")

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

February 2002: The "during the past year" time period was implemented in interviews done after February 2002. Prior to that, participants were asked "did you ever...".

QC: See pages [215](#) and [280](#).

FORM II

- VARIABLE NAME: The CAGE – Total Score
- DESCRIPTION: This variable is the total score for the 4 CAGE items in variables 237_1, 237_2, 237_3 and 237_4.
- This variable can be generated by the NSCISC’s software.
- CHARACTERS: 1
- CODES: **0 to 4 Valid range**
- 8 Not applicable, never ever drank alcohol** (*use this code if V233 = 0*)
- 9 Unknown, interview not done, respondent’s current age is less than 18**
- Blank** (*only if V201 = “5”*)
- COMMENTS: This is a “Window variable” (see rules on page 215).
- REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.
- February 2002: The “during the past year” time period was implemented in interviews done after February 2002. Prior to that, participants were asked “did you ever...”.
- QC: See pages [215](#) and [280](#).
- If 237_1 = “9” (or “8”) or 237_2 = “9” (or “8”) or 237_3 = “9” (or “8”) or 237_4 = “9” (or “8”) then, V237T must = “9” (or “8”).
- SOFTWARE: The software includes a function key to calculate this variable. To use: place the cursor on V237T (in the data entry box), the software will then ask *Calculate this variable?* Place the cursor on *Yes* and *click once* with the left mouse button.

FORM II

VARIABLE NAME: Pain: Severity of Pain

DESCRIPTION: The following question is asked:

Using a 0-10 scale with 10 being pain so severe you could not stand it and, 0 being no pain, what has been the usual level of pain over the past 4 weeks?

CHARACTERS: 2

CODES: **00** **No pain** (code variable 239 "8")

00 to 10 **Valid range**

99 **Unknown, interview not done, respondent's current age is less than 18**

Blank (only if V201 = "5")

COMMENTS: If there is more than one pain site, code the worst site.

Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

REVISIONS: October 2000: this variable was added to the database. Data are required for new Form IIs entered on or after 03/01/2001.

QC: If V238 = "00" then, V239 must = "8" and vice versa. This check applies only to records entered into the database after December 2000.

See [page 215](#).

FORM II

VARIABLE NAME: Pain: Interfering With Work

DESCRIPTION: The following question is asked:

During the past 4 weeks, how much did pain interfere with your normal work including both work outside the home and housework?

CHARACTERS: 1

CODES:

- 0 Not at all**
- 1 A little bit**
- 2 Moderately**
- 3 Quite a bit**
- 4 Extremely**
- 6 Don't know**
- 7 Refuses**
- 8 Not applicable, no pain during the past 4 weeks** *(use this code if variable 238 = "00")*
- 9 Unknown, interview not done, respondent's current age is less than 18**

Blank *(only if V201 = "5")*

COMMENTS: Only responses from the patient are acceptable. This is a "Window variable" (see rules on page 215).

If the patient does not do (house)work, ask *During the past 4 weeks, how much did pain interfere with your usual activities?* Let the patient determine what "usual activities" are.

SOURCE: SF-12 How to Score the SF-12 Physical and Mental Health Summary Scales. John E. Ware, Jr. Ph.D., Mark Kosinski, M.A., Susan D. Keller, Ph.D. The Health Institute, England Medical Center, Boston, Massachusetts.

REVISIONS: May 1998: this variable was added to the database.

QC: If variable 238 = "00" then, variable 239 must = "8" and vice versa. This check applies only to records entered into the database after December 2000.

See [page 215](#).

FORM II

VARIABLE NAME: Outpatient Rehabilitation - Physical and/or Occupational Therapy from Injury to the First Anniversary of Injury

DESCRIPTION: This variable documents:
 if outpatient physical and/or occupational therapy was prescribed by a Model System physician anytime after the initial SCI to the first anniversary of injury (**V240A**);
 number of hours of outpatient physical and/or occupational therapy completed anytime after the initial SCI to the first anniversary of injury (**V240B**); and
 the location of outpatient physical and/or occupational therapy received anytime after the initial SCI to the first anniversary of injury (**V240C**).
If a year 02 Form II is substituted for the year 01 Form II (because the patient was still in initial hospitalization past his first anniversary), this variable documents outpatient rehab prescribed after the initial SCI to the end of the last treatment phase documented on Form I.

CHARACTERS: 1 for each entry, 3 entries

CODES: Outpatient PT and/or OT Prescribed by a Physician (V240A):

- 0 No**
- 1 Yes**
- 9 Unknown**

Blank (only if V201 = "5")

Outpatient Hours Completed (V240B):

- 0 None**
- 1 1 to 5 hours**
- 2 6 to 20 hours**
- 3 21 to 40 hours**
- 4 41 to 60 hours**
- 5 61 to 80 hours**
- 6 81 to 100 hours**
- 7 more than 100 hours**
- 8 Therapy received, number of hours unknown**
- 9 Unknown**

Blank (only if V201 = "5")

Location (V240C):

- 1 System**
- 2 Non-system**
- 3 Both**
- 8 Not applicable, no outpatient OT or PT (V240B=0)**
- 9 Unknown**

Blank (only if V201 = "5")

FORM II

VARIABLE NAME: Outpatient Rehabilitation - Physical and/or Occupational Therapy from Injury to the First Anniversary of Injury

COMMENTS: Report all OT and PT outpatient treatments received from the time of injury to the first anniversary of injury:

- o including outpatient OT and PT treatments that were not prescribed by the Model System physician
- o including outpatient OT and PT whether it is provided by the System or by another provider.
- o DO NOT include therapy received in the home unless the therapist actually makes home visits.
- o DO include therapy received at “day hospitals” (i.e., facilities at which the patient receives therapy but does not spend the night).

If there is a subsequent SCI prior to the first (or second) anniversary of the initial SCI, do not count the outpatient rehab received for that subsequent injury in this variable. Document the subsequent injury in Number of Days Rehospitalized and Reason for Rehospitalization (variables 218 and 219).

See [page 17](#) for the rules for rounding fractions of an hour.

Self-report is acceptable for this variable. However, to assure reliable data collection, it is suggested that the patient be contacted and data obtained several times during this period (e.g., every 2 months).

REVISIONS: These variables were added to the database in November 1995 and modified in February 1996.

October 2000: these variables were moved to Form II and data collection was changed from “from discharge to first anniversary” to “from injury to first anniversary”.

QC: If component B (Hours Completed) = “0” (None) then component C (Location) must = “8” (Not Applicable) and vice versa.

EXAMPLE 1: Outpatient physical therapy was prescribed, however, the patient did not complete any hours of post-discharge rehab.

240. Injury to the First Anniversary - Physical and/or Occupational Therapy:

A. Prescribed 1 B. Hours Completed 0 C. Location 8

EXAMPLE 2: Twenty hours of outpatient occupational therapy were prescribed and received at a non-system rehab center.

240. Injury to the First Anniversary - Physical and/or Occupational Therapy:

A. Prescribed 1 B. Hours Completed 2 C. Location 2

EXAMPLE 3: Out-patient occupational or physical therapy were not prescribed at the time of discharge from inpatient rehab or through the end of the first year following injury. However, the patient received 10 hours of outpatient occupational therapy at a non-system rehab center.

240. Injury to the First Anniversary - Physical and/or Occupational Therapy:

A. Prescribed 0 B. Hours Completed 2 C. Location 2

FORM II

VARIABLE NAME: Outpatient Rehabilitation - Psychological or Vocational Counseling from Injury to the First Anniversary of Injury

DESCRIPTION: This variable documents:
 if post-discharge outpatient psychological or vocational counseling was prescribed by a physician anytime after the initial SCI to the first anniversary of injury (**V241A**);
 number of hours of outpatient psychological or vocational counseling completed anytime after the initial SCI to the first anniversary of injury (**V241B**); and
 the location of post-discharge outpatient psychological or vocational counseling received anytime after the initial SCI to the first anniversary of injury (**V241C**).

If a year 02 Form II is substituted for the year 01 Form II (because the patient was still in initial hospitalization past his first anniversary), this variable documents outpatient rehab prescribed after the initial SCI to the end of the last treatment phase documented on Form I.

CHARACTERS: 1 for each entry, 3 entries

CODES: Outpatient Counseling Prescribed by a Physician (V241A):

0 No
1 Yes
9 Unknown

Blank (only if V201 = "5")

Outpatient Hours Completed (V241B):

0 None
1 1 to 5 hours
2 6 to 20 hours
3 21 to 40 hours
4 41 to 60 hours
5 61 to 80 hours
6 81 to 100 hours
7 more than 100 hours
8 Counseling received, number of hours unknown
9 Unknown

Blank (only if V201 = "5")

Location (V241C):

1 System
2 Non-system
3 Both
8 Not applicable, no outpatient counseling (V241B=0)
9 Unknown

Blank (only if V201 = "5")

FORM II

VARIABLE NAME: Outpatient Rehabilitation - Psychological or Vocational Counseling from Injury to the First Anniversary of Injury

COMMENTS: Report all outpatient psychological and vocational counseling received from the time of injury to the first anniversary of injury:

- o Including outpatient psychological and vocational that was not prescribed by the Model System physician
- o including outpatient psychological and vocational counseling whether it is provided by the System or by another provider.
- o Do not include outpatient counseling received in the home unless the counselor actually makes home visits.

If there is a subsequent SCI prior to the first (or second) anniversary of the initial SCI, do not count the outpatient rehab received for that subsequent injury in this variable. Document the subsequent injury in Number of Days Rehospitalized and Reason for Rehospitalization (variables 218 and 219).

See page 17 for the rules for rounding fractions of an hour.

Self-report is acceptable for this variable. However, to assure reliable data collection, it is suggested that the patient be contacted and data obtained several times during this period (e.g., every 2 months).

Referrals by VRS (Vocational Rehab Service) are included in this variable. Includes only professional counseling (not support groups).

REVISIONS: November 1995: these variables were added to the database and modified in February 1996.

October 2000: these variables were moved to Form II and data collection was changed from “from discharge to first anniversary” to “from injury to first anniversary”.

QC: If component B (Hours Completed) = “0” (None) then component C (Location) must = “8” (Not Applicable) and vice versa.

EXAMPLE 1: Outpatient psychological counseling was prescribed, however, the patient did not complete any hours of post-discharge counseling.

241. Injury to the First Anniversary – Psychological and/or Vocational Counseling:
A. Prescribed 1 B. Hours Completed 0 C. Location 8

EXAMPLE 2: Twenty hours of outpatient vocational counseling was prescribed and received at a non-system rehab center.

241. Injury to the First Anniversary – Psychological and/or Vocational Counseling:
A. Prescribed 1 B. Hours Completed 2 C. Location 2

EXAMPLE 3: Outpatient psychological or vocational counseling were not prescribed at the time of discharge through the end of the first year after injury. However, the patient received 10 hours of outpatient vocational counseling at a non-system rehab center.

241. Injury to the First Anniversary – Psychological and/or Vocational Counseling:
A. Prescribed 0 B. Hours Completed 2 C. Location 2

PERSONAL DATA

VARIABLE NAME: Export Status

DESCRIPTION: This is a computer-generated variable used by the EXPORT function of the software to determine if the Patient Name, Social Security Number, Date of Birth and/or the Zip Codes are to be exported to the NSCISC. The software generates the ExStat code based on the user's selection of the Personal Data items.

CHARACTERS: 4

CODES: **0000 None of the items may be exported to the NSCISC**

1111 All of the items are to be Exported to the NSCISC

All other combinations of 1's and 0's as generated by the software

COMMENTS: It is advisable that Systems obtain separate permission to allow the Personal Data to be shipped to the NSCISC. Only the Patient Name (V102), Social Security Number (V103), Date of Birth (V104) and Zip Codes for Places of Residence during Follow-up (V105_1, V105_5, V105_10, V105_15, V105_20, V105_25 and V105_30) are available for shipment to the NSCISC.

REVISIONS: October 2000: this variable was added the database.

February 2003: this variable is computer-generated based on the user's selections.

SOFTWARE: Check the appropriate boxes to select the items the patient has agreed to have exported to the NSCISC. See the Users' Manual for details.

EXAMPLE: The patient has agreed to export his name and zip codes. The data entry person has checked the appropriate boxes and the software generates code 1001 in the ExStat variable. Note: the user sees only the checked boxes (not the "1001" code).

Name ✓ SSN Birth Date Zip Codes ✓

CONVERSION: February 2003: If the old ExStat variable was coded 0 then, the new variables (Name, SSN, Birth Date and Zip Codes) are not checked (on the data entry screen) and, the ExStat variable is coded 0000 in the database.

If the old ExStat variable was coded 1 then, the new variables (Name, SSN, Birth Date and Zip Codes) are checked (on the data entry screen) and the ExStat variable is coded 1111 in the database.

FORM I

VARIABLE NAME: Sample

DESCRIPTION: This variable indicates whether or not yearly follow-up data were required (as determined by a sampling process). The NSCISC's sampling process was in effect from November 1995 through September 2000 and was instituted to reduce the burden of data submission for those systems with large patient populations. The sampling system required "Core" (i.e., limited) follow-up data on the Sample patients.

Although the 1995-2000 sampling scheme is no longer used, this variable has been retained in the database to identify the patients for whom complete follow-up was (or was not) required.

CHARACTERS: 1

CODES: **0 Non-sample patient**
1 Sample patient - group 1
2 Sample patient - group 2
3 Sample patient - group 3
4 Sample patient - group 4

COMMENTS: The sampling method did not affect clinical follow-up efforts. All patients were still encouraged to return to the system for medical evaluation as often as needed.

Code "0" will be inserted (by the software) in all Form Is entered after the sampling method was discontinued. Users are not allowed to modify this variable because it is a data management variable.

PERSONAL DATA, REGISTRY, FORM I and FORM II

VARIABLE NAME: Quality Control (QC) Status

DESCRIPTION: This is a computer-generated variable used by the EXPORT function of the software to determine which records have passed quality control and may be shipped to the NSCISC.

CHARACTERS: 1

CODES: **1 Not passed QC**
2 Passed QC
3 Shipped to NSCISC

COMMENTS: This is a data management variable that is generated by the NSCISC's software. Users are not allowed to modify this variable.

PERSONAL DATA, REGISTRY, FORM I and FORM II

VARIABLE NAME: Batch Number

DESCRIPTION: This is a computer-generated data management variable (see Software paragraph below) that uniquely labels a group of records processed during a period of time.

This number is displayed during the data entry process and should be copied on the data collection forms entered in that batch. The NSCISC refers to this number when it sends the system a verification of data received and merged into the national database.

This variable could also be useful as a computerized means by which a system may identify forms completed and/or entered by different persons.

CHARACTERS: 10 (2 for the System ID, 8 for the date)

COMMENTS: The Batch Number consists of:

- > the system's alphabetic identification code (the same as that used in variable 100)
- > the year, month and day a batch was started.

A date stamper may be used to place this portion of the Batch Number on the data collection forms.

This is a data management variable that is generated by the NSCISC's software. Users are not allowed to modify this variable.

SOFTWARE: During the LOAD process (the installation of the software onto a system's computer) the user will be asked to enter a batch number. The program will place this batch number on every record newly entered or updated from that point until the user EXPORTS this batch of data to the NSCISC.

After a system's first batch has been exported, the software will assign batch numbers (based on the date the current batch was exported.)

EXAMPLE: The system's ID is "B " and the date assigned to the batch is June 30, 1990.

The batch number is: B _ 1 9 9 0 0 6 3 0

PERSONAL DATA, REGISTRY, FORM I and FORM II

VARIABLE NAME: Record Indate

DESCRIPTION: This is the date on which a particular record is first entered into the computer. It is a data management variable that is computer-generated.

Once entered, this date never changes.

CHARACTERS: 8

SOFTWARE: After a record is SAVED during the data-entry process, the computer inserts the present date in this variable.

COMMENTS: Several records in the national database have indates equal to 19861001. These records were in the database prior to the revision of the definitions for the Associated Injuries, Medical Complications and Operative Procedures. It is a common practice to exclude these records whenever any analyses are performed on these variables.

Records with Indates after 02/01/1996 used the November 1995 version of the data collection syllabus.

Records with Indates after 03/01/2001 used the 2000-2005 version of the data collection syllabus.

This is a data management variable that is generated by the NSCISC's software. Users are not allowed to modify this variable.

PERSONAL DATA, REGISTRY, FORM I and FORM II

VARIABLE NAME: Record Update

DESCRIPTION: This is the last date on which an existing record was modified.
This date changes each time a record is modified and saved.

CHARACTERS: 8

FORMAT: mmddyyyy

COMMENTS: This is a data management variable that is generated by the NSCISC's software. Users are not allowed to modify this variable.

SOFTWARE: After a record is SAVED during the data-entry process, the computer inserts the present date in this variable (even if changes have not been made to the record.)

Select "Exit without saving data" if you do not want the Update date to change.

FORM II

VARIABLE NAME: Ambulation

DESCRIPTION: This variable asks the participant these 3 questions regarding ambulation:

A) Are you able to walk (with or without mobility aid) for 150 feet in your home?

B) Are you able to walk (with or without mobility aid) for one street block outside?

C) Are you able to walk (with or without mobility aid) up one flight of steps?

CHARACTERS: 1 for each entry (V250A, V250B, V250C)

CODES: 0 No

1 Yes

9 Unknown or interview not done

QC: If V250A, V250B and V250C = 0 then, V251_1 must = 8 and V251_2 through V251_5 = blank.

If V250A, V250B and V250C = 9 then, V251 must = 9 and V251_2 through V251_5 = blank.

SOFTWARE: When code 0 is entered in V250A, V250B and V250C, the software inserts code 8 in V251_1 and advances the user to V252. When code 9 is entered in V250A, V250B and V250C, the software inserts code 9 in V251_1 and advances the user to V252.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Mobility Aid(s)

DESCRIPTION: This variable documents the type of mobility aid the participant uses. The following question is asked:

Tell me which of the following mobility aids you currently use most often.

CHARACTERS: 1 for each entry, up to 5 entries (V251_1 to V251_5)

CODES:

- 0 None
- 1 Straight cane
- 2 Quad cane
- 3 Walker
- 4 Crutches
- 5 Ankle-Foot-Orthotic (AFO, short leg brace)
- 6 Knee-Ankle-Foot-Orthotic (KAFO, long leg brace)
- 7 Other
- 8 Not applicable participant is not ambulatory (V250A, V250B and V250C=0)
- 9 Unknown or interview not done

COMMENTS: Go through the entire list all mobility aids during the interview. Code up to 5 that apply.

QC: See page 301.
If V251_1 = 0, 8 or 9, V251_2 through V251_5 must = blank.

SOFTWARE: See page 301.
If V251_1 = 0 the software advances to V252.
If V251_1 = 9 the software advances to V252.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Wheelchair or Scooter Use

DESCRIPTION: This variable documents whether or not the participant is a wheelchair or scooter user on a regular basis. The following question is asked:

Do you use a wheelchair or scooter over 40 hours per week?

CHARACTERS: 1

CODES 0 No

1 Yes

9 Unknown or interview not done

COMMENTS: If the participant uses a wheelchair or scooter LESS than 40 hours per week, code this variable 0 (No).

QC: IF V252 = 0 THEN
 V253 = 8 and V254A = 88 and V254B = 88 and V255 = 88 and
 V256_1 = 8 and blank in V256_2 through V256_6 and
 V257 = 88 and V258_1 = 8 and V258_2 to V258_4 = blank and
 V259A = 88 and V259B = 88 and V259C = 88 and V259D = 88 and
 V259E = 88.

IF V252 = 9 THEN
 V253 = 9 and V254A = 99 and V254B = 99 and V255 = 99 and
 V256_1 = 9 and blank in V256_2 through V256_6 and
 V257 = 99 and V258_1 = 9 and V258_2 to V258_4 = blank and
 V259A = 99 and V259B = 99 and V259C = 99 and V259D = 99 and
 V259E = 99.

See page 310.

SOFTWARE: When code 0 is entered in V252 the software inserts 8s in V253 through V259E and the user is advanced to V260.

When code 9 is entered in V252 the software inserts 9s in V253 through V259E and the user is advanced to V260.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Type of Wheelchair or Scooter Used Most Often

DESCRIPTION: This variable documents the type of wheelchair or scooter documented in variable 252. The following question is asked:

What type of wheelchair (or scooter) do you use most often?

CHARACTERS: 1

CODES

| | |
|---|---|
| 1 | Manual Wheelchair - Propelled by the individual without assistance from motors. Includes lever drive or one arm drive chairs. |
| 2 | Power Wheelchair - Generally controlled by a joystick and the force needed to go forward comes entirely from battery power. |
| 3 | Power Assist Wheelchair - Receives some force from the user and some force from the motor. In general these wheelchairs appear like a manual wheelchair; however, they have motors that respond to a push on the pushrim and provide extra force to the push. |
| 4 | Scooter |
| 7 | Other (e.g., a golf cart) |
| 8 | Not applicable (V252 = 0) |
| 9 | Unknown or interview not done |

COMMENTS: If more than one type is used, code the one used most often. A list of all wheelchair and scooter models may be found starting on page 305.

QC: See page 303.

If V253 = 1 then, V254B must = 100 to 155, 777 or 999.

If V253 = 2 then, V254B must = 200 to 292, 777 or 999.

If V253 = 3 then, V254B must = 400, 401, 777 or 999.

If V253 = 4 then, V254B must = 500 to 517, 777 or 999

SOFTWARE: See page 303.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Manufacturer and Model for Wheelchair or Scooter Used Most Often

DESCRIPTION: These variables document the manufacturer and model of the wheelchair (or scooter) that is coded in variables 252 through 258. The following question is asked:

Who is the manufacturer and what is the model of the wheelchair (or scooter) you use most often?

CHARACTERS: 2 characters for manufacturer (V254A); 3 characters for model (V254B)

CODES:

| MANUAL CHAIRS | Manufacturer V254A | V254B...Model |
|----------------------|---|---|
| | Invacare.....01 | 100 900 SERIES 101 9000 102 A-4 103 A4 Titanium 104 A-6S Rigid Suspension 105 Action A4 106 Comet 107 Compass SPT 108 IVC Tracer 109 MVP 110 MX 111 Patriot 112 Solara 113 Spyder 114 Top End 115 Tracer SX5 116 Xtra |
| | Sunrise.....02 | 117 2 or 2 HP 118 Breezy 119 GP (S, V or Ti) 120 Guardian Escort 121 Quickie GPV Titanium (EITI) 122 Quickie 2 123 Quickie Chameleon 124 Quickie GP Swing-Away 125 Quickie GP/GPV 126 Quickie Iris 127 Quickie LX 128 Quickie LXI 129 Quickie R2 130 Quickie ST/DT 131 Quickie T45 132 Quickie TI Titanium (EIT3) 133 Quickie TS 134 Quickie XTR 135 Revolution |
| | Permobil/04 Colours/ | 136 Avenger 137 Avenger - QS 138 Boing 139 Challenger 140 Chump 141 Classx 142 Eclipse 143 Eclipse – QS 144 Xtreme |
| | Everest & Jennings.....05 | 145 EZ Light 146 Metro 147 Vision(Barracuda,Epic,FX,Nitro,Reactor,Record) 148 Lancer 2000 |

FORM II

VARIABLE NAME: Manufacturer and Model for Wheelchair or Scooter Used Most Often

CODES:

| <u>MANUAL CHAIRS</u> | <u>Manufacturer V254A</u> | <u>V254B.... Model</u> |
|----------------------|---------------------------------|---|
| (continued) | Tisport.....06 | 149 TiLite EVO 150 TiLite TC 151 TiLite TR C 152 TiLite TT 153 TiLite X 154 TiLite XC 155 TiLite X SX |
| <u>POWER CHAIRS</u> | <u>Manufacturer V254A</u> | <u>V254B.... Model</u> |
| | Invacare.....01 | 200 3G Storm Series Ranger X 201 3G Storm Series Torque SP 202 Action Arrow 203 Pronto M50 With Surestep 204 Pronto M51 With Surestep 205 Pronto M71 With Surestep 206 Pronto M91 With Surestep 207 Ranger (II or X or Storm) 208 Ranger II Fwd 250 Series 209 Ranger II MWD 210 Ranger II MWD 250 Series 211 Ranger II RWD 212 Ranger II RWD 250 Series 213 Storm Arrow 214 Storm Series 3G Arrow W/True Track 215 Storm Series Arrow FWD 216 Storm Series TDX3 217 Storm Series TDX4 218 Storm Series TDX5 219 Xterra GT |
| | Sunrise.....02 | 220 Guardian Aspire F10 221 Guardian Aspire F11 222 Guardian Aspire M10 223 Guardian Aspire M11 224 P (190 or 200) 225 P (300 or 320) 226 Quickie Freestyle F11 227 Quickie Freestyle M11 228 Quickie G-424 229 Quickie P200 230 Quickie P210 Power 231 Quickie P220 Power 232 Quickie P-222SE 233 Quickie S-646 234 Quickie S-646SE 235 Quickie V-100 236 Quickie V-121 237 Quickie V-521 238 Quickie Z-500 |

FORM II

VARIABLE NAME: Manufacturer and Model for Wheelchair or Scooter Used Most Often

CODES:

| <u>POWER CHAIRS</u> | <u>Manufacturer V254A</u> | <u>V254B.... Model</u> |
|---------------------|--------------------------------------|--|
| (continued) | Pride Health Care.....03 | 239 Jazzy PHC (1 or 5) 240 Jazzy PHC-10 241 Jazzy 11 (00-70) 242 Jazzy 1100 (Discontinued) 243 Jazzy 1101 244 Jazzy 1103 245 Jazzy 1103 Ultra 246 Jazzy 1104 (Discontinued) 247 Jazzy 1105 (Discontinued) 248 Jazzy 1113 249 Jazzy 1113 ATS 250 Jazzy 1115 (Discontinued) 251 Jazzy 1120 (Discontinued) 252 Jazzy 1120V (Discontinued) 253 Jazzy 1121 254 Jazzy 1122 255 Jazzy 1133 256 Jazzy 1143 257 Jazzy 1170 XL 258 Jazzy 14 (00-70) 259 Jazzy 1400 260 Jazzy 1420 261 Jazzy 1470 262 Jet 1 263 Jet 1-HD 264 Jet 2 265 Jet 3 Ultra 266 Jet 7 267 Jet 10 268 Jet 12 269 LX 10 270 LX 11 271 LX 12 272 Quantum 1650 273 Quantum Blast 650 274 Quantum Blast 850 275 Quantum Blast HD 276 Quantum Blast X-TREME 277 Vibe 278 Wrangler 4 Wheel PMV |
| | Permobil/04 | 279 Chairman Basic 280 Chairman 2K Corpus 281 Chairman 2K Lowrider 282 Chairman 2K MPSB 283 Chairman 2K Stander 284 Chairman Corpus 285 Chairman Entra Corpus 286 Chairman HD3 287 Chairman J 288 Chairman Stander 289 Chairman Trax Corpus 290 Chairman Trax TS 291 Entra MPSB |
| | Everest & Jennings.....05 | 292 Lancer |

FORM II

VARIABLE NAME: Manufacturer and Model for Wheelchair or Scooter Used Most Often

CODES:

| <u>POWER ASSIST</u> | <u>Manufacturer V254A</u> | <u>V254B.... Model</u> |
|---------------------|---------------------------------|--|
| <u>CHAIRS</u> | <u>Frank Mobility.....07</u> | 400 E.Motion 401 The Duet |
| | | |
| <u>SCOOTERS</u> | <u>Manufacturer V254A</u> | <u>V254B.... Model</u> |
| | <u>Invacare01</u> | 500 Buzz Highly Maneuverable Vehicle (HMV) 501 Lnyx |
| | <u>Pride Health Care 03</u> | 502 Celebrity Scooters 503 Flash 504 Go Go 3 Wheel Travel Vehicle 505 Hurricane 4 Wheel PMV 506 Laser 3 & 4 Wheel Scooters 507 Legend Scooters 508 Legend XL 4 Wheel Scooter 509 Luxury Scooter (Discontinued) 510 Maxima 3 & 4 Wheel Scooter 511 Rally 3 & 4 Wheel Scooter 512 Revo 3 Wheel Scooter 513 Sonic 3 Wheel Scooter 514 Sundancer 3 Wheel Scooter 515 Value Line Scooter (Discontinued) 516 Victory 3 & 4 Wheel Scooters 517 Victory XL-4 4 Wheel Scooters |
| | | |
| <u>OTHER CODES</u> | <u>Manufacturer V254A</u> | <u>V254B.... Model</u> |
| | Other, not listed above77 | 777 Other, not listed above |
| | Not applicable (V252=0) 88 | 888 Not applicable (V252=0) |
| | Unknown99 | 999 Unknown |

FORM II

VARIABLE NAME: Manufacturer and Model for Wheelchair or Scooter Used Most Often

COMMENTS: See page 304.

QC: See page 303.

If V254B = 100 to 155 then, V253 must = 1.

If V254B = 200 to 292 then, V253 = 2.

If V254B = 400 or 401 then, V253 = 3.

If V254B = 500 to 517 then, V253 = 4.

SOFTWARE: See page 303.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

July 2004: the list of Manufacturers and Models was expanded; the Models field (V254B) was changed from 2 to 3 characters.

EXAMPLE 1: The participant has a Pride Jet 1 wheelchair.

254.Wheelchair (or Scooter) Used Most Often 03 Manufacturer (V254A) 262 Model (V254B)

EXAMPLE 2: The participant has a new wheelchair manufactured by Everest & Jennings. The model number for this chair is not on the list.

254.Wheelchair (or Scooter) Used Most Often 77 Manufacturer (V254A) 777 Model (V254B)

EXAMPLE 3: The participant has a wheelchair manufactured by Sunrise. The model number is not known.

254.Wheelchair (or Scooter) Used Most Often 02 Manufacturer (V254A) 999 Model (V254B)

EXAMPLE 4: The participant has a scooter. The manufacturer and model are not on the list.

254.Wheelchair (or Scooter) Used Most Often 77 Manufacturer (V254A) 777 Model (V254B)

Blank Page

FORM II

VARIABLE NAME: Primary Funding Source for Wheelchair or Scooter Used Most Often

DESCRIPTION: This variable documents the primary funding source that paid for the wheelchair (or scooter) documented in variables 252 through 258. The following question is asked:

*What funding source **paid the most** for the wheelchair (or scooter) you use most often?*

CHARACTERS: 2

CODES:

- 01 Private Insurance
- 02 Department of Vocational Rehab (DVR)
- 03 Medicaid [including Medicaid administered by another sponsor (e.g. an HMO); see page 95]
- 04 Worker's Compensation
- 05 Medicare [including Medicare administered by another sponsor (e.g. an HMO); see page 95]
- 06 County medical
- 07 Self-pay
- 08 Veterans Administration
- 09 Public Health Service (e.g., Bureau of Indian Affairs)
- 10 Crippled Children's Service
- 11 No Pay (indigent, no resources)
- 12 Other insurance, unclassified: includes Champus
- 13 Other private funds (e.g., hometown fund raisers)
- 14 Prepaid health plans: includes HMOs, PPOs, Kaiser Foundation, etc.
- 15 Other, unclassified (e.g., SCI system patient care funds, Homebound, victim's assistance funds, etc.)
- 88 Not applicable (V252= 0)
- 99 Unknown or interview not done

COMMENTS: If the participant indicates that the chair he/she uses most often is on loan or donated, code this variable '15' (Other, unclassified) if you do not know from whom the chair is on loan/donated. However if the chair is on loan/donated from a known source, use code '13' (Other private funds).

QC: See page 303.

SOFTWARE: See page 303.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Features on the Wheelchair or Scooter Used Most Often

DESCRIPTION: This variable documents the features of the wheelchair (or scooter) documented in variables 252 through 258. The following question is asked:

Does the wheelchair (or scooter) you use most often have any of the following features?

CHARACTERS: 1 for each entry, up to 6 entries (V256_1 to V256_6)

CODES: 0 None of the listed features

1 Tilt-in-space

2 Recline

3 Standing

4 Seat elevation

5 Leg elevation

8 Not applicable (V252= 0)

9 Unknown or interview not done

COMMENTS: Go through the entire list all features during the interview. Code all features that apply. If the participant is unsure and the interview is being conducted over the phone, ask the participant if he/she is able to push buttons that make the seatback recline, the seat elevate, the seat and back both tilt at the same time, or the legs elevate.

QC: See page 303.

SOFTWARE: See page 303.

If V256_1 = 0 or 9, the user is advanced to V257.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Number of Repairs of the Wheelchair or Scooter Used Most Often

DESCRIPTION: This variable documents the number of times the wheelchair (or scooter) documented in variables 252 through 258 was repaired during the past 6 months. The following question is asked:

How many times in the past 6 months has the wheelchair (or scooter) you use most been repaired?

CHARACTERS: 2

CODES: 00 No repairs done
 01 to 86 1 to 86 times
 87 Repairs done, number unknown
 88 Not applicable (V252 = 0)
 99 Unknown or interview not done

COMMENTS: If repairs were needed but none were done, use code 00.

QC: See pages 303 and 312.

If V257 = 00 then, V258_1 must \leq 0.

If V257 = 99 then, V258_1 must = 9.

SOFTWARE: See page 303.

When code 99 is entered in V257 the software inserts 9 in V258_1 and the user is advanced to V259A.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Consequences of Breakdown of the Wheelchair or Scooter Used Most Often

DESCRIPTION: This variable documents the consequences of the breakdown(s) of the wheelchair (or scooter) documented in variables 252 through 257. The following is asked:

From the following list, select all that apply regarding breakdown (in the past 6 months) of the wheelchair (or scooter) you use most often.

CHARACTERS: 1 for each entry, up to 4 entries (V258_1 through V258_4)

CODES:

- 0 Repairs were done but none of the listed consequences occurred
- 1 I have been stranded (either at home or away from home) because of a wheelchair (or scooter) breakdown
- 2 I have been injured because of a wheelchair (or scooter) breakdown
- 3 I have missed work or school because of a wheelchair (or scooter) breakdown
- 4 I have missed medical appointments because of a wheelchair (or scooter) breakdown
- 8 Not applicable (V252 = 0 wheelchair/scooter not used more than 40 hours/week) or (V257 = 00 no repairs were done)
- 9 Unknown or interview not done

COMMENTS: “Stranded” means left with no means of mobility. The interviewer should ask about all 4 consequences during the interview.

QC: See pages 303 and 311.
 If V258 = 0, 1, 2, 3 or 4 then, V257 must not = 88 or 99.
 If V258_1 = 8 then, V252 must = 0 or V257 must = 00.

SOFTWARE: See pages 303 and 311.
 If V258_1 = 0 or 9, the user is advanced to V259A.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Additional Wheelchairs or Scooters

DESCRIPTION: This variable documents the number of additional wheelchair(s) or scooter(s) the participant currently uses. The following question is asked:

How many manual, power, power assisted or other wheelchairs (or scooters) do you use [(in addition to the wheelchair (scooter) you use most often]?

CHARACTERS: 2 for each variable
 V259A (manual); V259B (power); V259C (power assisted); V259D (other wheelchair); V259E (scooter)

CODES: 00 None
 01 to 87 01 to 87
 88 Not applicable (V252 = 0)
 99 Unknown or interview not done

COMMENTS: For each category (Manual, V259A; Power, V259B; Power assisted, V259C; Other V259D; and Scooter V259E), list the number of working devices the participant uses. This number should **not** include the primary wheelchair coded in variables 252 to 258.

If the participant has only one wheelchair (or only one scooter): V259A, V259B, V259C and V259D must all be coded 00.

If V252 is coded 0: V259A, V259B, V259C and V259D must all be coded 88.

If V252 is coded 9: V259A, V259B, V259C and V259D must all be coded 99.

Wheelchairs that are not manual, power or power assisted should be counted in “other wheelchair” category.

QC: See page 303.
 If V252 = 0 then, V259A, V259B, V259C and V259D must all = 88.
 If V252 = 9 then, V259A, V259B, V259C and V259D must all = 99.

SOFTWARE: See page 303.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

EXAMPLE: In addition to his primary wheelchair, the participant uses 1 manual and 1 power assisted chair. The participant does not use a scooter.

259. Number of Additional Wheelchairs or Scooters:
 A. Manual0 1
 B. Power0 0
 C. Power Assisted0 1
 D. Other Wheelchair0 0
 E. Scooter0 0

FORM II

VARIABLE NAME: Computer Use

DESCRIPTION: This variable documents whether or not the participant uses a computer (including laptops). The following question is asked:

Do you use a computer?

CHARACTERS: 1

CODES: 0 No
 1 Yes I use a computer at home only
 2 Yes I use a computer outside the home only
 3 Yes I use a computer at home and outside the home
 9 Unknown or interview not done

QC: If V260 = 0 then
 V261_1 = 88 and V261_2 through V261_10 = blank and
 V262 = 8 and
 V263_1 = 8 and V263_2 and V263_3 = blank and
 V264A, V264B, V264C, V264D, V264E = 8.

If V260 = 9 then
 V261_1 = 99 and V261_2 through V261_10 = blank and
 V262 = 9 and
 V263_1 = 9 and V263_2 and V263_3 = blank and
 V264A, V264B, V264C, V264D, V264E = 9.

SOFTWARE: When code 0 is entered in V260 the software inserts 8s in V261 through V264G and the user is advanced to V265.

When code 9 is entered in V260 the software inserts 9s in V261 through V264G and the user is advanced to V265.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Type of Computer Access Device(s)

DESCRIPTION: This variable documents the type of computer access device(s) available to the participant. The following question is asked:

Which of the following types of computer device(s) do you have that help you use a computer?

CHARACTERS: 2 for each entry, up to 10 entries (V261_1 through V261_10)

CODES:

- 00 No computer access devices
- 01 Voice activation (hardware and software) for commands
- 02 Voice recognition (hardware and software) for typing
- 03 Mouth stick
- 04 Head pointer
- 05 Foot pedals
- 06 Eye control
- 07 Typing brace/splint on hand
- 08 Modified or on-screen keyboard
- 09 Modified mouse
- 10 Other special software not included in codes 01 and 02 (e.g., screen readers)
- 11 Other
- 88 Not applicable, does not own (or use) a computer
- 99 Unknown or interview not done

COMMENTS: Go through the entire list all computer access devices during the interview. Code all that apply.

QC: See page 314.

SOFTWARE: See page 314.

If V261_1 = 00 or 99, the software advances to V262.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Internet or Email Usage

DESCRIPTION: This variable documents how often the participant uses the Internet or EMail. The following question is asked:

How often do you access the Internet or Email?

CHARACTERS: 1

CODES: 0 Owns (or uses) a computer but never uses the Internet and never uses EMail
 1 Daily (5 to 7 days every week of the month)
 2 Weekly (less than 5 days per week and more than 3 days per month)
 3 Monthly (3 days or less per month)
 8 Not applicable, does not own (or use) a computer
 9 Unknown or interview not done

QC: See page 314.

If V262 = 0 then, V263_1 must = 8 and V263_2 and V263_3 must = blank and V264A must = 8 and V264B must = 8 and V264C must = 8 and V264D must = 8 and V264E must = 8 and V264F must = 8 and V264G must = 8.

If V262 = 9 then, V263_1 must = 9 and V263_2 and V263_3 must = blank and V264A must = 9 and V264B must = 9 and V264C must = 9 and V264D must = 9 and V264E must = 9 and V264F must = 9 and V264G must = 9.

SOFTWARE: See page 314.

When code 0 is entered in V262 the software inserts 8 in V263_1 and 8s in V264A through V264G and the user is advanced to V265.

When code 9 is entered in V262 the software inserts 9 in V263_1 and 8s in V264A through V264G and the user is advanced to V265.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

- VARIABLE NAME:** Location for Internet or Email Use
- DESCRIPTION:** This variable documents up to 3 locations where the participant uses the Internet or EMail. The following question is asked:
Where do you use the Internet or EMail?
- CHARACTERS:** 1 for each entry, up to 3 entries (V263_1, V263_2, V263_3)
- CODES:**
- 1 Home
 - 2 Work/school
 - 3 Other Locations [e.g., library, café, wireless location (mobile location)]
 - 8 Not applicable, does not own (or use) a computer OR uses a computer but never uses the Internet AND never uses EMail
 - 9 Unknown or interview not done
- COMMENTS:** Code all the locations used.
- QC:** See page 314.
If V263_1 = 8 or 9, V263_2 and V263_3 must = blank.
- SOFTWARE:** See pages 314 and 316.
If V263_1 = 8 or 9, the software advances to V264A.
- REVISIONS:** This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Internet Categories

DESCRIPTION: This variable documents the frequency of Internet usage for specified Internet activities. The following question is asked:

How frequently you use each of the following categories on the Internet: Employment/vocation information, Disability/ Health information, EMail, Chat rooms, Games (on the Internet), Shopping, Other.

CHARACTERS: 1 for each variable:

Employment/vocation information (V264A); Disability/ Health information (V264B); EMail (V264C); Chat rooms (V264D); Games; (V264E); Shopping (V264F); Other (V264G).

CODES: 0 Never use this category

1 Sometimes

2 Frequently

8 Not applicable, does not own (or use) a computer OR

uses a computer but never uses the Internet AND never uses EMail

9 Unknown or interview not done

COMMENTS: Ask the participant about all the categories during the interview.

QC: See page 314.

SOFTWARE: See pages 314 and 316.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Internet Categories

EXAMPLE #1: The participant sends and receives EMail daily. Occasionally, he uses the Internet to play games and search for information on health issues. He sometimes shops on EBay. Once he uploaded his digital camera pictures up to the Sam’s Club photo web site. He never uses chat rooms.

| | |
|---|---|
| 264A. Employment/vocation information | 1 |
| 264B. Disability/health information | 1 |
| 264C. EMail | 2 |
| 264D. Chat rooms..... | 0 |
| 264E. Games | 1 |
| 264F. Shopping..... | 1 |
| 264G. Other | 1 |

EXAMPLE #2: The participant uses a computer but never uses the Internet or EMail.

| | |
|---|---|
| 264A. Employment/vocation information | 8 |
| 264B. Disability/health information | 8 |
| 264C. EMail | 8 |
| 264D. Chat rooms..... | 8 |
| 264E. Games | 8 |
| 264F. Shopping..... | 8 |
| 264G. Other | 8 |

EXAMPLE #3: The participant does not use or own a computer.

| | |
|---|---|
| 264A. Employment/vocation information | 8 |
| 264B. Disability/health information | 8 |
| 264C. EMail | 8 |
| 264D. Chat rooms..... | 8 |
| 264E. Games | 8 |
| 264F. Shopping..... | 8 |
| 264G. Other | 8 |

EXAMPLE #4: The participant uses EMail regularly but never uses the Internet. He sometimes plays games that are on his computer.

| | |
|---|---|
| 264A. Employment/vocation information | 0 |
| 264B. Disability/health information | 0 |
| 264C. EMail | 2 |
| 264D. Chat rooms..... | 0 |
| 264E. Games | 0 |
| 264F. Shopping..... | 0 |
| 264G. Other | 0 |

FORM II

VARIABLE NAME: Modified Vehicle

DESCRIPTION: This variable documents the type of modified vehicle the participant or his/her family owns. The following question is asked:

What type of modified vehicle does you or your family own?

CHARACTERS: 1

CODES: 0 Do not own a modified vehicle
 1 Car (includes SUVs)
 2 Van
 3 Other (e.g. truck)
 4 Combination (car and van; van and other; car and other)
 9 Unknown or interview not done

COMMENTS: “Family” refers to those who do or do not live with the participant.

Any type of lifts on the mode of transportation will qualify as a modified vehicle

QC: If V265 = 0 then, V266 must = 8.

If V265 = 9 then, V266 must = 9.

SOFTWARE: When code 0 is entered in V265 the software inserts 8 in V266 and advances to V267.

When code 9 is entered in V265 the software inserts 9 in V266 and advances to V267.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

March 2005: code 4 was added.

FORM II

VARIABLE NAME: Driving the Modified Vehicle

DESCRIPTION: This variable documents whether or not the participant drives the modified vehicle documented in variable 265. The following question is asked:

Do you drive the modified vehicle?

CHARACTERS: 1

CODES: 0 No

1 Yes, I drive it from my wheelchair

2 Yes, I do not drive it from a wheelchair

8 Not applicable, does not own a modified vehicle

9 Unknown or interview not done

QC: See page 320.

SOFTWARE: See page 320.

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.

FORM II

VARIABLE NAME: Other Technology: Cell Phone

DESCRIPTION: This variable documents whether or not the participant owns a cell phone. The following question is asked:

Do you own a cell phone?

CHARACTERS: 1

CODES: 0 No

1 Yes

9 Unknown or interview not done

REVISIONS: This variable was added in April 2004. Data are required in all interviews done after April 2004.