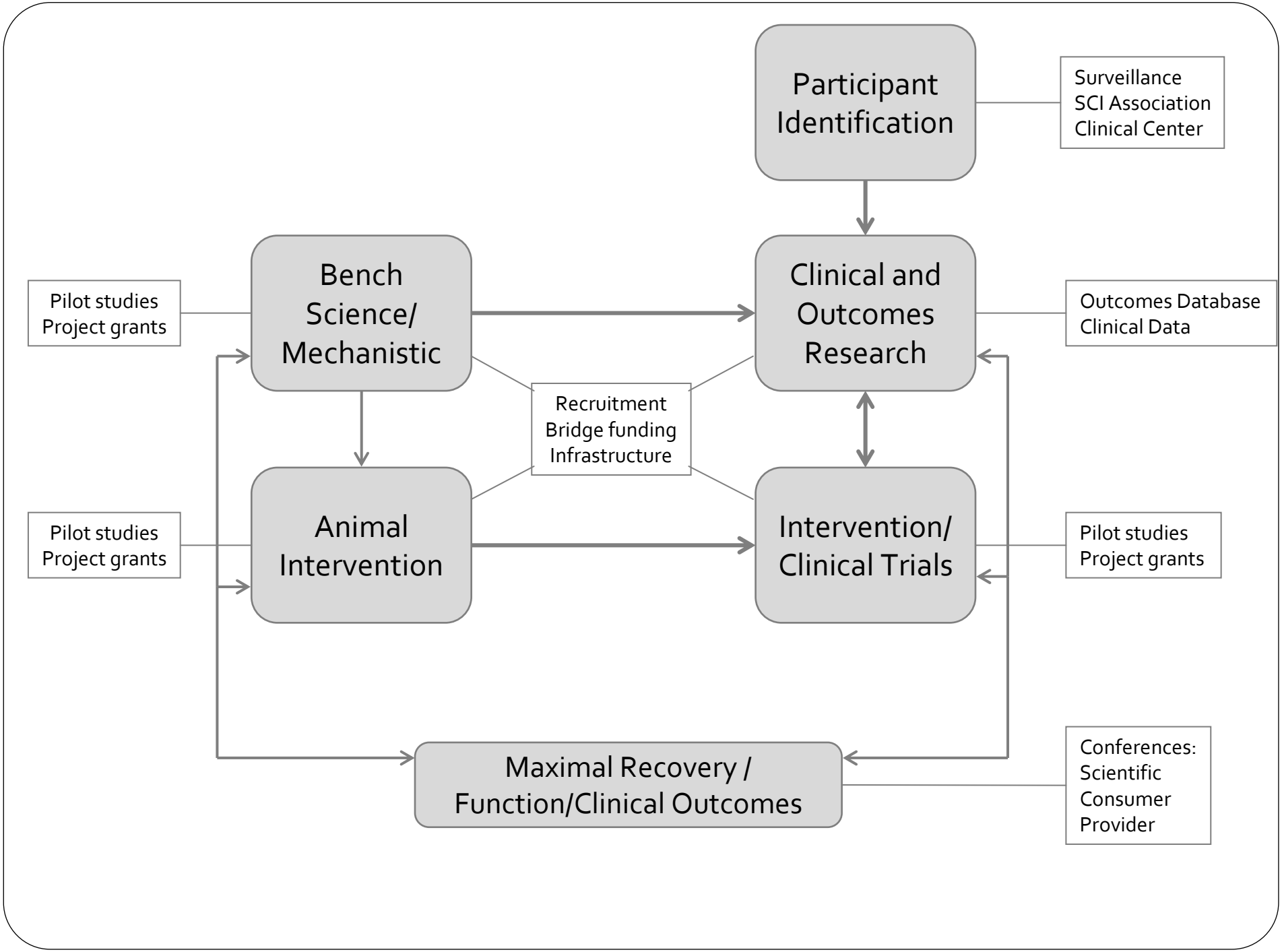
Surveillance, Outcomes Assessment, and Intervention Capacity


Participant Identification
Surveillance
SCI Association
Clinical Center
Bench Science/ Mechanistic
Pilot studies
Project grants
Clinical and Outcomes Research
Outcomes Database
Clinical Data
Recruitment
Bridge funding
Infrastructure
Animal Intervention
Pilot studies
Project grants
Intervention/ Clinical Trials
Pilot studies
Project grants
Maximal Recovery / Function/Clinical Outcomes
Conferences:
Scientific
Consumer
Provider

The South Carolina Spinal Cord Injury Surveillance Registry

Uses and Findings

Anbesaw W. Selassie
Biostatistics and Epidemiology

The South Carolina Spinal Cord Injury Surveillance Registry

Goal: Improve the lives of persons with SCI

Objectives:

1. Collect, organize, and analyze SCI data from all existing data sources.
2. Validate and enhance the data though medical chart review and telephone interviews as needed.
3. Provide the foundation for SCI research by creating secondary database of persons with SCI willing to be contacted for further studies.

Major Achievements: 2000-2010

1. Collected surveillance data on 3,039 persons diagnosed with acute spinal cord injury

2. Provided data-related information for 18 research applications at MUSC and around the state

3. Published 16 manuscripts, 3 under review

4. Supported 2 clinical trials and 2 community intervention trials

Examples of Data Usefulness

1. Clinical trials

- **Abhay Varma** — *Premarin* and acute TSCI recovery
- **Mark George** —TMS conduction and perception of sensation

2. Community trials

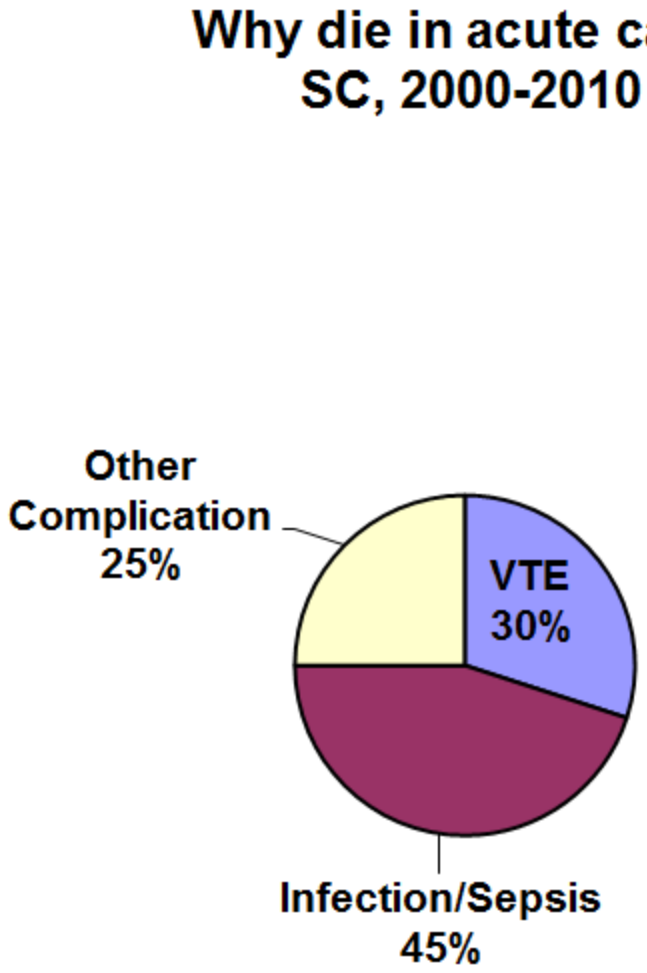
- **Stephen Haines** — Comparison of hospitals with and without MPS protocol in TSCI outcomes
- **Ernest McCutcheon** — Cost and mortality analysis as a function of use of MPS
- **Hon Yuen** — Effectiveness of oral telehealth among quadriplegics in the community setting

Examples of Data Usefulness (...cont)

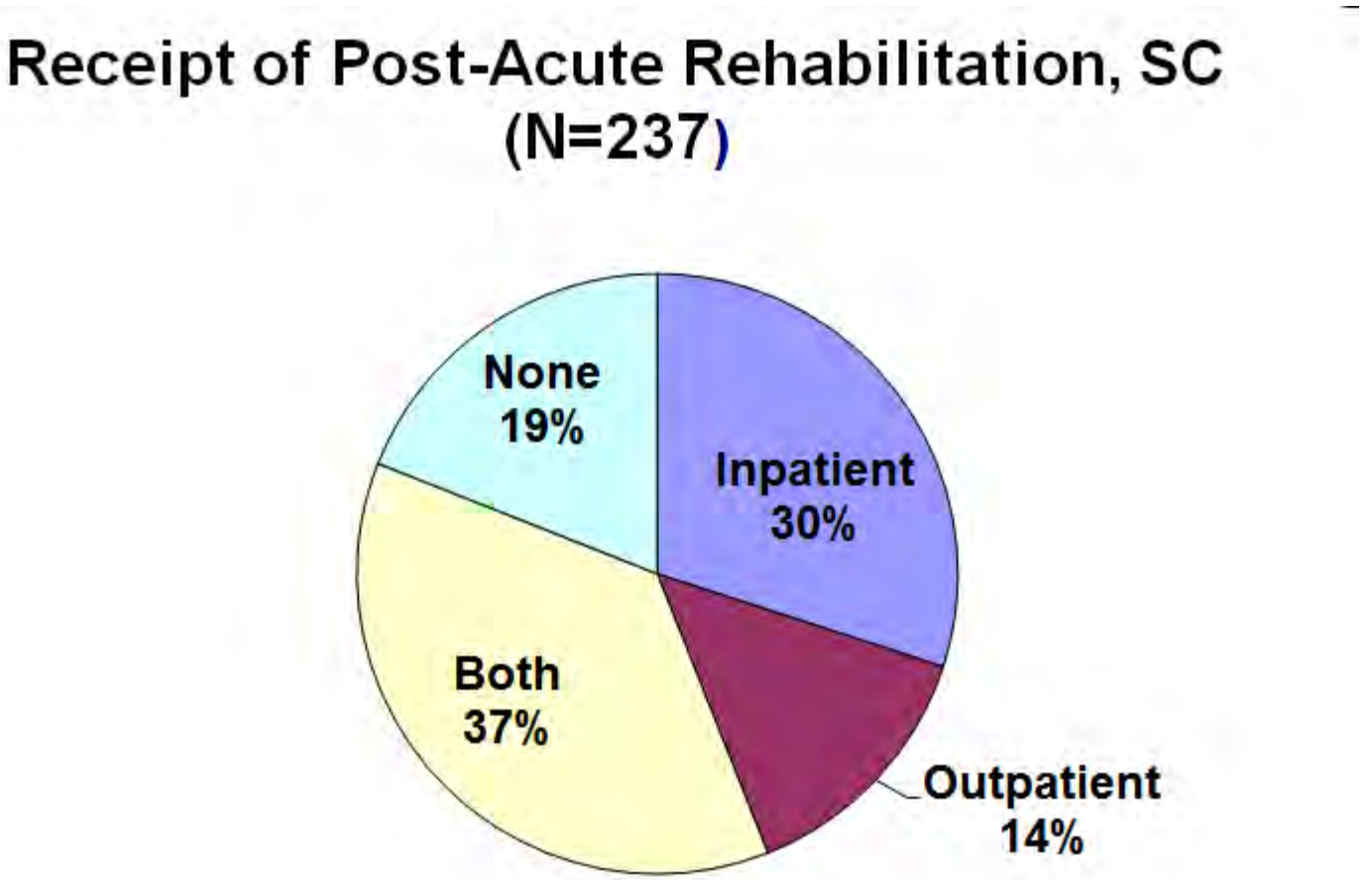
3.Research applications

- **Jim Krause** – In US DoE NIDRRR applications
- **Mark George** – In US DoD vet health applications
- **Elisabeth Pickelsimer** – In SCIRF applications
- **Susan Newman** – In NIH K21 application
- **Sarah Protho** – In HRSA application for advocacy
- **Mike Saladin** – In home based physical rehab
- **Mark Riffle** – In developing nutrition survey

Examples of Informative Data Findings

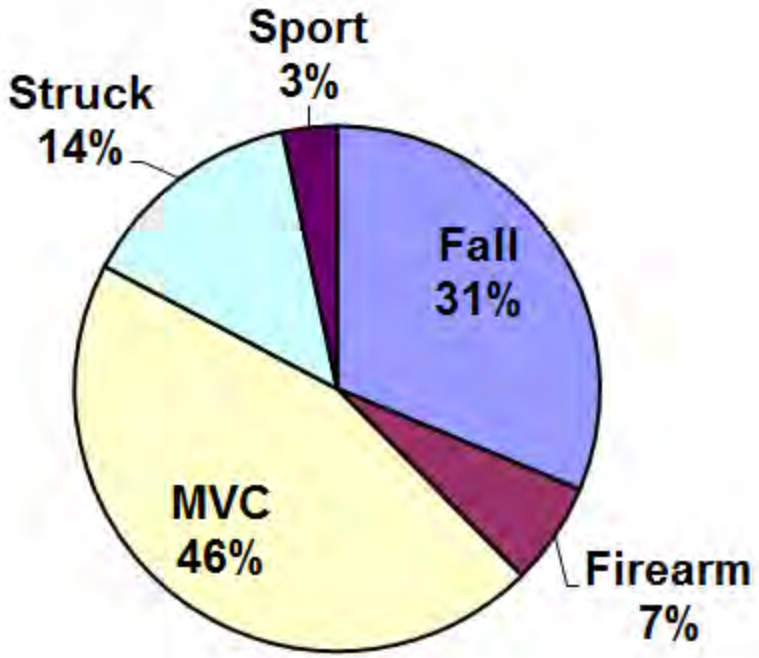


Examples of Informative Data Findings

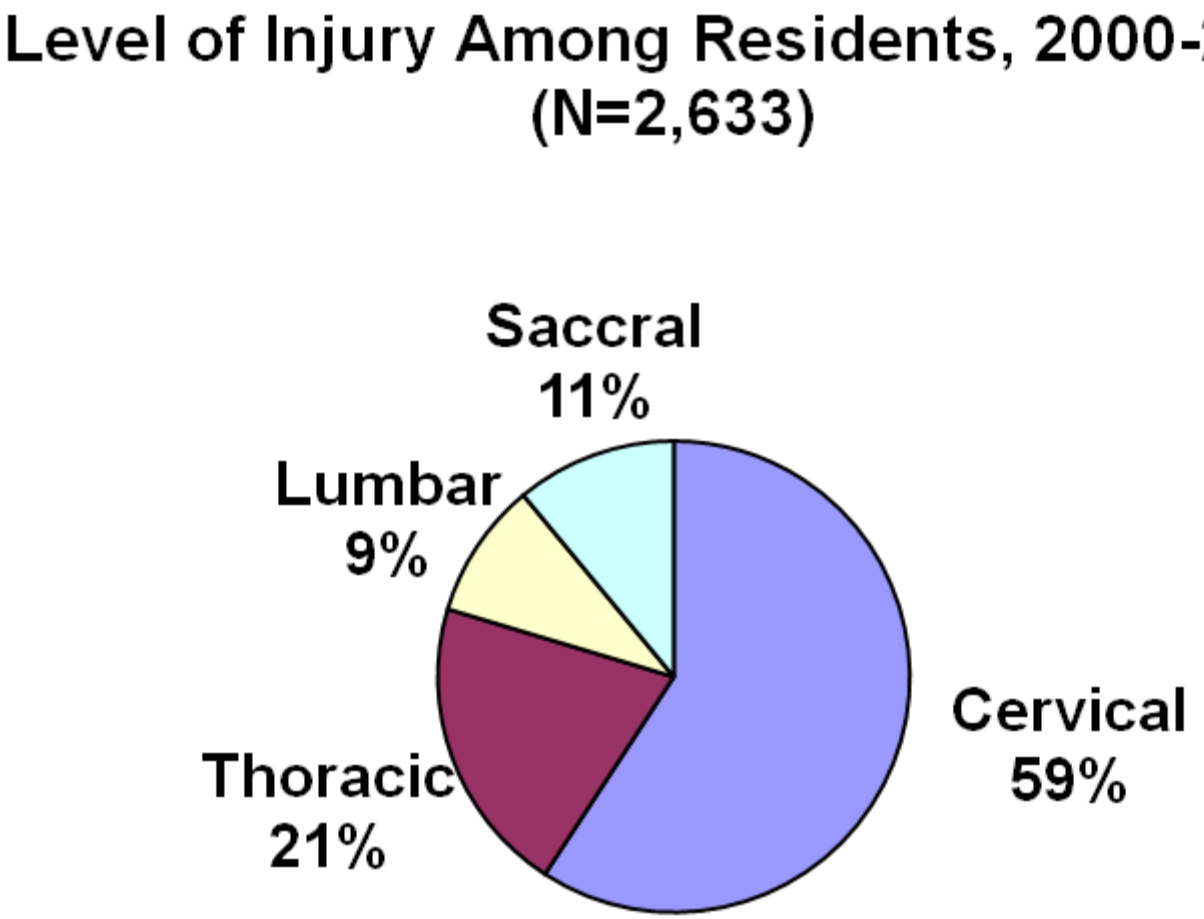


Etiology of Injury in South Carolina

TSCI in SC 2000-2010 Among State Residents by Cause (N=2,633)

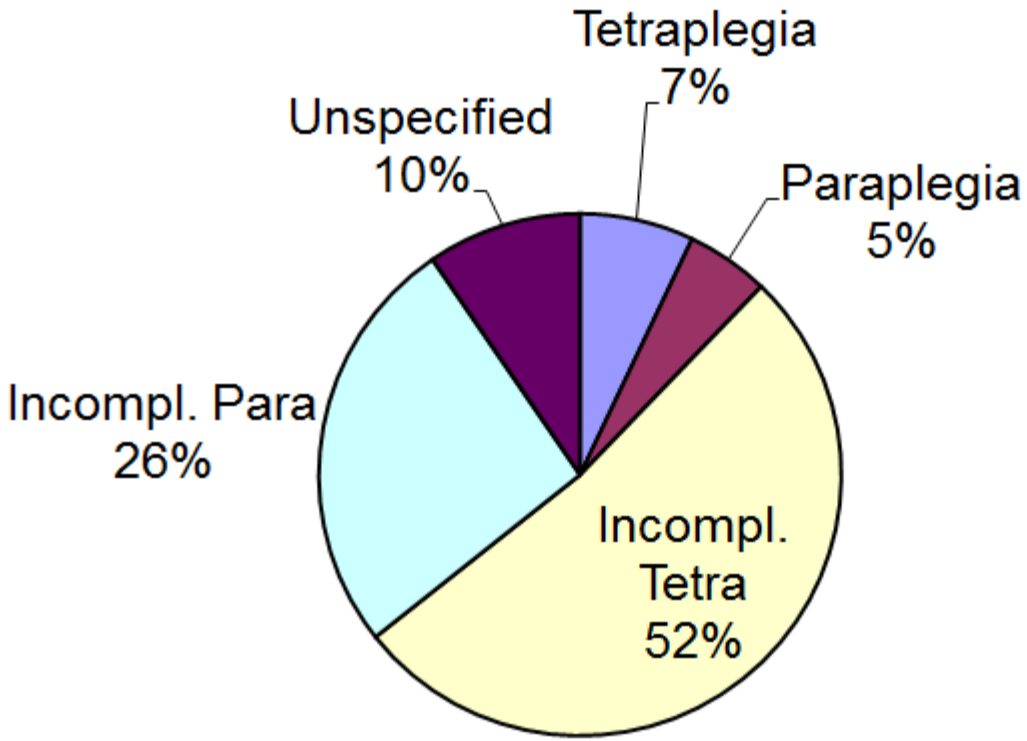


Level of Injury



Neurological Completeness of Injury

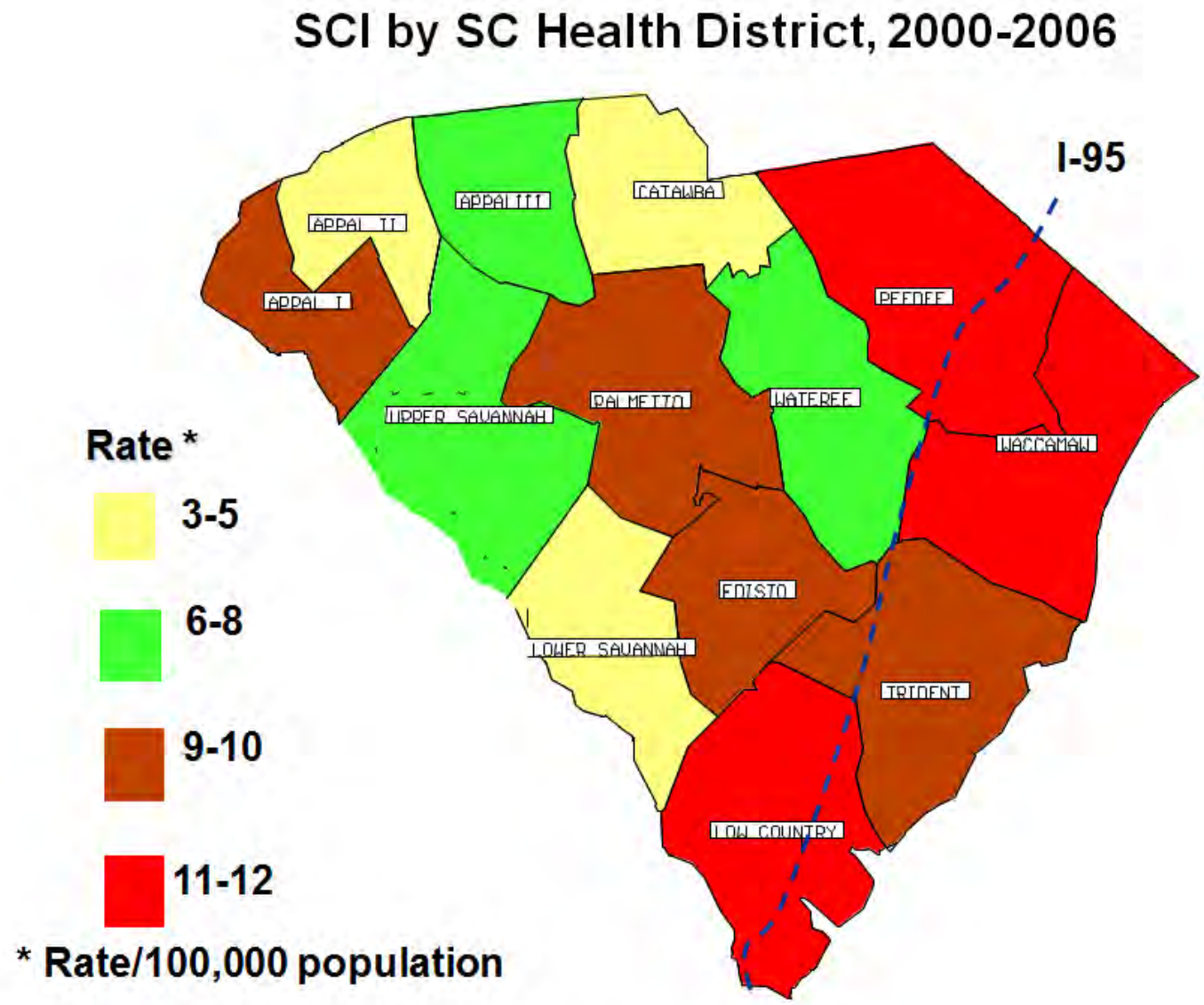
Neurological Lesion at Discharge Among SC Residents, 2000-2010 (N=2,333)



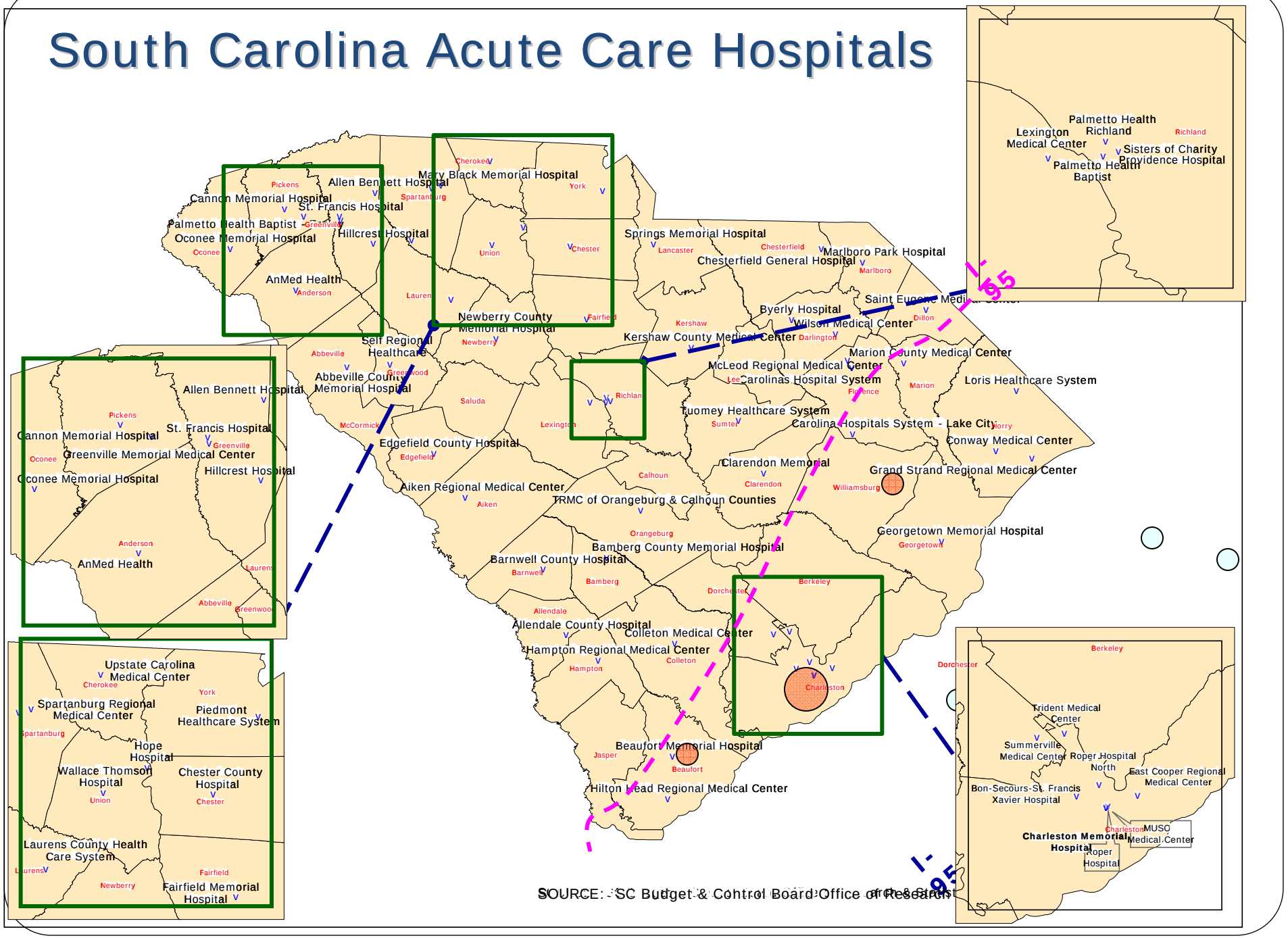
Vehicular SCI in South Carolina by Trauma Level & Urban-Rural Status, 2000-2010

	Acute Care Disposition After TSCI									
	Deceased				Alive					
	MSA				MSA					
	Urban		Rural		Urban		Rural		All	
Source of Definitive Care Trauma Level Status	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
Level I (n=4)	41	69.5	30	78.9	421	75.0	299	66.6	791	71.5
Level II (n=3)	12	20.3	5	13.2	60	10.7	69	15.4	146	13.2
Level III (n=19)	6	10.2	3	7.9	63	11.2	50	11.1	122	11.0
Undesignated (n=36)	0	0	0	0	17	3.0	31	6.9	48	4.3
All (N=62)	59	100	38	100	561	100	449	100	1107	100

Average Incidence Rate of SCI



South Carolina Acute Care Hospitals



SOURCE: SC Budget & Control Board Office of Research

Measuring outcomes after SCI throughout South Carolina: A system of tracking, research, and referral

Proposed Activities

- To better understand the healthcare needs of persons with SCI in South Carolina, we proposed to:
  1. Measure outcomes of individuals with SCI in the state of South Carolina routinely as they come into the surveillance system
  2. Measure outcomes on all existing cases
  3. Perform routine follow-ups during the first five years post-injury, then again at five year intervals thereafter
  4. Perform appropriate data analysis and dissemination, with a focus on the relationship of health services and risk factors with outcomes and the potential cost effectiveness of intervention
  5. Develop a de-identified dataset that includes variables similar to the SCI Model Systems, such that it could be utilized by qualified investigators in SCI throughout the state
  6. Routinely disseminate information on services and resources throughout the state of South Carolina to participants as they enter the surveillance system and during routine follow-ups

Discharge Date	Follow-up Year			
	2011	2012	2013	2014
	Baseline	Fup1	Fup2	Fup3
2010	1	1	1	1
2009	2	2	2	2
2008	3	3	3	3
2007	4	4	4	4
2006	5	5	5	5
2005	6			
2004	7			
2003	8			
2002	9			
2001	10	10	10	10
2000	11			
1999	12			
1998	13			

Participants by Injury Year

Year of Injury	# Participants
2009	52
2008	51
2007	34
2006	26
2005	27
2004	40
2003	28
2002	32
2001	25
2000	23
1999	28
1998	14

Progress

1. Measure outcomes of individuals with SCI in the state of South Carolina routinely as they come into the surveillance system
2. Measure outcomes on all existing cases

- Respondents: 671 of 957 (70.1%)

Progress (Cont.)

3. Perform routine follow-ups during the first five years post-injury, then again at five year intervals.

- Status:
  - Have preliminary IRB approval
  - Measure is in preliminary draft form
  - Preparing revised IRB to accommodate the new instrument
  - Have identified and set up data collection plan

Progress (Cont.)

4. Perform appropriate data analysis and dissemination, with a focus on the relationship of health services and risk factors with outcomes and the potential cost effectiveness of intervention

- Status: Preliminary analyses are being conducted. Some results will be presented.

Progress (Cont.)

5. Develop a de-identified dataset that includes variables similar to the SCI Model Systems, such that it could be utilized by qualified investigators in SCI throughout the state

- Status: Future goal. Too early to develop.

Progress (Cont.)

6. Routinely disseminate information on services and resources throughout the state of South Carolina to participants as they enter the surveillance system and during routine follow-ups

- Status: We have been routinely sending newsletters to all participants. We have had regular contact with the SCI Association for dissemination purposes.

Preliminary Results

Demographics & Injury Level

Characteristics	Mean (SD)
Average Age at Injury	38.9 (SD: 17.3)
Average Years Post-injury	8.2 (SD: 7.4)
Average Age at Survey	47.6 (SD: 16.5)
	Percent
Gender	
Women	30.1%
Men	69.9%
Race	
Black	34.8%
Hispanic	2.1%
White	61.7%
Other	1.3%
Injury Level	
C1-C4	29.0%
C5-C8	30.8%
Non-cervical	40.3%

Ambulation

- Not ambulatory: 37.5%
- Ambulatory: 62.5%
  - 2.5% cannot walk 10 meters
  - 10.4% can walk 10 meters, but not 150 meters
  - 13.8% can walk 150 meters, but not 1000 feet
  - 35.8% can walk 1000 feet

Injury Level and Ambulation

Injury Level	Non-ambulatory	Ambulatory
	Row %	
C1-C4	24.7%	75.3%
C5-C8	35.0%	65.0%
Non-cervical	53.0%	47.0%

Rehabilitation

- 66.6% received **inpatient rehabilitation** after their injury
- 69.8% received **outpatient rehabilitation** after injury

Healthcare Access

- 18.9% were without health insurance at some point in the past year
- 39.2% had problems paying medical bills in the past year
- 49.3% currently have unpaid medical bills

Current Health Care Coverage

Insurance type	%
Medicaid	36.1
Medicare	52.4
Worker's compensation	4.7
Private	26.7
Military	7.6
Other	8.4
No insurance	17.3

*Percentages don't add up to 100% as persons could select more than one type

Healthcare Access

% of persons who:	
Postponed care b/c of costs	26.2%
Postponed care b/c did not have transportation	18.1%
Had no insurance pre-injury	18.6%
Had no insurance currently	17.3%
% of persons who worry they:	
Can't afford care	28.3%
Can't afford medicine	23.8%
Can't afford supplies	27.9%
Will lose benefits	25.9%

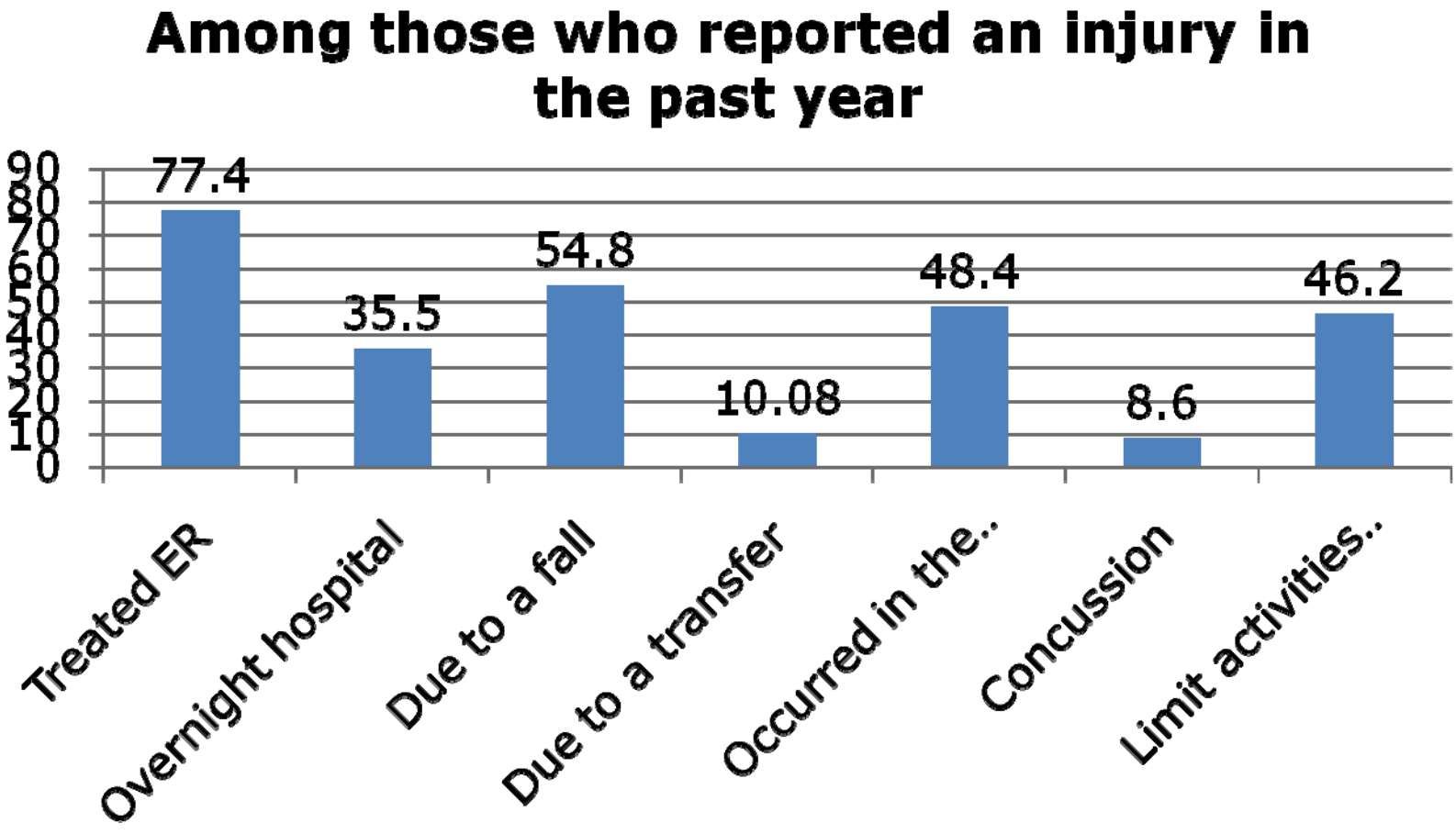
HCA Compared with Shepherd Center

	South Carolina	Shepherd
Could not see a Dr. because of cost	26.2%	11.4%
No health care coverage	17.3%	8.1%

Treatments in the past year

Emergency Room Visits	
Had at least one visit to the emergency room	42.9%
Hospitalizations	
Had 1 hospitalization	15.1%
Had 2+ hospitalizations	18.8%
Among those hospitalized, the average # days in the hospital	8.8 (range 1-90 days)
Surgeries	
Had 1+ surgeries	26.6%

25% reported an **injury** in the past year requiring medical care



Pressure Ulcers

- 30.5% had a pressure ulcer in the past year

Among those:

- 20.2% were hospitalized
- 21.3% had a surgery for a PU
- 15.8% had a current PU

Among those:

- 46.7% had a PU continuously for 6 or more months

Pressure Ulcers

	Ambulatory	Non-ambulatory
	Column %	
Had 1+ pressure ulcers in the past year	17.1%	51.6%
Had a current pressure ulcer	5.9%	32.6%
Among those with a PU in the past year:		
Were hospitalized for a PU	21.9%	20.5%
Had surgery for a PU	21.0%	20.5%

Pressure Ulcers

	Non-ambulatory	Walk<1000m	Walk 1000m
	Column %		
Had 1+ pressure ulcers in the past year	51.6%	19.8%	12.8%
Had a current pressure ulcer	32.6%	7.4%	3.2%
Among those with a PU in the past year:			
Were hospitalized for a PU	21.9%	27.8%	12.5%
Had surgery for a PU	21.0%	33.3%	6.3%

Chronic Conditions

Illness (EVER been told)	% reporting 'Yes'
Diabetes	15.0
Heart Attack	8.5
Coronary Heart Disease	8.4
Stroke	9.8
High BP	40.0
Low BP	19.4
High Cholesterol	30.0
Cancer (all types)	7.3

Depression

- **21.8% reported Probable Major Depression**

In the past year:

- Seen a counselor, psychologist or other mental health professional – 12.7% (23.1% among those w/ MDD)
- Felt you needed to but couldn't not because of cost – 22.1% (52.6% among those w/ MDD)
- Felt you needed to but couldn't get because of transportation – 11.5% (31.2% among those w/ MDD)

In the past 12 months, would you say you were worried or stressed a lot or always about having enough money…

	%
To pay your rent/mortgage	25.5
To buy nutritious meals	21.0
To pay attendants or caregivers	10.8
For recreation	30.6
For transportation	31.1
Out of pocket medical supplies/medications	28.9

Annual Household Income

Income Category	%
< $10,000	25.0
$10,000 to less than $15,000	18.2
$15,000 to less than $20,000	9.0
$20,000 to less than $25,000	8.2
$25,000 to less than $35,000	9.8
$35,000 to less than $50,000	10.6
$50,000 to less than $75,000	8.4
$75,000 to less than $100,000	6.8
$100,000 to less than $150,000	3.0
$150,000 or more	1.1

Employment

- 70.2% were employed at the time of their injury
- 34.8% have been employed at some point SINCE their injury
  - 59.0% were still working at the time of survey
- 20.8% were CURRENTLY working

Of those NOT currently working:

- 50.9% hope to return to the workforce
- 18.8% are actively looking for a job

Summary & Discussion