

Approved Data Requests

Last update: November 14, 2017

Table of Contents

Projects proposed by investigators within SCIMS or Form II Data Collection Centers 2

 2017 2

 2016 3

 2015 3

 2014 4

 2013 5

 2012 5

 2011 6

 2010 7

 2007 7

Projects conducted at the National Spinal Cord Injury Statistical Center before 2014 8

Projects proposed by non-SCIMS investigators..... 9

DeVivo Mentored Research Award projects 11

Courtesy notice of SCIMS Database Research -- Site or Module data only 12



The contents of this publication were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0083). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this publication do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

Archives of Physical Medicine and Rehabilitation special issues published in November 1999, November 2004, March 2011, and October 2016 also feature the approved SCIMS Database Research projects over the years.

Projects proposed by investigators within SCIMS or Form II Data Collection Centers

This list does not include projects solely proposed for the SCIMS research special issues published by the Archives of Physical Medicine and Rehabilitation in 2011 and 2016.

2017

Month	Lead investigators	Collaborators	Project title
Aug	Katharine Tam, MD, (ktam02@sralab.org), Deutsch, Chen; RIC	Botticello (Kessler), Kolakowsky-Hayner (Sinai), Schwab (OSU)	Functional outcomes of older adults with a new spinal cord injury
Aug	Steven Kirshblum, MD (skirshblum@selectmedical.com), Kline-Quiroz, Donovan, Botticello; Kessler Foundation	Heinemann (RIC), Taylor (TIRR), Kolakowsky-Hayner (Sinai), Houlihan (Spaulding)	Factors associated with return to education after spinal cord injury
Apr	Huacong Wen, MS, (hcwen@uab.edu), Chen (mentor); NSCISC	Botticello (Kessler), Heinemann (RIC), Boninger (Pitt), Houlihan (BU/Spaulding)	Race, neighborhood, and obesity after spinal cord injury
Mar	Steven Kirshblum, MD (skirshblum@selectmedical.com), Waggeman, Botticello; Kessler Foundation	Zafonte (Spaulding), Marino (Thomas Jefferson)	The impact of sensory sacral sparing in motor complete SCI
Mar	Ryan McGrath, PhD (mcgratry@med.umich.edu), Hall, Peterson, Kalpakjian; University of Michigan	Heinemann (RIC), DeVivo (UAB)	The effect of etiology of injury on the incidence of mortality in persons with a spinal cord injury
Mar	O Trent Hall, DO (ohall@med.umich.edu), McGrath, Chadd, Peterson, Kalpakjian; University of Michigan	Heinemann (RIC), Taylor (TIRR), DeVivo (UAB)	The burden of spinal cord injury in the United States: Disability-adjusted life years
Jan	Christopher Elliott, MD, PhD (christopher.elliott@hhs.sccgov.org), Shem; Santa Clara Valley Medical Center	Stampas (TIRR), Schwab (OSU)	Return of Volitional Voiding After Spinal Cord Injury

2016

Month	Lead investigators	Collaborators	Project title
Dec	Ryan McGrath, PhD (mcgratry@med.umich.edu), Hall, Forchheimer, Peterson, Kalpakjian; University of Michigan	Heinemann (RIC), Bogner (OSU)	The independent and joint effects of smoking and heavy drinking on diabetes in persons with a spinal cord injury
Sep	Stephen Burns, MD (Stephen.Burns@va.gov), Kou, Radkevich; University of Washington	Heinemann (RIC), Krause (Shepherd), Boninger (Pitt)	United States Veterans in the Spinal Cord Injury Model Systems (SCIMS) Database
Aug	Ralph Marino, MD (Ralph.Marino@jefferson.edu), Harrop, Leiby; Thomas Jefferson University	Chen (RIC), Kirshblum (Kessler), Donovan (Spaulding), Cardenas (Miami)	Trends in ASIA Impairment Scale conversion in spinal cord injury
Jun	Huacong Wen, MS, (hcwen@uab.edu), Bickel (mentor), Chen, He; NSCISC	Heinemann (RIC), Robinson-Whelen (TIRR)	Racial differences in weight gain after spinal cord injury

2015

Month	Lead investigators	Collaborators	Project title
Nov	Kelli W. Gary, PhD, MPH, OTR/L (williamsjonk@vcu.edu), Graham, McDonald; VCU/ Hunter Holmes McGuire VA Center. Hudson, Krause; Shepard Center	Heinemann (RIC), Burns (UW), Tate (UM), Felix (Miami), Cooper (Pitt)	Employment, Health, and Quality of Life Outcomes after Spinal Cord Injury: Comparison of Veterans and Non-Veterans
Sep	Mary Jo Roach, PhD (mroach@metrohealth.org), Kelly, Nemunaitis; MetroHealth, Cleveland. Chen; NSCISC	Bombardier (UW)	Long-term outcomes in patients with penetrating spine trauma: a multi-center longitudinal observational study
Jan	Christopher Elliott, MD, PhD (christopher.elliott@hhs.sccgov.org), Shem; Santa Clara Valley Medical Center		Why Do Patients with Spinal Cord Injury Stop Performing Intermittent Catheterization? – A Risk Factor Analysis
Jan	Christopher Elliott, MD, PhD (christopher.elliott@hhs.sccgov.org), Shem; Santa Clara Valley Medical Center		What Improvements in Upper Extremity Function Should Spinal Cord Injury Patients Expect as it Relates to Performing Intermittent Catheterization?
Jan	Dagmar Amtmann, PhD	Heinemann (RIC),	The Satisfaction with Life Scale

	(dagmara@uw.edu), Bombardier, Hoffman, Johnson, McMullen; UW Burn Model system National Data and Statistical Center, UW SCIMS, and UQ TBIMS	Cardenas (Miami), Richards (UAB)	using Burn Model System, Spinal Cord Injury Model System, and Traumatic Brain Injury Model System Data
--	--	-------------------------------------	---

2014

Month	Lead investigators	Collaborators	Project title
Nov	James Krause, PhD (krause@musc.edu), Saunders & Cao; Medical University of South Carolina/Shepherd Center	Cardenas (Miami), Richards (UAB), Bombardier (UW), Heinemann (RIC), Tate (UM), Botticello (Kessler)	Prevalence of smoking and alcohol use after spinal cord injury: Relationship with secondary health conditions
Oct	Michael Wandling, MD (mwandling@gmail.com), Chen, Deutsch, Heinemann & Shapiro; Northwestern University Feinberg School of Medicine	Hoffman (UW)	The Effect of Payer on Acute Inpatient Rehabilitation Length of Stay and Functional Status in Patients with Spinal Cord Injuries: Do Payer-Based Outcome Disparities Exist?
Mar	James Krause, PhD (krause@musc.edu), Saunders & Cao; Medical University of South Carolina/Shepherd Center	DeVivo (UAB); Heinemann (RIC)	Risk and protective factors for cause-specific mortality after spinal cord injury
Mar	David Apple, MD & John Kramer, PhD (John_Kramer@Shepherd.org); Shepherd Center	Borisoff & Cragg (University of British Columbia); Chen (UAB); Hoffman (UW)	Relationship between secondary complications following spinal cord injury: a longitudinal analysis
Feb	Jayne Donovan, MD (jdonovan13@partners.org), Vora, Morse & Zafonte ; Spaulding Rehabilitation Hospital	Dijkers (Mt Sinai); Krause (Shepherd)	Life Satisfaction and Self-Perceived Health as Predictors of Mortality and other Adverse Events in Individuals with Spinal Cord Injury
Feb	Christopher Elliott, MD, PhD (christopher.elliott@hhs.sccgov.org), Shem, Kolakowsky- Hayner & Wright; Santa Clara Valley Medical Center	Tate (UM)	Epidemiology of Bladder Management in Patient with Spinal Cord Injury
Feb	Timothy Belliveau, PhD, ABPP		Development of a clinical decision

	(tbelliveau@hfsc.org), Alan Jette, PhD, PT (ajette@bu.edu), Seetharama, Breitburg, Axt, Rosenblum, Houlihan, Slavin & Zazula; New England Regional Spinal Cord Injury Center		support tool for optimal prognostication of functional recovery after spinal cord injury
Jan	Shu Cole, PhD (colest@indiana.edu) & Whiteneck; Craig Hospital	Houlihan (BUMC)	The importance of travel to life satisfaction of people with SCI

2013

Month	Lead investigators	Collaborators	Project title
June	Felipe Fregni, MD PhD MPH (felipe.fregni@ppcr.hms.harvard.edu) & Morse; Spaulding Rehabilitation Hospital	Tate (UM)	A longitudinal analysis of the association of total score from functional independence measure and pain scores in individuals with spinal cord injury
May	Chuck Bombardier, PhD (chb@u.washington.edu); University of Washington	Heinemann (RIC), Tate (UM)	Validity of the TBI self-report questions (site data only); Incidence and correlates of probable TBI; Relationship between comorbid TBI and outcomes at one year post injury
Feb	Elham Mahmoudi, PhD (elham.mahmoudi@gmail.com), Meade, Tate & Forchheimer; University of Michigan	Fyffe (Kessler) & Krause (Shepherd)	Racial/Ethnic Disparity in Re-hospitalization among Individuals with Spinal Cord Injury

2012

Month	Lead investigators	Collaborators	Project title
Nov	Shilpa Krishnan, MS (shk59@pitt.edu), Boninger, Brienza, Karg & Oyster; University of Pittsburgh	Heinemann (RIC)	Association of presence of pneumonia and incidence of pressure ulcers in individuals with spinal cord injury
Sep	Josie M Tyrer, BA (jtyrer@uab.edu), Richards, Richardson, Vance & Galindo; University of Alabama at Birmingham	Aisen (Rancho), Taylor (TIRR), Cardenas (Miami), Bombardier (UW), Tate (UM)	The effect of trauma etiology and depressive symptoms on pain severity following spinal cord injury
June	Ralph Marino, MD	Kirschblum (Kessler)	Neurological recovery after

	(ralph.marino@jefferson.edu) & Lee; Thomas Jefferson		traumatic thoracic spinal cord injury
May	Juleen Rodakowski, OTD, OTR/L (jur17@pitt.edu), Boninger, Skidmore, Anderson & Buhule; University of Pittsburgh	Charlifue (Craig) & Jensen (UW)	The additive effect of age on disability for adults aging with a spinal cord injury
Apr	Chuck Bombardier, PhD (chb@u.washington.edu), Cook, Bamer & Kim; University of Washington	Taylor (TIRR) & Dyson_Hudson (Kessler)	Evaluating differential item function of the PHQ-9 depression scale items between early and late injury persons with SCI
Apr	Narineh Hartoonian (narhart@uw.edu), Bombardier & Hoffman; University of Washington	Taylor (TIRR) & Kalpakjian (UM)	Towards a SCI-Specific Model of Depression: Spinal Cord Injury Model Systems data from the 2006-2011 NSCI Database
Apr	Danielle K Powell, MD (dkpowell@uab.edu) & Chen; University of Alabama at Birmingham	Dyson_Hudson (Kessler) & Crane (UW)	Weight Changes after Spinal Cord Injury: Racial and Gender Differences
Feb	Christopher R Pretz, PhD (cpretz@craighospital.org), Cuthbert & Charlifue; Craig Hospital	Kozlowski, Heinemann (RIC), Chen (UAB), Tate (UM), Krause (Shepherd), Aisen (Rancho) & Taylor (TIRR)	Modeling of Various Longitudinal Outcome Measures within the SCI Model Systems National Database

2011

Month	Lead investigators	Collaborators	Project title
Nov	Jim Krause, PhD (krause@musc.edu), Saunders, Cao & McArdle; Shepherd Center	Heinemann (RIC)	Work life after SCI
July	Denise Fyffe, PhD (dfyffe@kesslerfoundation.org), Dyson-Hudson, Botticello & Kirshblum; Kessler Foundation Research Center	Boninger (Pitt), Krause (Shepherd), Deutsch (RIC) & Ottenbacher	"Predictors of functional disparities among individuals living with SCI". This project was recently awarded pilot grant through the Center for Rehabilitation Research Using Large Datasets (PI: Ottenbacher)
Jun	Jeffrey Cuthbert, MPH, MS (JCuthbert@craighospital.org), Whiteneck, Charlifue & Lammertse; Craig Hospital	Heinemann (RIC), Dijkers (Mt Sinai), Corrigan, Graham, Coronado, Deutsch, D Chen (RIC) & Y Chen (UAB)	Evaluation of the representativeness of the SCIMS National Dataset
Apr	Allan J Kozlowski, PhD	Botticello (Kessler),	"Modeling Post-Acute Recovery in

	(akozlowski@ric.org) & Heinemann; Rehabilitation Institute of Chicago	Pretz, Cuthbert, Kreider (Craig)	Activity Limitations for Persons with Traumatic Spinal Cord Injury," will apply individual latent growth modeling methodology to describe the long-term outcome after SCI as non-linear trajectories using FIM data
Apr	Juan Carlos Arango, PhD (jcarangolasp@vcu.edu), Ketchum, Cifu, Castillo & Jennings; Virginia Commonwealth University	Dijkers (Mt Sinai) & investigators (RIC & Shepherd)	1. "The association between FIM items and extended rehabilitation length of stay following traumatic SCI" 2. "Predictors of Extended Inpatient Rehabilitation Length of Stay after Traumatic SCI"
Jan	Dan Graves, PhD (dgraves@bcm.edu); TIRR		PhD dissertation project to investigate the computer usage, internet access and depression

2010

Month	Lead investigators	Collaborators	Project title
Nov	Jim Krause, PhD (krause@musc.edu); Shepherd Center		Manuscript preparation: 1. Relationship of behaviors and health conditions with all-cause mortality 2. Development of models for specific causes of death, starting with a competing risk model
Nov	Stephen Burns, MD (Stephen.Burns@va.gov); University of Washington		Descriptive analysis of colorectal cancer deaths for a review article or commentary

2007

1. David Chen, MD (dchen@ric.org) requested a copy of the database for research on:
 - a. Patients' characteristics in SCIMS database and Medicare assessment data for inpatient rehabilitation facilities
 - b. Relationship between raw FIM scores and Rasch-derived FIM measures
 - c. FIM data before and after the implementation of PPS.
2. Stephen Burns, MD (Stephen.Burns@va.gov) requested a copy of the database, in collaboration with colleagues in the VA Puget Sound Health Care System and Hines VA, to study:
 - a. SCI in OIF/OEF Veterans
 - b. SCI and Automobile Collisions

Projects conducted at the National Spinal Cord Injury Statistical Center before 2014

1. In collaboration with Drs. Heinemann, Tate, and Saunders, NSCISC began a series of descriptive analyses in July 2013 to examine the external causes of spinal cord injury, documented by ICD-10 CM codes.
2. In partnership with the National SCI Statistical Center, Robert Shavelle, PhD (Shavelle@lifeexpectancy.org) from the Life Expectancy Project (www.LifeExpectancy.org) was provided access to the database in August 2011 to investigate:
 - a. Mortality after minimal deficit (AIS D) SCI. Collaborating investigators include Dr. DeVivo, Dr. Jim Krause, Dr. David Strauss, and Mr. Jordan Brooks.
 - b. Impact of secondary complications on all-cause mortality after SCI. Collaborating investigators include Dr. DeVivo, Dr. Jim Krause, Dr. Chuck Bombardier, Dr. David Strauss, and Mr. Jordan Brooks.
3. With support from the Paralyzed Veterans of America (2009-2010) and South Carolina Spinal Cord Injury Research funds (2009-2012), in collaboration with Drs. Krause, Cao, and Saunders, a series of analyses are conducted to examine:
 - a. Trends in mortality, causes of death, and related racial/ethnic disparity
 - b. Trends in risk and risk factors for suicide deaths
 - c. Mortality risk and risk factors for bladder cancer
 - d. SMR by different causes of death across various demographic and injury characteristics.
4. In partnership with the National SCI Statistical Center, Vieri Failli, PhD (vieri.failli@wingsforlife.com) and Jan Schwab, MD, PhD (jan.schwab@charite.de) from the Wing for Life Spinal Cord Research Foundation (www.wingsforlife.com) in Salzburg, Austria and Charité – Universitätsmedizin Berlin, Germany were provided access to the database in July 2009 and October 2012 for a series of analyses to examine the impact of infection on neurologic recovery and functional outcomes:
 - a. Infections are associated with prolonged hospitalization time after traumatic SCI. Collaborating SCIMS investigators include Drs. Burns and Krause (December, 2014).
 - b. Effect of Pressure Ulcers as sources for chronified inflammation on neurological outcome after Spinal Cord Injury (SCI) – A role as Disease Modifying Factor? Collaborating SCIMS investigators include Drs. Brienza and Boninger (February, 2014).
 - c. Functional neurological recovery after spinal cord injury (SCI) is impaired in patients with pneumonia and wound infections: a longitudinal cohort study (April, 2011).
5. A longitudinal investigation on the impact of the loss to follow-up on SCI outcome research began in 2007.

Projects proposed by non-SCIMS investigators

July 2017

1. The InVivo Therapeutics Corporation (Alex Aimetti, PhD) was provided database statistics by the NSCISC to be used as comparators for the ongoing INSPIRE (InVivo Study of Probable Benefit of the *Neuro-Spinal Scaffold™* for Safety and Neurologic Recovery in Subjects with Complete Thoracic AIS A Spinal Cord Injury) project. The responsible party agrees that these data will not be used for marketing purposes by InVivo and that the NSCISC and SCIMS Executive Committee will have an opportunity to review and approve a manuscript draft before submission to a journal for peer review.

June 2017

2. Brittney Otruba, MA (mentor: Henry Soper, PhD), a PhD student of Psychology at The Fielding Graduate University, was granted a limited data set for a project entitled “Premorbid Mental Health Impact Upon Post-Injury Perceived Life Satisfaction: Spinal Cord Injury Versus Concomitant Traumatic Brain Injury.” Collaborators included Yuying Chen (SCIMS mentor), Allen Heinemann, and Liz Felix.

August 2016

3. The InVivo Therapeutics Corporation (Alex Aimetti, PhD) and Policy Analysis Inc (Gerry Oster, PhD and Ellen Dukes, PhD) were provided database statistics by the NSCISC to: 1) examine the relationship between AIS grade at post-injury year 1, functional outcomes, and healthcare utilization and 2) estimate expected financial burden for persons with these injuries. The responsible party agrees that these data will not be used for marketing purposes by InVivo and that the NSCISC and SCIMS Executive Committee will have an opportunity to review and approve a manuscript draft before submission to a journal for peer review.

December 2015

4. Larry Miller, PhD and Louise Anderson, PhD, Miller Scientific Consulting, Inc., were provided database statistics by the NSCISC to conduct Markov model and cost analysis to assess the influence of ambulatory ability on 5-year complication rates and health care costs. This project is financially supported by the ReWalk Robotics. The responsible party agrees that these data will not be used for marketing purposes by ReWalk and that the NSCISC and SCIMS Executive Committee will have an opportunity to review and approve a manuscript draft before submission to a journal for peer review.

May 2015

5. Kurt Herzer, MSc (mentor: Marlis Gonzalez-Fernandez, MD, PhD, mgonzal5@jhmi.edu), a MD/PhD student at Johns Hopkins University, was granted limited access to the database for a project entitled “Time-To-Rehabilitation and Outcomes in Spinal Cord Injury”. Collaborators included Dr. Yuying Chen (SCIMS mentor) and Dr. Allen Heinemann.

December 2014

6. Annette Bourbonniere (mentor: Dr. James Opaluch Jimo@uri.edu), a doctoral student in the Department of Environmental and Natural Resource Economics, University of Rhode Island, was granted limited access to the database for her dissertation project entitled "Using revealed preferences to eliminate work disincentives for persons with disabilities." Dr. Mike DeVivo served as the SCIMS mentor for this project.

September 2010

7. Josh Cohen, PhD (jcohen@tuftsmedicalcenter.org) of the Tufts Medical Center, Boston, MA was granted limited access to the database for a project entitled "*Clinical benefits and health care cost savings associated with improved Functional Independence Measure scores following spinal cord injury*". Dr. Marcel Dijkers was appointed by projects directors as a mentor for this project.

December 2007

8. James Gear, PhD (JGear@mwecc.com) of the Midwest Employers Casualty Company was granted limited access to the SCIMS database to investigate occupational and work-related SCI and associated trend and costs. The results will primarily be for the internal use of Midwest Employers Casualty Company to help support internal risk analyses so that more precise future cost estimates can be derived and better decisions regarding such estimates may be made.

DeVivo Mentored Research Award projects

2017

1. Cristina Kline-Quiroz, DO (mentor: Jayne Donovan, MD and Amanda Botticello, PhD), Rutgers-New Jersey Medical School, Kessler Institute for Rehabilitation, West Orange, NJ. Project title "Factors Associated with Return to Education after Spinal Cord Injury".

2014

2. Hannah W Mercier, MS, OTR/L (mentor: Alan Jette, PhD, PT), Massachusetts General Hospital Institute of Health Professions, Charlestown, MA. Project title "Effects of Rehospitalization among Adults with Spinal Cord Injury on Quality of Life, Independence, and Participation".
3. Jordan Garman, DO (mentor: Keneshia Kirksey, MD and Elizabeth Richardson, PhD, MSPH), UAB Department of Physical Medicine and Rehabilitation, Birmingham, AL. Project title "Factors Contributing to Transition of Bladder Management Method Following Traumatic Spinal Cord Injury".

2012

4. Hwasoon Kim, MS (mentor: Garry Cutter, PhD), UAB Department of Biostatistics, Birmingham, AL. Project title "Modeling to Predict Loss to Follow-up In the Spinal Cord Injury Model Systems Database".

2010

5. Katya Radkevich, MD (mentor: Stephen Burns, MD), VA Puget Sound Health Care Systems, Seattle, WA. Project title "United States Veterans in the Spinal Cord Injury Model Systems Database".
6. Katherine W Stenson, MD (mentor: Anne Deutsch, PhD, CRRN, RN and David Chen, MD), Rehab Institute of Chicago, Chicago, IL. Project title "A Comparison of Medicare Patients in the SCI Model System Database and the National Medicare Databases".

2009

7. Gina Armstrong, MD (mentor: Marcel Dijkers, PhD), Mt. Sinai School of Medicine, New York, NY. Project title "Do Gender Differences Exist in Patterns and Consequences of Alcohol Use Following Spinal Cord Injury?"
8. Yue Cao, MS (mentor: Sean-Shong Hwang, PhD), UAB Department of Sociology, Birmingham, AL. Project title "Cumulative Advantage of Education on the Health and Life Quality After Spinal Cord Injury".

**Courtesy notice of SCIMS Database Research -- Site or Module data only
2015**

Month	Lead investigators	SCIMS Sites	Project title
Nov	Alan Jette, PhD, PT; New England Regional Spinal Cord Injury Center	Module and Form I data from SCI-FI module collaborating centers	The Spinal Cord Injury Functional Index (SCI-FI) Enhancement and Evaluation study

2012

Month	Lead investigators	SCIMS Sites	Project title
Feb	Don Gerber, PsyD MEd ABPP; Craig Hospital	Craig data only	Dual Diagnosis Spinal Cord Injury and Traumatic Brain Injury: the TBI Effect on Outcome