

**The South Carolina Traumatic Brain Injury Follow-up Registry**  
Quick Reference—Domains, Sources, and Purposes for Variables in the Follow-up Questionnaire, Version 1.0

Section	Question Number	Source	Purpose
Introduction—Interviewer In-house Information/ Proxy Screen/Subject Demographics/ Confirmation of Injury/Family Changes	INI-01 - INI-14; INT-01; PRX-01 - 03; PRX-05 - 06; PRX-08; PRX-10-PRX-19; PAI-01 - 03; PAI-05-08; PAI-10-18s  PRX-04  PAI-09	Non-standard  Behavioral Risk Factor Surveillance System (BRFSS)—Remington PL, Smith MY, Williamson DF, Anda RF, et al. Design, characteristics, and usefulness of state-based behavioral risk factor surveillance: 1981-1987. Public Health Reports. 1988;103:366-375.  Rehabilitation Services Administration Community Re-Integration Questionnaire—High WM Jr, Gordon WA, Lehmkuhl LD, Newton DN, Vandergoot D, Thoi L, et al. Productivity and service utilization following traumatic brain injury: results of a survey by the RSA regional TBI centers. J Head Trauma Rehabil 1995;10:64-80.	To confirm baseline and follow-up information, to determine if participants are capable of self report, to obtain demographical data on proxies.
Pre-Existing Health Conditions/Concomitant Conditions	MCC-01 - MCC-02; PEC-01 - PEC-02, PEC-04  PEC-03, PEC-05-PEC-06	Non- standard  National Health and Nutrition Examination Survey—McDowell AJ. The Health and Nutrition Examination Survey. HSMHA Health Reports. 1971;86:592-595.	To determine history of pre-injury and concomitant health conditions, including brain injuries and common medical conditions.
Life Satisfaction	LIS-01 - LIS -05	Satisfaction With Life Scale—Diener E. Subjective well-being. Psychol Bull. 1984;95:542-575.	To determine how participants feel about their lives.
General Health Status	GEH-01 - GEH-36	Short Form-36—Ware JE, Sherbourne CD. The MOS 36-Item Short-Form Health Survey (SF-36): I. Conceptual framework and item selection. Med Care. 1992;30:473-483.	To document current overall general health, including general mental health and functional status. To be able to compare with population norms and results of studies from other disabling conditions.

Substance Use	DRA-01 - DRA-04 DRA-05 DRA-06 DRA-07	Behavioral Risk Factor Surveillance System  Non-standard  National Household Survey on Drug Abuse(NHSDA)— Gfroerer J, Brodsky M. The incidence of illicit drug use in the United States, 1962-1989. <i>British J Addiction.</i> 1992;87:1345-1351.  Adapted NHSDA	To determine current and pre-injury alcohol consumption and drug use.
Service Utilization and/or Needs	SDN-01 - SDN-12  SDN-13 - SDN-14	Non-standard, Lower Extremity Assessment Project (LEAP) format— MacKenzie EJ, Burgess AR, McAndrew MP, Swiontkowski MF, et al. Patient-oriented functional outcome after unilateral lower extremity fracture. <i>J Orthopaedic Trauma.</i> 1993;7:393-401.  Non-standard	To determine whether participants have received specific services after injury; whether they feel they need each service; and if they need it, why haven't they received it.
Post-Injury Complaints	PIS-01, PIS-03 - 05, PIS-08  PIS-03e  PIS-06  PIS-07  PIS-02, PIS-09 - PIS-11, PIS-13  PIS-12	Adapted Trauma Complaints List— van Zomeren AH, van den Burg W. Residual complaints of patients two years after severe head injury. <i>J Neuro, Neurosurg, and Psychia.</i> 1985;48:21-28.  Adapted Epilepsy Surgery Inventory— Vickrey BG et al. A health-related quality of life instrument for patients evaluated for epilepsy surgery. <i>Med Care,</i> 1992; 30:299-319  Adapted from Established Populations for Epidemiologic Studies of the Elderly (EPESE)— Foley DJ; Monjan AA; Brown SL; Simonsick EM; Wallace RB; Blazer DG. Sleep complaints among elderly persons: an epidemiologic study of three communities. <i>Sleep</i> 1995 Jul;18(6):425-32.  Modified Hopkins Symptom Checklist— Derogatis LR, Lipman RS, Rickels K, Uhlenhuth EH, Covi L. The Hopkins Symptom Checklist (HSLC): a self-report symptom inventory. <i>Behavioral Science.</i> 1974;19(1):1-15.  Non-standard  Non-standard, Lower Extremity Assessment Project (LEAP) format— MacKenzie EJ, Burgess AR, McAndrew MP, Swiontkowski MF, et al. Patient-oriented functional outcome after unilateral lower extremity fracture. <i>J Orthopaedic Trauma.</i> 1993;7:393-401.	To determine whether participants are experiencing symptoms that are common after a brain injury and whether they impact on their current abilities.



Instrumental Activities of Daily Living	IAD-01 - IAD-03b  IAD-04	Adapted from the National Health Interview Survey  Non-standard	To determine if participants have difficulty or need help and/or supervision during selected instrumental activities of daily living.
Marital Status	MAS-01 MAS-02	Behavioral Risk Factor Surveillance System Adapted BRFSS	To determine if participants are married, including changes since injury.
Living Situation	LIV-01 - LIV-04	Non-standard	To determine where participants live and with whom, including changes since their injuries.
Social Integration	SOI-01, SOI-02  SOS-04	Adapted Harris Poll (Disabled Americans) 1994— Louis Harris and Associates, Inc. 630 Fifth Ave New York, New York 10111  Community Integration Questionnaire— Willer B, Ottenbacher KJ, Coad ML. The community integration questionnaire: a comparative examination. Am J Phys Med Rehabil. 1994;73:103-111.	To determine whether participants engage in social or social activities.  Social integration
Social Support/Practical Assistance	SOS-01 - SOS-03	Adapted from Inventory of Socially Supportive Behaviors— Barrera MJ, Ainlay SL. The structure of social support: a conceptual and empirical analysis. Am J Community Psychol. 1983;11:133-143.	To determine if participants have practical assistance from others.
Violence and Neglect	VIO-01, VIO-03  VIO-02, VIO-04	Adapted from Feldhaus KM, Koziol-McLain J, Amsbury HL, et al. Accuracy of 3 Brief Screening Questions for Detecting Partner Violence in the Emergency Department. JAMA. 1997; 277:1357-1361.  Non-standard	To screen for potential violence, neglect, and sexual abuse.
Transportation	TRN-01 - TRN-02a	Non-standard	To determine driving status, transportation needs, and changes since injury.

Insurance	INS-01, INS-01a, INS-02a - INS-02e INS-01b INS-03	Adapted from Lower Extremity Assessment Project—MacKenzie EJ et al. Non-standard Adapted from Kaiser/Commonwealth Fund Health Insurance Survey II, 1993.— Davis K, Rowland D, Altman D, Collins KS, Morris C. Health insurance: the size and shape of the problem. Inquiry. 1995;32(2):196-203.	To document whether participants' health insurance status changed since injury.
Education	EDU-01 EDU-02 - EDU-03	Behavioral Risk Factor Surveillance System (BRFSS) Non-standard	To document participants' educational history.
Income	INC-01, INC-02, INC-03 INC-01a, INC-03a, INC-04	Wording adapted from LEAP. Non-standard	To determine participants' personal annual income, including changes since injury.
Spirituality	SPR-01	The SIBS-R is unpublished and was used, with permission, from the author, R. Hatch.	To determine how spiritual participants feels they are.
Contact Information	CON-01 - CON-13	Non-standard	To confirm address and contact information for correspondence and follow-up.