TRAUMATIC BRAIN INJURY & SPINAL CORD INJURY SURVEILLANCE PROJECT

FISCAL YEAR 2001 FINAL REPORT

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FOR MORE INFORMATION

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INTRODUCTION

This report summarizes data on traumatic brain injury (TBI), spinal cord injury (SCI), and acquired brain injury (ABI) in Kentucky. These injuries are a major source of morbidity and mortality in Kentucky, resulting loss of productivity, use of medical resources, and human suffering. For this reason, there is a critical need to have a data-based understanding of these injuries. Through probabilistic data linkage of three data sets and the abstraction of hundreds of hospital records, the staff at the Kentucky Injury Prevention and Research Center (KIPRC) has created complete TBI, SCI, and ABI data sets. Whenever possible, methods and standards from the Centers for Disease Control (CDC) publication, *Guidelines for the Surveillance of Central Nervous System Injuries*[1] have been employed.

OBJECTIVES OF THE PROJECT

Objective One

The first objective of this project was to answer six specific questions about TBI, SCI, and ABI in Kentucky during 1998. The questions are as follows:

1. How many Kentuckians sustained fatal or serious (hospitalization required) TBI, SCI, or ABI in 1998, and what were the statewide rates for each?

2. What were the demographic and geographic distributions of these cases?

3. What were the causes of TBI, SCI, and ABI?

4. What was the extent of hospitalization?

5. What was the hospital discharge status?

6. How many cases were work-related and who were the primary payers?

Objective Two

The second objective of this project was to abstract a 10% sample of TBI records, SCI records, and a selection of ABI records.

TBI CASE DEFINITION

Many brain injuries are caused by trauma. The CDC have established standards for TBI case identification. The following International Classification of Diseases, 9th Revision (ICD-9) diagnosis codes (n-codes) were used for this study:

Fracture of vault or base of skull 800.0-801.9

Other, unqualified, and multiple fractures of skull 803.0-804.9

Intracranial injury, including concussion, cerebral laceration, subdural hemorrhage, unspecified intracranial injury, etc. 850.0-854.1

These diagnoses are referred to in this report as simply "TBI".

ABI CASE DEFINITION

In addition to CDC-defined TBI, there are many brain injuries that are caused by non-traumatic medical conditions and are referred to in this report as acquired brain injuries, or "ABI". Because these diagnoses are not included in the CDC definition of TBI, they have been linked and analyzed separately. These conditions were also identified by ICD-9 diagnosis codes, as follows:

Anoxia/Hypoxia 348.1, 411.8, 639.8, 668.2, 669.4, 768.1, 768.5, 768.6, 768.9, 799.0, 994.1

Allergy/Anaphylaxis 995.0, 999.4, 999.5

Acute Medical Clinical Incidents 320.0-320.9, 321.0-321.8

Toxic Substances 964.2, 967.0-967.9, 968.0-968.9, 980.0-980.9, 985, 986, 988.0-988.2, 989.0, 994.1, 994.7, 995.4, 995.5, 997.0, 998.0

SCI CASE DEFINITION

The CDC define SCI by the following ICD-9 diagnosis codes:

Fracture of vertebral column with spinal cord injury 806.0-806.9

Spinal cord injury without evidence of spinal bone injury 952.0-952.9

METHODS

Data Preparation

Three data sets were computer linked in this study:

- National Center for Health Statistics (NCHS) Kentucky Supplemental Death File
- Kentucky Hospital Discharge Data, or HDD (Uniform Billing-1992 [UB-92], Inpatient only)
- Level-I trauma data from the University of Kentucky Hospital, University of Louisville Hospital, and Tennessee state TBI registry (for Kentucky residents treated in Tennessee)

Before these data were linked, duplicate records were removed from the KHDD, and formats for items such as dates, times, age, etc. were standardized. Dates of various formats (mm/dd/yy, yyyymmdd, etc.) were all reformatted to Julian dates (number of days elapsed since January 1, 4713 BCE). This makes comparing dates much easier, as Julian dates are just whole numbers. Ages were all reformatted to 3-digits (e.g. 001, 089, 101), gender was formatted to simply "M" and "F", and races were placed into one of only three categories--white, black, and other/unknown. In this way the data were standardized, then copied to a text-only format for linkage.

To identify cases of TBI, ABI, and SCI, Microsoft FoxPro programs were written to search for the appropriate ICD-9 codes within the diagnosis fields of the respective data sets. For example, to identify TBI in the HDD, a program was written which searched for the CDC-recommended codes within all diagnosis fields of each record. If at least one of the nine fields contained a TBI diagnosis code, that record was selected for subsequent linkage.

Data Linkage

During the linkage process, birth date, date of death, date of discharge, gender, age, race, county of residence, zip code of residence, and county of injury were all considered as linking variables. Not all were used, however, for every linkage. Birth date, date of death/discharge, county of residence, and zip code of residence are the most discriminating variables, and therefore most valuable for linkage purposes. For this reason, data quality is essential with regard to these particular variables. In many cases, a seldom-occurring birth date coupled with an equally seldom occurring zip code was enough to label a pair of records a match, by AUTOMATCH standards. AUTOMATCH recommends a 9-1 ratio of true-false matches. In most cases, the ratio used in this study was higher.

Data Abstraction

In fiscal year 2001, the medical records abstractor visited 55 hospitals to abstract TBI records, 25 hospitals for SCI records, and 13 for ABI records. About 120 hospitals were asked to participate, and more than 80% agreed. For TBI and SCI, HDD records were chosen for abstraction if they did not link to either of the other data sets. For ABI, HDD records were abstracted if they did not link to either of the other data sets, and the diagnosis was relatively rare.

Data were entered into a Microsoft Access data entry form on a laptop computer while at the hospital, or were recorded on paper and entered into the computer at the office. In the latter case, the paper records were shredded after data entry. At no time during data abstraction were personal identifiers such as name, Social Security Number, street address, or telephone number collected. A protocol developed for the data abstraction is located in the Appendix.

Seven hundred eighty-five hospital records were abstracted this year: 684 TBI, 76 SCI, and 25 ABI. Abstraction was attempted for data elements not included in the UB-92 hospital discharge data, such as:

County of Injury
Alcohol (Blood Alcohol Concentration)
Toxicology / Drug Screen
Position in Motor Vehicle (if motor vehicle related)
Safety Equipment Used (if motor vehicle related)
Glasgow Coma Score (GCS)
Work-Related
Site of Injury

In addition, the abstractor also collected E-codes and other data elements missing from the UB-92 HDD. Unfortunately, many of these data elements were often not present in the medical records. But among the more notable findings are the following:

- County of injury was available for 445 TBI records (65%), but only 16 SCI records (21%)
- Position in Motor Vehicle was recorded for 114 TBI records (63%) and 4 SCI records (25%) E-coded as "Motor Vehicle Traffic Accident" (E810-E819)
- A GCS was available in medical records for 369 (54%) of TBI records and 16 of SCI (21%) records abstracted
- Only 50 TBI records (7.3%) and 2 SCI records (1.2%) contained a toxicology report that was positive for illicit drug use

These data may prove useful for other studies, especially evalutations of the surveillance system, but a lengthy discussion of each data element is beyond the scope of this report. For specific data requests or questions, please contact the Project Manager.

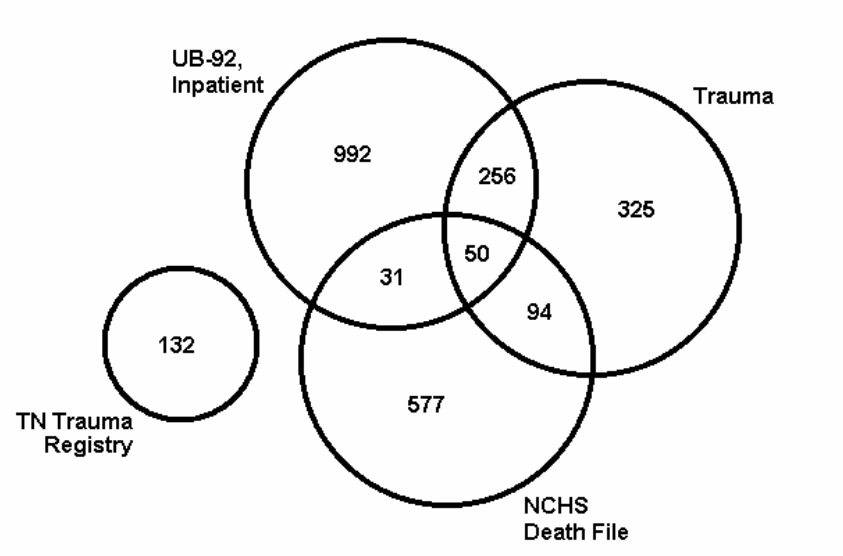
RESULTS—TBI IN KENTUCKY, 1998

After unduplication and linkage, the total number of actual TBI, ABI, and SCI cases was ascertained. The following table and Venn diagram show the number of fatal and non-fatal TBI cases found only in a single data set, in two data sets, in all three, and also those provided by the Tennessee state TBI registry.

Table 1. Total TBI (1998) Identified After Linkage

DATA SET(S)	NON-FATAL	FATAL	TOTAL
HDD Inpatient only	940	52	992
Trauma only	298	27	325
NCHS Death only	-	577	577
Trauma & HDD	249	7	256
Trauma & NCHS Death	-	94	94
HDD & NCHS Death	-	31	31
Trauma & NCHS Death & HDD	-	50	50
Tennessee TBI Registry	122	10	132
TOTAL TBI	**1613**	**844**	**2457**

Figure 1. Overlap of TBI Cases among Data Sets



The surveillance system identified 2457 cases of TBI, for an incidence rate of 62.5 per 100,000 residents of Kentucky in 1998. The following tables summarize TBI by age and gender (Table 2), geographic location (Figure 2), cause (Table 3), length of hospital stay (Table 4), primary payer (Table 5), and discharge status (Table 5). (Please note totals may not equal 100%, due to rounding.)

TBI by Age, Gender

Age was unknown in less than 1% of cases. Males outnumbered females by almost 2 to 1. The age group 25-44 accounts for more than a quarter of TBI, and males in this age group outnumber females by about 2.5 to 1.

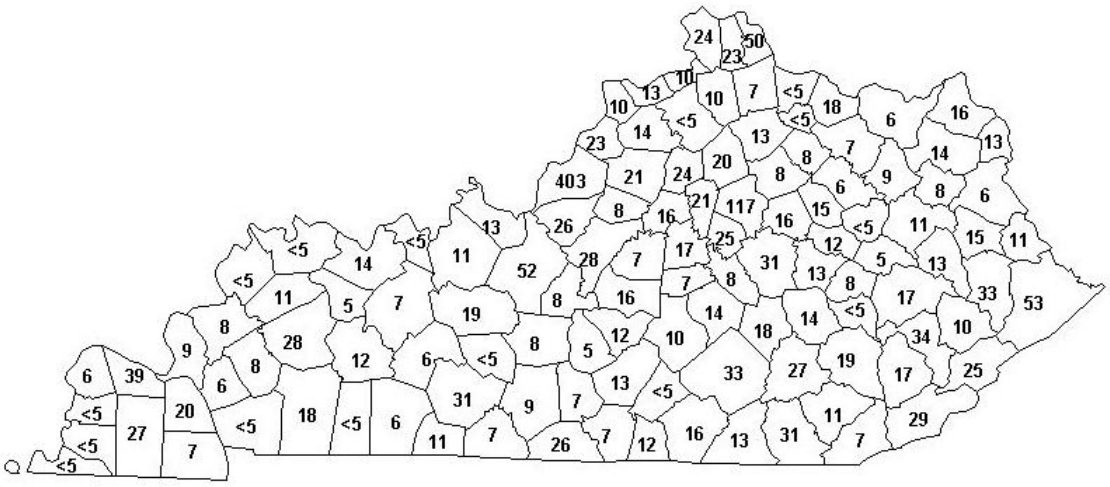
Table 2. Kentucky TBI by Age & Gender, 1998

	MALE			FEMALE			TOTAL	
AGE	**Non-Fatal**	**Fatal**	**Total**	**Non-Fatal**	**Fatal**	**Total**	**No.**	**%**
0-4	71	15	86	44	7	51	137	**5.6%**
5-14	119	19	138	59	11	70	208	**8.5%**
15-24	242	119	361	99	41	140	501	**20.4%**
25-44	279	188	467	117	64	181	648	**26.4%**
45-64	161	114	275	90	38	128	403	**16.4%**
65+	152	120	272	176	95	271	543	**22.1%**
Unk	7	1	8	7	2	9	17	**0.7%**
Total	**1031**	**576**	**1607**	**592**	**258**	**850**	**2457**	**100%**

Geographic Distribution of TBI

The map in Figure 2 displays the number of TBI cases in each county. Counties with less than 5 cases are labeled "<5".

Figure 2. Geographic Distribution of TBI, 1998



Causes of TBI

Causes for TBI were compiled using ICD-9 E-codes from all data sets and abstraction. Less than 9% of E-codes were unknown.

Table 3. Causes of Fatal & Non-Fatal TBI, 1998

E-CODED CAUSE	NON-FATAL	FATAL	TOTAL
Motor Vehicle Traffic Accidents (E810-E819)	569 (35.1%)	361 (43.4%)	930 (37.9%)
Falls (E880-E888)	414 (25.5%)	103 (12.4%)	517 (21.0%)
Motor Vehicle Non-Traffic Accidents (E820-E825)	194 (12.0%)	53 (6.4%)	247 (10.1%)
Homicide & Assault (E960-E969)	91 (5.6%)	76 (9.1%)	167 (6.8%)
Other Accidents (E916-E928)	83 (5.1%)	80 (9.6%)	163 (6.6%)
Suicide / Self-Inflicted (E950-E959)	3 (0.2%)	96 (11.5%)	99 (4.0%)
Other	77 (4.7%)	42 (5.0%)	119 (4.8%)
Unknown	192 (11.8%)	23 (2.8%)	215 (8.8%)
TOTAL	**1623 (100%)**	**834 (100%)**	**2457 (100%)**

Length of Stay for TBI

In Table 4, the length of stay was calculated for every hospital discharge and trauma record that had both an admit date and discharge date (n = 1819).

Table 4. Lengths of hospital stay for TBI, 1998

# Cases	Mean	Median	Mode	Maximum	Total
1819	7.4 days	3 days	1 day (376 records)	512 days	13,460 days

Primary Payers for TBI

Primary payers are summarized for hospital discharge records in Table 5. Fifteen percent of records contained no information on the primary payer.

Table 5. Primary payers for TBI hospital stays, 1998

Primary Payer	Non-Fatal	%	Fatal	%	Total	%
Insurance Company	430	36%	49	36%	479	36%
Medicare	246	21%	30	22%	276	21%
Medicaid	108	9%	15	11%	123	9%
Self Pay	75	6%	4	3%	79	6%
Other	60	5%	7	5%	67	5%
Blue Cross	43	4%	6	4%	49	4%
Workers' Compensation	43	4%	4	3%	47	4%
CHAMPUS	7	1%	1	1%	8	1%
Other Federal Program	2	0.2%	-	-	2	0.2%
Unknown	179	15%	20	15%	199	15%
Total	**1193**	**100%**	**136**	**100%**	**1329**	**100%**

Discharge Status for TBI

Table 6 summarizes the discharge status for all hospital discharge records. Less than 3% of records had an unknown discharge status.

Table 6. Discharge status for TBI, 1998

Type of Discharge	UB-92 Discharge Code	Number of Cases	%
Discharged to home or self care	01	837	63%
Discharged / transferred to another type of institution for inpatient care or referred for outpatient services to another institution	05	149	11%
Expired	20	105	7.9%
Discharged / transferred to skilled nursing facility (SNF)	03	92	6.9%
Discharged / transferred to home under care of organized home health service organization	06	48	3.6%
Discharged / transferred to another short term general hospital for inpatient care	02	33	2.5%
Discharged / transferred to an intermediate care facility (ICF)	04	16	1.2%
Left against medical advice or discontinued care	07	7	0.5%
Still patient or expected to return for outpatient services	30	4	0.3%
Other / Unknown	-	38	2.9%
Total	**-**	**1329**	**100%**

Work-Related TBI

After linkage and abstraction were completed, a total of 90 work-related cases were identified. Of these 90 cases, 34 were fatal and workers' compensation was listed as the primary payer in 47 records. Seventy-four cases were males, and the average age was 39.8 years, with a range of 13 to 83 years. Table 7 summarizes primary payers for work-related TBI in 1998.

Table 7. Primary Payers for Work-Related TBI, 1998

Primary Payer	Cases
Workers' Compensation	47
Insurance Company	8
Medicaid	3
Medicare	1
Blue Cross	1
Other	1
None or Unknown	29
Total	**90**

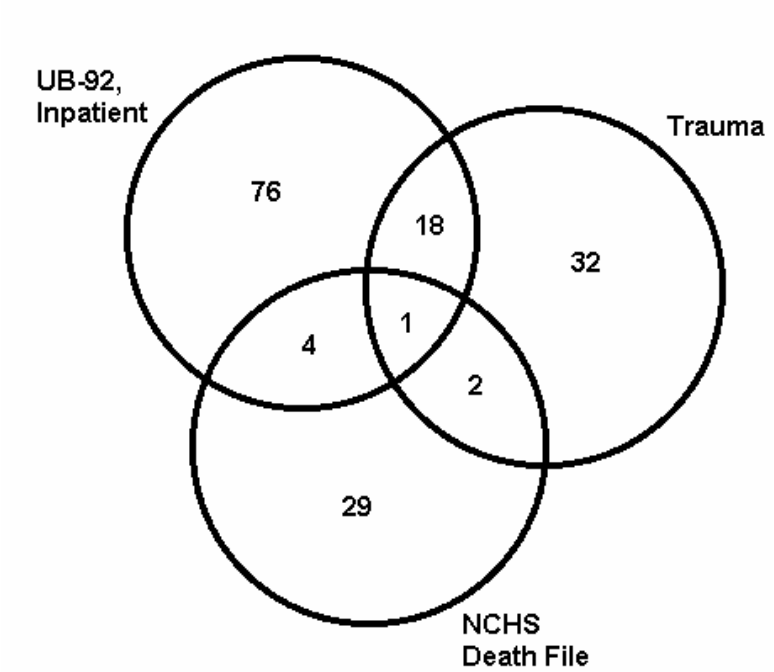
RESULTS—SCI IN KENTUCKY, 1998

The same methods were employed in the linkage, abstraction, and analysis of SCI. The following table and Venn diagram show the number of fatal and non-fatal SCI cases found only in a single data set, in two data sets, or in all three.

Table 8. Total SCI Identified After Linkage, 1998

DATA SET(S)	NON-FATAL	FATAL	TOTAL
HDD Inpatient only	74	2	76
Trauma only	28	4	32
NCHS Death only	-	29	29
Trauma & HDD	18	-	18
Trauma & NCHS Death	-	2	2
HDD & NCHS Death	-	4	4
Trauma & NCHS Death & UB92	-	1	1
TOTAL SCI	**120**	**42**	**162**

Figure 3. Overlap of SCI Cases among Data Sets, 1998



The surveillance system identified 162 cases of SCI, for an incidence rate of 4.1 per 100,000 residents of Kentucky in 1998. The following tables summarize the SCI data by age and gender (Table 9), geographic location (Figure 4), cause (Table 10), length of hospital stay (Table 11), discharge status (Table 12), and primary payer (Table 13). (Totals may not necessarily equal 100%, due to rounding.)

SCI by Age, Gender

Similarly to TBI, males outnumber females by about 2 to 1.

Table 9. Kentucky SCI by Age & Gender, 1998

	MALE			FEMALE			TOTAL	
AGE	**Non-Fatal**	**Fatal**	**Total**	**Non-Fatal**	**Fatal**	**Total**	**No.**	**%**
0-4	-	1	1	1	-	1	2	**1.2%**
5-14	3	2	5	2	1	3	8	**4.9%**
15-24	8	5	13	5	3	8	21	**13%**
25-44	39	6	45	10	7	17	62	**38%**
45-64	18	7	25	5	2	7	32	**20%**
65+	17	3	20	12	5	17	37	**23%**
Total	**85**	**24**	**109**	**35**	**18**	**53**	**162**	**100%**

Geographic Distribution of SCI

The geographic distribution of SCI is not presented in map form, as the great majority of counties in Kentucky had either less than 5 cases, or none at all. As one would expect, however, Jefferson and Fayette counties had the greatest number of cases—23 and 10, respectively. Perry County had 6 cases, and all other counties had 5 or less.

Causes of SCI

Causes of SCI were compiled using ICD-9 E-codes from all data sets and abstraction. Nearly 20% of E-codes were unknown. There were almost three times as many fatal cases as non-fatal.

Table 10. Causes of Fatal & Non-Fatal SCI, 1998

E-CODED CAUSE	NON-FATAL	FATAL	TOTAL
Motor Vehicle Traffic Accidents (E810-E819)	26 (22%)	22 (52%)	48 (30%)
Falls (E880-E888)	32 (27%)	7 (17%)	39 (24%)
Motor Vehicle Non-Traffic Accidents (E820-E825)	13 (11%)	2 (4.8%)	15 (9.3%)
Other Accidents (E916-E928)	8 (6.7%)	1 (2.4%)	9 (5.6%)
Homicide & Assault (E960-E969)	2 (1.7%)	3 (7.1%)	5 (3.1%)
Other	11 (9.2%)	4 (9.5%)	15 (9.3%)
Unknown	28 (23%)	3 (7.1%)	31 (19%)
TOTAL	**120 (100%)**	**42 (100%)**	**162 (100%)**

Length of Stay for SCI

Length of stay was calculated for every hospital discharge and trauma record that had both an admit date and discharge date (n=127).

Table 11. Hospital stays for SCI, 1998

# Cases	Mean	Median	Mode	Maximum	Total
127	11.9 days	6 days	0 and 1 days (bi-modal)	126 days	1485 days

Discharge Status for SCI

Table 12 summarizes the discharge status for all hospital discharge records. Four percent of records had an unknown discharge status.

Table 12. Discharge status for SCI, 1998

Type of Discharge	UB-92 Discharge Code	Number of Cases	%
Discharged to home or self care	01	40	40%
Discharged / transferred to another type of institution for inpatient care or referred for outpatient services to another institution	05	24	24%
Discharged / transferred to skilled nursing facility (SNF)	03	9	9.1%
Discharged / transferred to home under care of organized home health service organization	06	9	9.1%
Discharged / transferred to another short term general hospital for inpatient care	02	9	9.1%
Expired	20	3	3.0%
Left against medical advice or discontinued care	07	1	1.0%
Other / Unknown	-	4	4.0%
Total	**-**	**99**	**100%**

Primary Payers for SCI

Primary payers are summarized for hospital discharge records only. Four percent of records contained no information on the primary payer. Insurance companies were the leading primary payer (32%), but Medicare and Medicaid together accounted for 39% of primary payers.

Table 13. Primary payers for SCI hospital stays, 1998

Primary Payer	Non-Fatal	%	Fatal	%	Total	%
Insurance Company	30	33%	2	29%	32	32%
Medicare	21	2%	2	29%	23	23%
Medicaid	15	16%	1	14%	16	16%
Self Pay	7	8%	1	14%	8	8%
Blue Cross	7	8%	-	-	7	7%
Workers' Compensation	6	7%	-	-	6	6%
Other	2	2%	-	-	2	2%
CHAMPUS	1	1%	-	-	1	1%
Unknown	3	3%	1	14%	4	4%
Total	**92**	**100%**	**7**	**100%**	**99**	**100%**

Work-Related SCI

After linkage and abstraction were completed, 6 records were identified as work-related. All records listed the primary payer as workers' compensation, and there were no fatalities. All cases were males, and the average age was 42 years, with a range of 25 to 52 years.

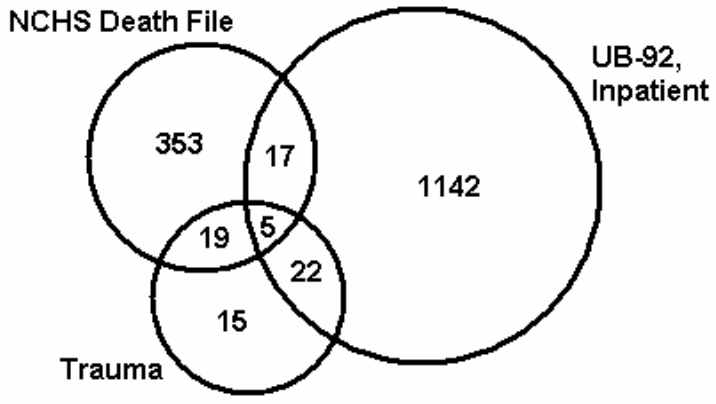
RESULTS—ABI IN KENTUCKY, 1998

The same methods applied to TBI and SCI data were employed in the linkage and analysis of ABI data. The following table and Venn diagram show the number of fatal and non-fatal ABI cases found only in a single data set, in two data sets, or in all three.

Table 14. Total ABI Identified After Linkage, 1998

DATA SET(S)	NON-FATAL	FATAL	TOTAL
HDD Inpatient only	1045	97	1142
Trauma only	10	5	15
NCHS Death only	-	353	353
Trauma & HDD	21	1	22
Trauma & NCHS Death	-	19	19
HDD & NCHS Death	-	17	17
Trauma & NCHS Death & UB92	-	5	5
TOTAL ABI	**1076**	**497**	**1573**

Figure 4. Overlap of ABI Cases among Data Sets



The surveillance system identified 1573 cases of ABI, for an incidence rate of 40 per 100,000 residents of Kentucky in 1998. The following tables summarize the ABI data by age and gender (Table 15), geographic location (Figure 6), cause (Table 16), length of

hospital stay (Table 17), discharge status (Table 18), and primary payer (Table 19). (Totals may not equal 100%, due to rounding.)

ABI by Age, Gender

As opposed to TBI and SCI, ABI was only slightly more common in males than females. However, males were much more likely to die as a result of the ABI.

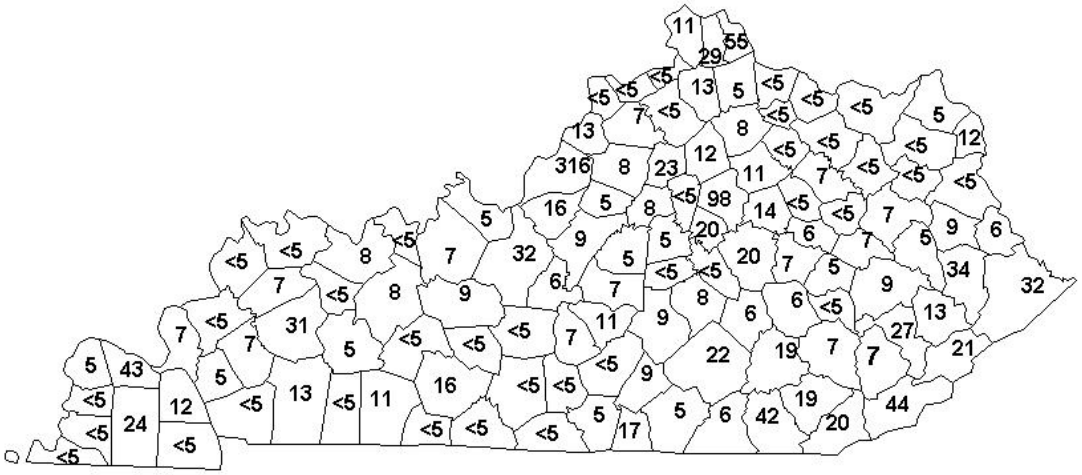
Table 15. Kentucky ABI by Age & Gender, 1998

	MALE			FEMALE			TOTAL	
AGE	**Non-Fatal**	**Fatal**	**Total**	**Non-Fatal**	**Fatal**	**Total**	**No.**	**%**
0-4	32	22	54	18	12	30	84	**5.3%**
5-14	19	15	34	25	3	28	62	**3.9%**
15-24	46	35	81	39	7	46	127	**8.1%**
25-44	148	112	260	168	59	227	487	**31%**
45-64	127	78	205	134	33	167	372	**24%**
65+	142	59	201	178	62	240	441	**28%**
Total	**514**	**321**	**835**	**562**	**176**	**738**	**1573**	**100%**

Geographic Distribution of ABI

The map in Figure 5 displays the number of ABI cases in each county. Counties with less than 5 cases are labeled "<5".

Figure 5. Geographic distribution of ABI, 1998



Causes of ABI

Causes of ABI were compiled using ICD-9 N-codes from all data sets and abstraction. All records contained an N-code, since these were initially used to identify records as ABI. N-codes were used, rather than E-codes, because not all ABI are injury-related. The category of "Other" in Table 16 accounts for 35% of ABI because there are so many more causes of ABI. Only those causes with greater than 100 cases are listed in Table 16.

Table 16. Causes of Fatal & Non-Fatal ABI, 1998

N-CODED CAUSE	NON-FATAL	FATAL	TOTAL
Nervous system complications (997.0)	277 (26%)	63 (13%)	340 (22%)
Poisoning by opiates & related narcotics (965.0)	102 (9.5%)	37 (7.4%)	139 (8.8%)
Drowning & non-fatal submersion (994.1)	11 (1.0%)	105 (21%)	116 (7.4%)
Asphyxiation & strangulation (994.7)	5 (0.5%)	107 (22%)	112 (7.1%)
Poisoning by Sedatives (967)	107 (9.9%)	4 (0.8%)	111 (7.1%)
Asphyxia (799.0)	101 (9.4%)	6 (1.2%)	107 (6.8%)
Toxic Effect of Alcohol (980)	90 (8.4%)	15 (3.0%)	105 (6.7%)
Other	383 (36%)	160 (32%)	543 (35%)
TOTAL	**1076 (100%)**	**497 (100%)**	**1573 (100%)**

Length of Stay for ABI

Length of stay was calculated for every hospital discharge and trauma record that had both an admit date and discharge date (n = 1217), and are shown in Table 17.

Table 17. Hospital stays for ABI, 1998

# Cases	Mean	Median	Mode	Maximum	Total
1217	15.5 days	62.5 days	1 day	338 days	8265 days

Discharge Status for ABI

Table 18 summarizes the discharge status for all hospital discharge records. All records included a known discharge status.

Table 18. Discharge status for ABI, 1998

Type of Discharge	UB-92 Discharge Code	Number of Cases	%
Discharged to home or self care	01	667	56%
Expired	20	120	10%
Discharged / transferred to another type of institution for inpatient care or referred for outpatient services to another institution	05	114	9.6%
Discharged / transferred to skilled nursing facility (SNF)	03	108	9.1%
Discharged / transferred to home under care of organized home health service organization	06	73	6.2%
Discharged / transferred to another short term general hospital for inpatient care	02	39	3.3%
Left against medical advice or discontinued care	07	31	2.6%
Other	-	34	2.9%
Total	**-**	**1186**	**100%**

Primary Payers for ABI

Primary payers are summarized for hospital discharge records only, in Table 19. Less than 5% of records contained no information on the primary payer.

Table 19. Primary payers for ABI hospital stays, 1998

Primary Payer	Non-Fatal	%	Fatal	%	Total	%
Medicare	447	42%	69	58%	516	44%
Insurance Company	213	20%	20	17%	233	20%
Medicaid	152	14%	12	10%	164	14%
Self Pay	93	8.7%	5	4.2%	98	8.3%
Blue Cross	48	4.5%	-	-	48	4.0%
Other	41	3.8%	4	3.3%	45	3.8%
Workers' Compensation	14	1.3%	4	3.3%	18	1.5%
CHAMPUS	1	0.1%	2	1.7%	3	0.3%
Other Federal Program	3	0.3%	-	-	3	0.3%
Unknown	54	5.1%	4	3.3%	58	4.9%
Total	**1066**	**100%**	**120**	**100%**	**1186**	**100%**

Work-Related ABI

After linkage and abstraction were completed, a total of 32 work-related cases were identified. Of these 32 cases, 18 were fatal and workers' compensation was listed as the primary payer for 18 cases. No other primary payers were listed in other records. Twenty-seven cases were males, and the average age was 50.2 years, with a range of 18 to 81 years.

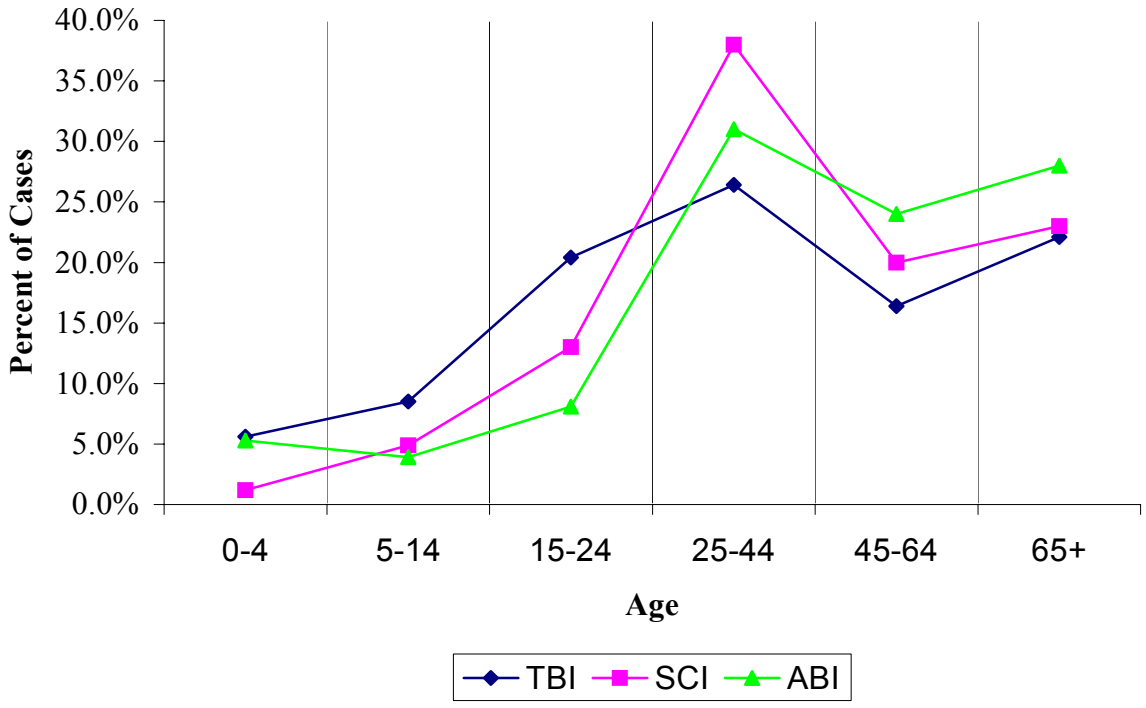
COMPARISONS

Figures 6, 7, and 8 highlight some of the differences and similarities among TBI, SCI, and ABI for Age, Primary Payer, and Cause, respectively. For other comparisons, analyses, or questions, please contact the Program Manager.

Age

For TBI, SCI, and ABI alike, most cases occurred in persons age 25-44. TBI occurred more often in children, teens, and young adults, whereas SCI occurred more often in adults age 25-44, and ABI was more common in adults over 44.

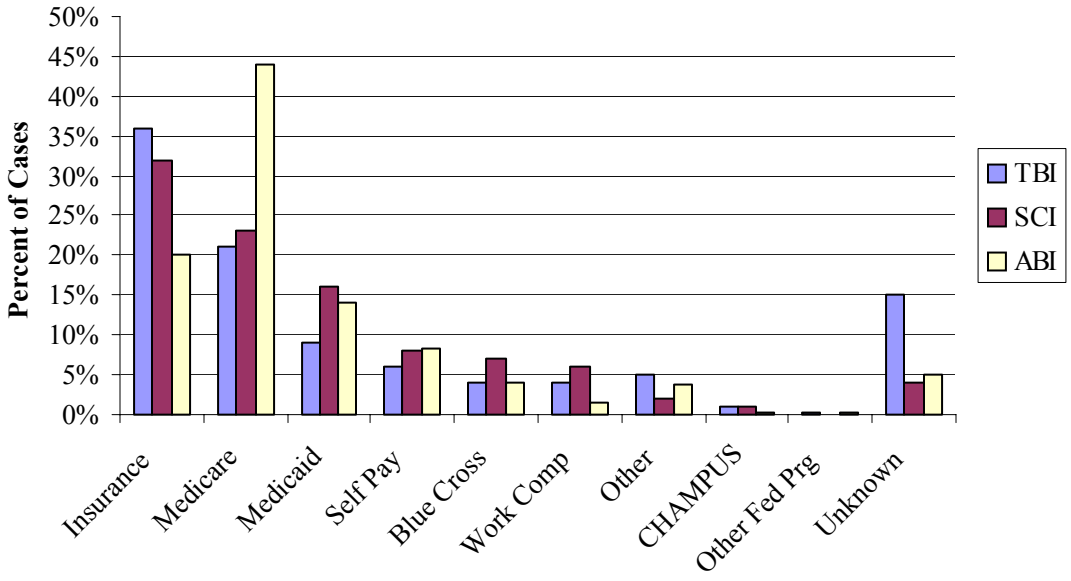
Figure 6. Age Distribution of TBI, SCI, and ABI, 1998



Primary Payer

Primary payers for TBI and SCI records are similarly distributed. ABI records, however, have Medicare listed much more frequently as the primary payer.

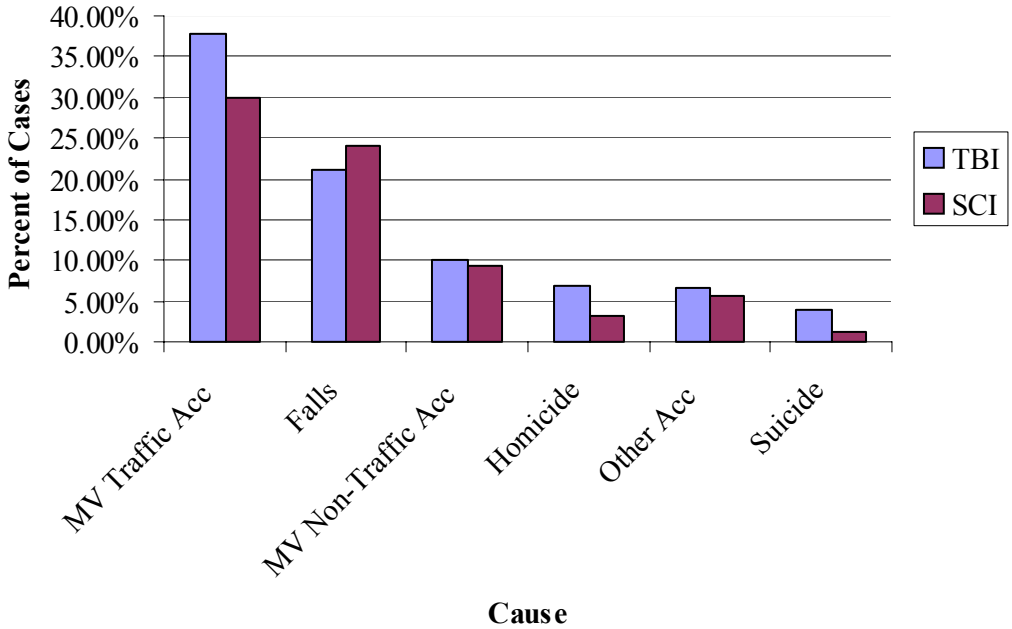
Figure 7. Primary Payers, TBI, SCI, and ABI, 1998



Cause of Injury

SCI is more often caused by falls than TBI, and vice versa for homicide/assault. In general, however, top causes are very similar for these two types of injury. (ABI is not included because the causes of ABI are determined by N-codes instead of E-codes.)

Figure 8. Causes of TBI, SCI, 1998



Discussion

Data Quality and Completeness

The final results for 1998 presented in this report are similar to those for 1997. Discrepancies between 1997 and 1998 data are usually attributable to differences in the completeness and quality of individual data sets. For example, it is difficult to compare incidence rates from 1997 and 1998 due to these differences. However, many positive developments in the area of data collection and quality should ameliorate this situation in the coming year. First, KIPRC has recently formed more solid relationships with the three Level-I trauma centers in Kentucky, and the establishment of a statewide trauma registry is imminent. This trauma registry will guarantee immediate, consistent access to trauma data. Second, the hospital discharge data for 1999 contains 24% more records (45,804 vs. 36,805) than the 1998 data, indicating improved reporting. Third, the state's switch to a new vendor, Compdata, for UB-92 data processing, should also improve the quality of these data. Finally, the number of E-coded records has increased greatly due to the abstraction process, because the abstractor found many E-codes in the medical records that were not present in the electronic data. While the external cause of injury (E-code) was unknown for 27.2% of TBI records from 1997, only 8.8% of E-codes of TBI records from 1998 were unknown. Positive developments such as these suggest a promising outlook for the surveillance system in coming years.

Data Linkage

The processes associated with data linkage, from the standardization of data to the compiling of linked data into a single data set, have all matured. Standard formats for temporal, demographic, and geographical variables are routinely employed. Linkage programs written for 1997 data were easily altered to custom fit the 1998 data, and will be similarly altered for the linkage of 1999 data. The CDC's *Guidelines for the Surveillance of Central Nervous System Injuries* has proved useful in the construction of the final data sets. In short, linkage now progresses more smoothly and expediently. This has allowed for the development of other components such as data abstraction.

Data Abstraction

As mentioned above, data abstraction greatly contributed to the completeness of E-coding in the final data sets. Efforts to collect other data yielded mixed results.

TBI data abstraction was by far the most successful, with many data elements often present in hospital records in 50% or more of cases. Much of this information may be useful in future case-control studies or for other project or service development.

SCI data abstraction was less successful, as many hospitals simply could not locate the records requested. However, the abstraction was instrumental in eliminating records where the initial injury occurred before 1998, but late effects of the injury warranted medical attention.

ABI abstraction, which was limited to records with relatively rare diagnoses (20 or fewer cases), has only just been completed. However, the data abstractor has indicated that almost none of these records mention brain injury or damage in any way. This may suggest that the definition of ABI, or perhaps the ICD-9 codes used to identify ABI, should be re-formulated.

Incidence Rates

The incidence rate for TBI is likely an underestimation. The CDC have estimated that the nationwide incidence of TBI is 95/100,000[1]. Other recent studies have shown similar incidence[2,3,4]. The incidence rate for TBI in 1998 calculated by this study is 62.5/100,000. This is largely attributable to the data collection problems discussed above, and future rates will probably increase due to improved data collection methods. In any case, data from 1997 and 1998 show remarkably similar characteristics, suggesting that clear demographic, geographic, and other trends have already been identified, regardless of whether the incidence rate is correct. In addition, there are signs that the actual incidence of TBI is increasing. For example, in the 1997 NCHS death data, there are 653 records identifiable as TBI cases. In 1998, there were 713, a 9.2% increase.

The incidence rate for SCI (4.1/100,00) is very similar to what has been found in other studies[5,6]. This is an interesting situation, since the incidence of TBI is underestimated. More study is needed to understand this contradiction.

Since ABI is not a universally recognized category of injuries, no comparisons can be made to other states or the nation as a whole.

Future Development of the Surveillance System

Although this surveillance system has succeeded in recognizing basic demographic, geographic, and other patterns of central nervous system injury, there is much more that can be done. The addition of an epidemiologist to the staff would immediately enhance the project. An epidemiologist has the expertise to design and conduct case-control studies and capture-recapture studies. This work could lead to the development of prevention efforts, and enhance understanding of the surveillance system's ability to identify cases.

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5. Centers for Disease Control and Prevention. Current Trends in Traumatic Spinal Cord Injury -- New York, 1982-1988. MMWR 1991;40(31):535-537, 543.
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APPENDIX

PROTOCOL FOR DATA ABSTRACTING TBI/SCI and IPVS

After the TBI/SCI and IPVS projects' data managers have made a list of selected records and their respective hospitals, the abstraction of records will consist of many steps. The following procedures should be followed as closely as possible. These guidelines may be altered in order to accommodate the needs of individual hospitals. However, ***any major deviation from the protocol should be discussed with the project managers in advance***. Above all, the hospital targeted for abstraction should feel comfortable participating. The hospitals are volunteering to do this for us they are not required to participate, so building and maintaining a professional relationship with them is vital to the success and continuation of our projects.

- TBI/SCI Surveillance is a state-funded project, and IPVS is CDC-funded through the KDPH.
- Some cases from their hospital will be **randomly** selected for abstraction, in the case of TBI/SCI Surveillance. For IPVS, only specific cases of both suspected and confirmed intimate partner violence will be abstracted. *(not every hospital will be selected, but we want them on board just in case)*
- We will send them written documentation about the project.
- We will enter into any necessary confidentiality agreement, and/or complete any necessary paperwork.
- Remind them we **do not need** and **will not abstract** any of the following confidential information:
    - Patient name
    - Social Security Number
    - Street address
    - Phone number

Setting up Appointments

- Abstractor will telephone the contact person in the Medical Records department at the hospital:
- Set time and date to arrive – at the hospitals' convenience.
- Create and double check separate lists of patient records for each hospital
- Fax the list of the patient records to the hospital so that records can be pulled prior to the Abstractor's arrival.

Visit to Hospital

- Abstractor will arrive at appointed time and date
- Abstractor should dress professionally/appropriately as representatives of UK/KIRPC
- Abstractor should be as unobtrusive as possible while at the hospital, i.e.
- Abstractor should not comment on record keeping to the hospitals, that is not our place.
- Abstractor is not to set up meetings with the Hospital Administrators
- ***Double-check*** to make certain the correct records were pulled.
- ***Double-check*** information we already have for each patient.
- Enter new information into Microsoft Access data forms completely and accurately.
    - The Microsoft Access data form is loosely divided into sections (e.g. Pre-hospital, ED, etc.) in order to aid data entry (for SCI/TBI).
    - Fill every data field with information, unless unavailable. If anomalies exist, **do not enter non-standard data into form**--enter any notes into Abstractor Comment field at the end of the form.
    - Offer to allow medical records staff to inspect the abstracted data to show them that no confidential information has been recorded.
    - A KIPRC annual report and a summary of the TBI/SCI and IPVS projects along with project manger and abstractors business cards should be left with the records section staff member listed as the contact on the participation cards (or the person they actually deal with). Thank and leave.
    - At all times, the Abstractor should keep the project managers informed on progress and any problems, changes in schedule (i.e., phone when arriving or leaving hospitals, phone with questions, etc.).

Saving the Data

- Abstractors should save abstracted records to **both** their hard drive and a 3.5" disk. In the event of a laptop crash, the 3.5" disk will serve as a back up. The 3.5" disks do not have the capacity to hold the completed electronic forms - it should first be saved to the Excel spreadsheet and then saved to the 3.5" disk.
- The collected data will be uploaded by the IPVS Surveillance Coordinator and the TBI/SCI Project Manager. Once the data has been uploaded to KIPRC's computers, the 3.5" disk can be reformatted and reused for the next batch of data, as KIPRC regularly backs up data located on the server. The data will be erased from the hard drive of the laptops.

Other Correspondence

- All written correspondence regarding the projects comes from the project managers.
- The hospitals' medical records director/administrator should always have the contact numbers for the project managers and should be encouraged to call us.

Abstractor Evaluation

- Evaluation will be carried out on several levels:

(1) Quality of data collected

- The project managers will go to hospitals and re-abstract data. The hospitals will be selected randomly.

(2) Ability to schedule and keep appointments with the hospitals

(3) Providing supervisor with accurate schedule of hospital appointments along with the name and telephone number for each hospital records section contact prior to the visit.

(4) Report about how each visit went – confirmation of who they dealt with when they arrived at the hospital records section. (i.e. completed hospital visit log)

(5) Communication with the project manager(s) regarding progress and/or problems in the field/problems with abstracting.

(6) Feedback from hospitals regarding the abstractors' behavior. The project managers will randomly conduct a short evaluation survey. The evaluation criteria are:

- Scheduling the visit to the hospital at a convenient time
- Giving hospitals enough notice
- Disruption to the hospital staff
- Courtesy and professional conduct while making appointments and while at the hospital
- Use of the hospitals' office facilities
- Leaving Annual Report/Projects description/Project Managers contact details
- Other comments

I have read and will comply with the above abstractor protocol.

Signature: _____

Date: _____