

INTERNATIONAL SPINAL CORD INJURY DATA SETS

ACTIVITIES AND PARTICIPATION BASIC DATA SET

Version 1.0; august 2012

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Acknowledgements

Coloplast A/S Denmark supported this project with an unconditional grant.

Dr. A. Catz gracefully granted permission to use items from the Spinal Cord Independence Measure.

Dr. G. Whiteneck gracefully granted permission to use items from the Craig Handicap Assessment & Reporting Technique.

We thank Annelie Leilufsrud, Apichana Kovindha and Eric Weerts for their comments.

Introduction

Survival after spinal cord injury (SCI) with a reasonable quality of life has become an expected outcome worldwide. As a result, there is an increasing need for data pertaining to living with an SCI. To facilitate comparisons regarding injuries, treatments, and outcomes between patients, centres and countries, ideally such data should be in the form of a common international data set.¹ An international project was started in 2002 to select elements to be included in International Spinal Cord Injury Data Sets. The structure of these data sets is depicted in figure 1.

There is a *core data set* (for personal and injury characteristics), *basic data sets* and *expanded data sets* on specific topics. Basic data sets consist of a minimum amount

of data that clinicians might want to collect on most or all of their SCI patients or clients. Although there is no limit on the number of items in a basic data set, it is important that it is as brief as possible in order to be used in clinical practice. Expanded data sets are primarily designed for research purposes and can be more comprehensive than basic data sets. Within a data set, a hierarchical structure is possible in which a gate question “opens” a series of more detailed questions if applicable for a particular SCI patient.

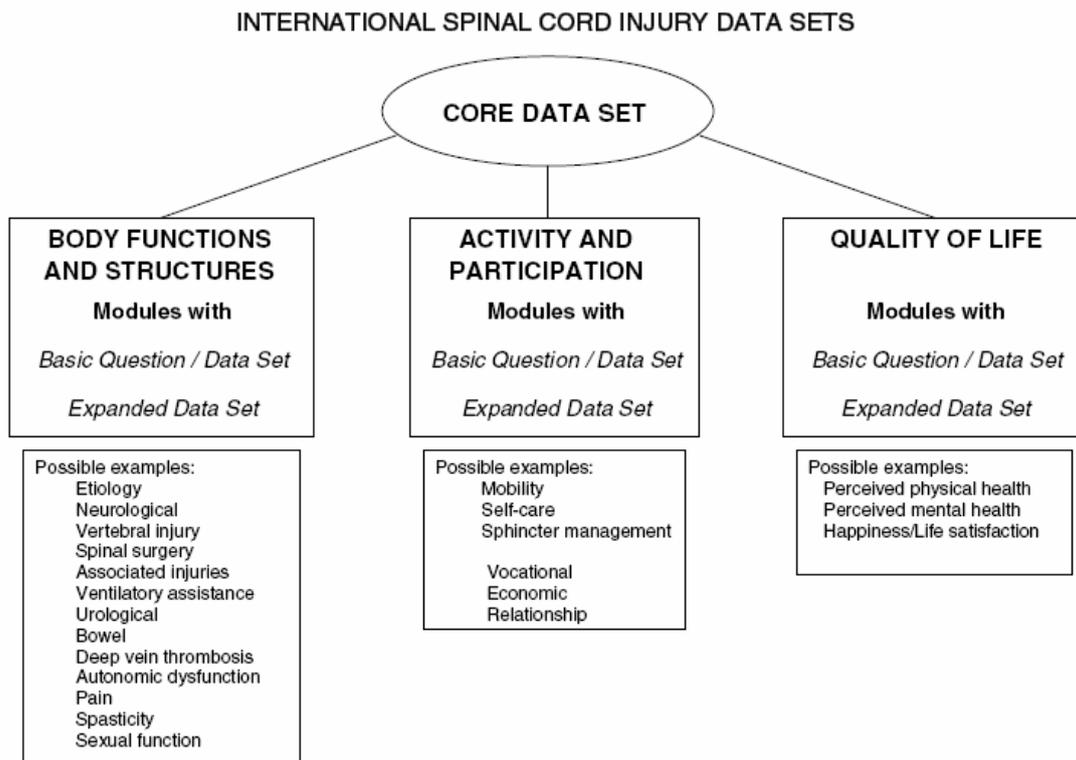


Figure 1: Structure of the International Spinal Cord Injury Data Sets.¹

In this document we describe the development of the basic Activities and Participation (A&P) data set. A working group of experts extensively discussed various issues connected with this undertaking. The most important considerations are briefly summarized here. The data form is enclosed as Appendix 1. In Appendix 2, the elements of this data set are described in detail, with their definitions, response categories and scoring guidelines.

Considerations in developing the A&P data set

Conceptualization of Activities (A) and Participation (P)

Whereas A appears a clear concept, referring to Activities of Daily Living (ADL), numerous definitions and operationalizations of P exist and consensus is not to be

expected.² In the ICF,³ *Activity limitations* are defined as difficulties an individual may have in the execution of a task or action, and *participation restrictions* are defined as problems an individual may experience in involvement in life situations.³ The components A and P are distinct conceptual entities in the well-known ICF model. However, the ICF classification contains a single list of A and P entries, with different options for coding categories to indicate the specific notions of “Activities” and “Participation”.^{3; 234ff} The findings of current research do not support a consistent differentiation of A and P in the sense of mutually exclusive categories.⁴ Research generated conflicting evidence for a supposed distinction between A and P domains.⁵⁻⁷ It has been argued that a distinction between A and P can best be made referring to the role of environmental factors.³ Others distinguish A from P referring to basic and extended ADL, or to task execution versus social integration,^{4,7} or refer to the interaction with other people to define participation.⁸ A recent review showed that recent P measures all included productivity, spare time activities and social relationships, but differed on the inclusion of other domains.⁹ Therefore, a pragmatic approach was taken in the development of the basic data set in how it covers the scope of A as well as P.

Coverage of the data set

As any data set, the A&P basic data set should be very brief in order to be used in clinical practice. It therefore should contain only the minimum number of items that all clinicians should record on persons with SCI seen in their daily clinical practice. The data set therefore is not comprehensive, but consist only of the items the working group considered the most important. The working group agreed upon inclusion of mobility, self-care, occupation and interpersonal relationships as core domains of A&P. Within the self-care domain, feeding, dressing and toileting were considered core activities. It was further decided to distinguish between work, household work and education, and to split work up into (a) paid work and (b) unpaid work (volunteering), and to split up interpersonal relationships into those with (a) spouse, (b) family, (c) friends.

Timing of collecting data on A&P

Data on self-care and mobility can be collected anytime from the start of initial rehabilitation to long-term follow-up. Data on occupation and relationships may not necessarily apply to the initial rehabilitation phase and are most relevant after discharge to the community. Community integration is a lengthy process that might take months or even years after discharge from the person’s initial inpatient rehabilitation to reach a relatively stable level of participation. Repeated collection of data is therefore recommended. It is also advised to use this data set to record the pre-injury situation to provide a “baseline” against which the status post SCI onset can be compared. After approval of this data set, a form to record the pre-injury situation will be developed that parallels the form in Appendix 1.

Use of existing measures for A& P

The most straightforward way to compose a data set for A, P or both, would be to adopt one of the many existing measures. On June 24, 2006, the National Institute on Disability and Rehabilitation Research (NIDRR) sponsored a pre-meeting course on SCI outcome measures at the American Spinal Injury Association and International Spinal Cord Society joint meeting held in Boston, Massachusetts.

Several work groups were formed prior to the pre-meeting course and given the task of reviewing the most commonly used measures for various SCI outcomes. The functional measures group performed a literature study and selected four measures: Modified Barthel Index (MBI), Quadriplegia Index of Function (QIF), Functional Independence Measure (FIM) and Spinal Cord Independence Measure (SCIM) as being of value. This review found both FIM and SCIM to be valid and reliable measures and supported use of the SCIM as a measure of global disability in persons with SCI.¹⁰ When the audience of the meeting was asked which measure best represented the SCI individual's functional status for clinical purposes, 94% voted for the SCIM (4% for FIM, 2% for MBI, 0% for QIF; N=52). The participation measures group performed a literature review and selected three measures: Craig Handicap Assessment and Reporting Technique (CHART), Assessment of Life Habits (Life-H) and Impact on Participation and Autonomy (IPA) for an extensive review. Two of these measures, CHART and Life-H, showed sufficient validity and reliability, but all three measures showed limitations. The authors described several newly developed measures, announced one of their own and concluded that ongoing efforts are necessary to develop and test participation measures.¹¹

In conclusion, a clear preference for the SCIM as Activities measure was found, but there is no preferred participation measure. The present working group discussed the usefulness of the SCIM to cover the domains of mobility and self-care, but it was decided that the SCIM is too comprehensive to be part of a Basic Data Set and the working group selected 4 representative items of the SCIM.¹² The working group further decided to adapt items from the CHART¹³ to measure the frequency of participation in the selected domains.

Rating of A and P

A and P can be described as performance or behaviours (outsider perspective) and from the point of view of perceived difficulty or satisfaction with performance (insider perspective). Distinguishing between both perspectives is important as low correlations between objective and subjective participation are often seen.¹⁴ Both perspectives need to be obtained in order to give complete information. Performance ratings provide insight in the actual functioning of persons with SCI in the rehabilitation setting or in the community. The experience of the person with SCI is necessary as functioning, especially social functioning, is judged differentially dependent on personal preferences or cultural norms. Recently developed participation measures therefore more and more include both perspectives.¹⁴⁻¹⁷ For ADL, the perceived satisfaction with, for example, dressing might indicate a need for additional help, assistive devices or specific settings. The working group did not reach consensus on the priority of objective versus subjective data, therefore both are included in this data set. Practical application and validation will show whether it is worthwhile to have both perspectives included.

Data on social status

The working group decided that data on, for example, domestic situation and level of education should not be incorporated in this data set. A variable on place of residence is already included in the Core Data Set.¹⁸ Level of education and similar "demographics" should be part of a standard record of socio-demographic variables

to be developed as they address issues within the Personal Factors component of the ICF framework, but do not constitute A and P domains.

Basic Activity and Participation Data Set

The Basic Activity and Participation Data Set thus consists of 8 items relating to chapters 4 (mobility) and 5 (self-care) of the ICF and 16 items relating to chapters 6 (domestic life), 7 (social interactions and relationships), 8 (major life areas) and 9 (community, social and civic life) of the ICF. The structure of the A&P data set is displayed in table 1. Appendix 1 contains the record form. Appendix 2 contains all items and definitions.

Table 1: items of the Activities and Participation Set

| Item | Performance | Experience |
|-----------------------|----------------------|--------------|
| Mobility | Task execution | Satisfaction |
| Dressing | Task execution | Satisfaction |
| Feeding | Task execution | Satisfaction |
| Toileting | Task execution | Satisfaction |
| Paid work | Hours a week | Satisfaction |
| Volunteer work | Hours a week | Satisfaction |
| Education | Hours a week | Satisfaction |
| Household work | Hours a week | Satisfaction |
| Spare time activities | Hours a week | Satisfaction |
| Spouse relationships | Type of relationship | Satisfaction |
| Family relationships | Contacts | Satisfaction |
| Friends relationships | Contacts | Satisfaction |

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APPENDIX 2

INTERNATIONAL SPINAL CORD INJURY DATA SETS

ACTIVITIES AND PARTICIPATION BASIC DATA SET - comments

VARIABLE NAME: Date of data collection

DESCRIPTION: This variable documents the date of data collection

CODES: YYYY/MM/DD

COMMENTS: The collection of data on Activities and Participation (A&P) may be carried out at any time during initial SCI rehab or after discharge to the community, whether private residence, congregate living or a nursing home or similar care facility. Community integration, however, is a lengthy process that might take months or even years after discharge from initial inpatient rehabilitation to reach a relatively stable level. The Date of data collection variable is necessary in order to identify when the data were collected. This variable provides a way to relate the collected data to other data collected on the same individual at various time points.

VARIABLE NAME: **Mobility moderate distances**

DESCRIPTION: This variable documents how the individual with SCI typically moves around for moderate distances in the last 4 weeks before data collection.

CODES:

| | |
|----|--|
| 0 | Requires total assistance |
| 1 | Needs electric wheelchair or partial assistance to operate manual wheelchair |
| 2 | Moves independently in manual wheelchair |
| 3 | Requires supervision while walking (with or without devices) |
| 4 | Walks with a walking frame or crutches (swing) |
| 5 | Walks with crutches or two canes (reciprocal walking) |
| 6 | Walks with one cane |
| 7 | Needs leg orthosis only |
| 8 | Walks without walking aids. |
| 99 | Unknown |

COMMENTS On even surface, for a moderate distance (10-100 metres). This is a SCIM item.

VARIABLE NAME: **Mobility satisfaction**

DESCRIPTION: This variable documents satisfaction with the current mode of locomotion

QUESTION: During the last 4 weeks, how satisfied were you with your current mode of getting around for moderate distances (10 to 100 meters) on an even surface?

CODES

| | |
|----|--------------------|
| 0 | Not satisfied |
| 1 | Somewhat satisfied |
| 2 | Very satisfied |
| 99 | Unknown |

COMMENTS None.

VARIABLE NAME: Dressing lower body

DESCRIPTION: This variable documents independence of the individual with SCI in dressing the lower body (clothes, shoes, permanent orthoses: dressing, undressing) in the last 4 weeks before data collection

CODES

- 0 Requires total assistance
- 1 Requires partial assistance with clothes without buttons, zippers or laces (cwobzl)
- 2 Independent with cwobzl; requires adaptive devices and/or specific settings (adss)
- 3 Independent with cwobzl; does not require adss; needs assistance or adss only for buttons, zipps or laces
- 4 Dresses (any clothes) independently; does not require adss.
- 99 Unknown

COMMENTS cwobzl: clothes without buttons, zipps or laces.
adss: adaptive devices or specific settings
This is a SCIM item.

VARIABLE NAME: Lower body dressing satisfaction

DESCRIPTION: This variable documents satisfaction with dressing

QUESTION: During the last 4 weeks, how satisfied were you with your current mode of dressing or undressing your lower body?
Dressing includes putting on/of clothes, shoes and permanent orthoses

CODES

- 0 Not satisfied
- 1 Somewhat satisfied
- 2 Very satisfied
- 99 Unknown

COMMENTS None.

VARIABLE NAME: Feeding

DESCRIPTION: This variable documents independence of the individual with SCI in feeding (cutting, opening containers, pouring, bringing food to mouth, holding cup with fluid) in the 4 weeks before data collection.

CODES

| | |
|----|--|
| 0 | Needs parenteral, gastrostomy or fully assisted oral feeding |
| 1 | Needs partial assistance with eating and/or drinking or for putting on/of adaptive device(s) needed for eating and/or drinking |
| 2 | Eats independently; needs adaptive devices or assistance only for cutting food and/or pouring and/or opening containers |
| 3 | Eats and drinks independently; does not require assistance or adaptive devices. |
| 99 | Unknown |

COMMENTS This is a SCIM item.

VARIABLE NAME: Feeding satisfaction

DESCRIPTION: This variable documents satisfaction with feeding

QUESTION: During the last 4 weeks, how satisfied were you with your current mode of eating? Eating includes cutting your food, opening containers, pouring beverages into a cup or glass, bringing food to your mouth, and holding a cup with a beverage.

CODES

| | |
|----|--------------------|
| 0 | Not satisfied |
| 1 | Somewhat satisfied |
| 2 | Very satisfied |
| 99 | Unknown |

COMMENTS None.

VARIABLE NAME: Toileting

DESCRIPTION: This variable documents independence of the individual with SCI in toileting (on toilet or in bed, personal hygiene, adjustment of clothes, use of napkins or diapers) in the 4 weeks before data collection

CODES

| | |
|----|---|
| 0 | Requires total assistance |
| 1 | Requires partial assistance, does not clean self |
| 2 | Requires partial assistance, cleans self independently |
| 3 | Independent in all tasks, but needs adaptive equipment or special setting (eg bars) |
| 4 | Independent, does not need adaptive equipment or special setting |
| 99 | Unknown |

COMMENTS This is a SCIM item.

VARIABLE NAME: Toileting satisfaction

DESCRIPTION: This variable documents satisfaction with toileting

QUESTION: During the last 4 weeks, how satisfied were you with your current mode of toileting? Toileting includes bowel and bladder management, whether you do this on a toilet or in bed. It involves seeing to your personal hygiene, adjustment of clothes, and the use of napkins or diapers.

CODES

| | |
|----|--------------------|
| 0 | Not satisfied |
| 1 | Somewhat satisfied |
| 2 | Very satisfied |
| 99 | Unknown |

COMMENTS None.

VARIABLE NAME: **Paid work**

DESCRIPTION: This variable documents actual participation in paid work

QUESTION: During the last 4 weeks, how many **hours per week** did you spend working in a job for which you get paid?

CODES _____ hours
99 unknown

COMMENTS This question is adapted from the CHART.
Self-employment of any type should be included here.
Participation in family livelihood (e.g. a farm or small shop) should be included here.
If a person does not have a job or self-employment, enter 0 hours
If a person works without getting paid otherwise, consider this voluntary work and report it under "volunteer work", not here.
Do not duplicate activities in different items.

VARIABLE NAME: **Paid work satisfaction**

DESCRIPTION: This variable documents satisfaction with paid work

QUESTION: If doing paid work: During the last 4 weeks, how satisfied were you with doing your paid work?

If not doing paid work: During the last 4 weeks, how satisfied were you with not having paid work?

CODES 0 Not satisfied
 1 Somewhat satisfied
 2 Very satisfied
 8 Not applicable
 99 Unknown

COMMENTS The "Not applicable" category applies to children, persons in full-time education and persons of pension (retirement) age.

VARIABLE NAME: **Volunteer work**

DESCRIPTION: This variable documents actual participation in volunteer work

QUESTION: During the last 4 weeks, how many **hours per week** did you spent in ongoing volunteer work for an organization? Consider all organized volunteer work; for example, that which is associated with churches or clubs. Work in a family business should not be considered here.

CODES _____ hours
 99 unknown

COMMENTS This question is adapted from the CHART.
 Do not duplicate activities in different items.
 If a person does not do volunteer work, enter 0 hours

VARIABLE NAME: **Volunteer work satisfaction**

DESCRIPTION: This variable documents satisfaction with volunteer work

QUESTION: If doing volunteer work: During the last 4 weeks, how satisfied were you with doing your volunteer work?
 If not doing volunteer work: During the last 4 weeks, how satisfied were you with not doing volunteer work?

CODES 0 Not satisfied
 1 Somewhat satisfied
 2 Very satisfied
 8 Not applicable
 99 Unknown

COMMENTS The “Non applicable” category will rarely be applicable; for example, it might apply only in young children.

VARIABLE NAME: **Education**

DESCRIPTION: This variable documents actual participation in education

QUESTION: During the last 4 weeks, how many **hours per week** did you spent in school working toward a diploma or degree or in a technical training program (including hours in class and studying)?

CODES _____hours
99 unknown

COMMENTS This question is adapted from the CHART.
If a person is not in school, enter 0 hours
Forms of education may include, for example, studying at home or in a library, home schooling, internships, and vocational re-integration training programs. Excluded are occasional courses or courses not part of primary, secondary or tertiary education, or not aimed at getting or maintaining paid work like, for example, taking an Italian language course for one's own pleasure.

VARIABLE NAME: **Education satisfaction**

DESCRIPTION: This variable documents satisfaction with attending school or other forms of education

QUESTION: If doing school or other educational activities: During the last 4 weeks, how satisfied were you with performing your school or other educational activities?
If not doing school or other educational activities: During the last 4 weeks, how satisfied were you with not performing school or other educational activities?
Other forms of education may include, for example, studying at home or in a library, home schooling, internships, and vocational re-integration training programs. Excluded are occasional courses or courses not part of primary, secondary or tertiary education, or not aimed at getting or maintaining paid work like, for example, taking an Italian language course for one's own pleasure.

CODES 0 Not satisfied
1 Somewhat satisfied
2 Very satisfied
8 Not applicable
99 Unknown

COMMENTS The "Non applicable" category applies to very young children, and to persons who finished their formal education and who have no desire for additional formal education.

VARIABLE NAME: **Household work**

DESCRIPTION: This variable documents actual participation in household activities

QUESTION: During the last 4 weeks, how many **hours per week** did you spend in active homemaking, including parenting, housekeeping and food preparation?

CODES _____hours
99 unknown

COMMENTS This question is adapted from the CHART. This question considers active household activities. Being at home with the children at night with everyone asleep is not considered “active” parenting. Helping children with homework, playing or supervising play, however, are active. 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 a short time 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. Do not duplicate activities in different items.

VARIABLE NAME: **Household work satisfaction**

DESCRIPTION: This variable documents satisfaction with household work

QUESTION: If doing household work: During the last 4 weeks, how satisfied were you with doing household activities?
If not doing household work: During the last 4 weeks, how satisfied were you with doing household activities?
This includes raising children (parenting), housekeeping and food preparation, and both doing these things yourself and supervising/ managing others who do the actual work..

CODES 0 Not satisfied
1 Somewhat satisfied
2 Very satisfied
8 Not applicable
99 Unknown

COMMENTS The “Non applicable” category will rarely be applicable, for example in young children. Persons living in a nursing home might still prefer doing certain household activities by themselves.

VARIABLE NAME: **Spare time activities**

DESCRIPTION: This variable documents actual participation in spare time activities

QUESTION: During the last 4 weeks, how many **hours per week** did you spend in spare time activities such as sports, exercise, playing cards, going to movies, or religious activities? Please do not include time spent watching TV or listening to the radio.

CODES _____hours
99 unknown

COMMENTS This question is adapted from the CHART.
Do not duplicate activities in different items.

VARIABLE NAME: **Satisfaction with spare time activities**

DESCRIPTION: This variable documents satisfaction with spare time activities

QUESTION: If doing spare time activities: During the last 4 weeks, how satisfied were you with doing these activities?
If not doing spare time activities: During the last 4 weeks, how satisfied were you with not doing spare time activities?

QUESTION: During the last 4 weeks, how satisfied were you with doing, or not doing, your spare time activities?
This includes play, sports, cultural events, hobbies, socializing, religious activities, etc.

CODES 0 Not satisfied
 1 Somewhat satisfied
 2 Very satisfied
 8 Not applicable
 99 Unknown

COMMENTS The "Non applicable" category will rarely be applicable.

VARIABLE NAME: **Spousal relationship**

DESCRIPTION: This variable documents having a spouse or being involved in a romantic relationship

QUESTION: Do you have a spouse or partner or are you involved in a romantic relationship?

| | | |
|-------|----|--|
| CODES | 0 | No |
| | 1 | Married or living together with spouse/partner |
| | 2 | Romantic relationship, not living together |
| | 8 | Not applicable |
| | 99 | Unknown |

COMMENTS This question is compiled from different CHART items. The "Non applicable" category will rarely be applicable, for example in young children.

VARIABLE NAME: **Spousal relationship satisfaction**

DESCRIPTION: This variable documents satisfaction with the spousal/romantic/partnership relationship

QUESTION: If having a spouse or partner: During the last 4 weeks, how satisfied were you with your relationship with your spouse or partner?
If not having a spouse or partner: During the last 4 weeks, how satisfied were you with not having a spouse or partner?

| | | |
|-------|----|--------------------|
| CODES | 0 | Not satisfied |
| | 1 | Somewhat satisfied |
| | 2 | Very satisfied |
| | 8 | Not applicable |
| | 99 | Unknown |

COMMENTS The "Non applicable" category will rarely be applicable, for example in young children.

VARIABLE NAME: **Family relationships**

DESCRIPTION: This variable documents participation in family relationships

QUESTION: During the last 4 weeks, how many relatives (not living in your household) did you visit, phone, e-mail or write at least once?

CODES _____ family members
99 unknown

COMMENTS This question is adapted from the CHART.
Include contacts through the internet (Skype, MSN, Myspace, Facebook, and other).
Count the number of different persons, not contacts.

VARIABLE NAME: **Family relationships satisfaction**

DESCRIPTION: This variable documents satisfaction with family relationships

QUESTION: If having family (in addition to a spouse or partner): During the last 4 weeks, how satisfied were you with your relationships with your family members other than your spouse or partner?
If not having family: During the last 4 weeks, how satisfied were you with not having relationships with your family members other than your spouse or partner?

CODES 0 Not satisfied
 1 Somewhat satisfied
 2 Very satisfied
 8 Not applicable
 99 Unknown

COMMENTS None.

VARIABLE NAME: **Friends relationships**

DESCRIPTION: This variable documents participation in relationships with friends (non-relatives, contacted outside business or organizational settings)

QUESTION: During the last 4 weeks, how many friends (non-relatives, contacted outside business or organizational settings) did you visit, phone, e-mail or write at least once?

CODES _____ friends
 99 unknown

COMMENTS This question is adapted from the CHART.
 Include contacts through the internet (Skype, MSN, Myspace, Facebook, and other).
 Count the number of different persons, not contacts.

VARIABLE NAME: **Friends relationships satisfaction**

DESCRIPTION: This variable documents difficulty satisfaction with relationships with friends

QUESTION: If having contacts with friends: During the last 4 weeks, how satisfied were you with you relationships with your friends?
 If not having contacts with friends: During the last 4 weeks, how satisfied were you with not having any relationships with friends?
 Consider all non-relatives, contacted outside business or organizational settings.

CODES 0 Not satisfied
 1 Somewhat satisfied
 2 Very satisfied
 8 Not applicable
 99 Unknown

COMMENTS None.