Incorporation of EMS Patient Care Data

In State Data Linkage Programs
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September 17, 2012

Greetings,

On behalf of the National Association of State Emergency Medical Services Officials, I am pleased to present our latest monograph, “Incorporation of EMS Patient Care Data in State Linkage Programs.” The monograph represents extensive work over the past year in instrument design, information gathering and data analysis.

The concept of data linkage originated in the 1940s, however it was the NHTSA Crash Outcome Data Evaluation System (CODES), initiated in 1992 after Congress passed the Intermodal Surface Transportation Efficiency Act (ISTEA) of 1991 that called for a study of the benefits of safety belts and motorcycle helmets, that successfully demonstrated the feasibility of probabilistic record linkage using large, statewide databases.

CODES projects focus on motor vehicle-related deaths and injury, but they represent only the first step in the use of data linkage for the study and improvement of public health and safety.

What remains to be seen is whether multi-system data linkage can now move beyond CODES for purposes broader in implication than motor vehicle crash and injury study.

This monograph examines the extent to which EMS patient care data are being linked with other datasets in the states.

We wish to thank the National Highway Traffic Safety Administration for the resources necessary to support this endeavor. We hope you will find the monograph useful in enhancing the ongoing development of data linkage efforts.

Sincerely,

D. Randy Kuykendall
President
NASEMSO
Acknowledgements and Disclaimer

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Electronic copies are available at no charge:
Executive Summary

Data linkage is a process whereby data from different databases are combined into a master dataset. Ideally, this would position the custodian of the master dataset in such a way as to assess the efficacies and performance of the system that could not otherwise be observed.

Though the theoretical underpinnings of data linkage date back to the 1940s, the technological capacity to link large datasets did not occur until computers were in wide use.

In 1992, the National Highway Traffic Safety Administration (NHTSA) funded a number of states to conduct probabilistic record linkage for the purposes of the study of patient outcomes in relation to motor vehicle crashes. This project, known as the Crash Outcome Data Evaluation System (CODES), demonstrated the feasibility of probabilistic record linkage using large, statewide databases.

What remains to be seen is whether the example of multi-system data linkage provided by CODES can be improved, broadened and implemented by the states, or whether alternative approaches exist.

This monograph reports the results of a survey of state EMS offices to assess the extent to which emergency medical services patient care records are linked with other record systems in the states, the history and near-future plans for data linkage efforts, the perceived issues that may impede data linkage efforts, steps that would likely reduce those impediments, and how those data are used by the states. The major findings are:

- The most prevalent linkages with EMS patient care data systems are remnants of or part of contemporary CODES projects.
- Many potentially useful linkages are not in place.
- Data linkage is ranked as important or mission-critical by 63 percent of respondents.
- Funding is the predominant issue preventing states from moving forward with data linkage projects.
- EMS access to existing linked databases is limited.
Incorporation of EMS Patient Care Data

Background and Introduction

For many years local law enforcement and emergency medical services agencies have captured and collected data by various means. Many captured data using colored pins on a map and then annually replaced the pins using corresponding colored markers to represent traffic tickets issued, non-injury crashes, injury crashes, structure fires, cardiac arrests and other items of interest indicating the locations of the events. These were often accompanied by log books that tracked incident counts, dates and times. Emergency departments often kept log books with similar information.

Personal computers and spreadsheets appeared in the 1980s and many agencies replaced their log books with spreadsheets. During the 1990s flat file and relational databases began to replace spreadsheets improving data capture and reporting. This era spawned the growth of hundreds of software applications for the agencies. Not only were the agencies interested in the data, but municipalities, states, federal agencies and organizations such as the American College of Surgeons, the American Heart Association, needed data and reports to evaluate best practices and patient outcomes.

Many challenges and incompatibilities presented themselves. Agencies used different hardware platforms using everything from mainframes, midrange to personal computers. Many different operating systems were utilized as well as numerous software programs. It was difficult if not impossible to have these systems export or exchange data with each other. The other complicating factor was there were few established standards and what few there were rarely adopted because the vendor or service had already invested significant time and money on their own system that met their needs.

During the continuum of care, a patient is passed from the care of one health care provider to another. The data may or may not follow the patient, may be hand written, may not be captured electronically and if captured electronically may not be compatible with the previous and subsequent computer systems. The result is that each agency has only a partial view of the patient’s signs and symptoms and treatment. It is possible that each discipline functions correctly and still unknowingly produce suboptimal patient outcomes. Because insufficient information is available to identify a cause and effect relationship, each discipline of the system would remain unaware of this. Comprehensive data linkage would provide a means to evaluate and refine each discipline’s actions that would lead to identifying, evaluating and establishing best practices by providing a global view all patients’ encounters.

Data linkage is a process whereby information from different databases is combined or linked together. With the advent of web services, (computer systems initiating and responding to data requests to other computer systems) requests can be made to the appropriate databases and only the necessary data fields are made available for the report or the query. This may also eliminate the necessity for a master database which reduces costs; reduces the potential of users having inappropriate access to data fields; and makes compliance with legal restrictions easier. Personnel with sufficient statistical and technical expertise must be available to implement and operate such a system.
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Imagine that one agency of the system implemented a new intervention, and that every patient who received that intervention experienced a less than desirable outcome. This could include road design, traffic signals, speed limits, or medications or treatments by any level of health care provider. Data linkage and evaluation of the data could identify the shortcomings and corrective action could be taken to improve any aspect of the system.

There were some very forward thinking agencies and individuals who recognized these problems and began to promote standards for the various disciplines and organizations. Among the standards were Health Level 7 (HL7), the American College of Surgeons (ACS) National Trauma Data Bank (NTDB), the National Fire Incident Reporting System (NFIRS), the Model Minimum Uniform Crash Criteria (MMUCC) and the National Emergency Medical Services Information System (NEMSIS). The standards for these data systems were promulgated by their respective disciplines without inter-disciplinary cooperation, creating incongruence between the data systems. The standards were promulgated within their respective disciplines, but did not cross pollinate to the other respective systems. These data existed in silos that substantially reduced the amount of valuable information available to all of the system users and researchers.

This began to change in the early 2000s. Again, individuals and organizations (e.g., ACS, the National Fire Data Center in the United States Fire Administration (USFA), Federal Highway Administration, NHTSA, and Governors Highway Safety Administration), recognized their data existed in silos within their respective disciplines, but they recognized the need to share and link data with the other disciplines and organizations. These organizations and the above organizations began to work with each other and develop uniform standards and data sets.

North Carolina is probably the leader in data sharing and linkage. They link data between crash reports, EMS credentialing, EMS patient care reports, emergency departments, trauma registry, stroke registry, cardiac registry, hospital discharge data and the medical examiners database. There are other states that have developed various linkages and are described in Appendix-2.

There are two methods widely recognized for facilitating the linkage of large datasets: deterministic and probabilistic.

Deterministic linkage is based on the number of individual identifiers that can be matched among the combined data sets. Two records are said to match via a deterministic record linkage procedure if all or some identifiers (above a certain statistical threshold) are identical. Deterministic record linkage would be the preferred option when the entities in the data sets use common identifiers, (e.g., name, address, date of birth, social security number, and gender when identifying a person) and if the data quality is high.

Probabilistic record linkage involves a wider range of potential identifiers, computing weights for each identifier based on its estimated ability to correctly identify a match or a non-match. These weights are used to calculate the probability that two given records refer to the same entity. Record pairs with
Incorporation of EMS Patient Care Data

probabilities above a certain statistical threshold are considered to be matches, while pairs with
probabilities below another threshold are considered to be non-matches; and those in between the two
thresholds are considered “possible matches” and can subsequently be singled out for inclusion,
exclusion or further review. Probabilistic record linkage would be the preferred option when the entities
do not require records to match in all fields and the data quality is acceptable but not necessarily high.

In 1992, the National Highway Traffic Safety Administration (NHTSA) funded a number of states to
conduct probabilistic record linkage for the purposes of the study of patient outcomes in relation to
motor vehicle crashes. This project, known as the Crash Outcome Data Evaluation System (CODES),
demonstrated the feasibility of probabilistic record linkage using large, statewide databases.

Since 1992, NHTSA has funded CODES in 26 states. The availability of statewide, population-based
datasets is a major strength of the project. The CODES project was specifically commissioned to study
the medical outcomes of motor vehicle crashes using probabilistically linked data. The data from these
projects have been useful to states in the development and implementation of policy relating to
improved public health and safety.

Though the CODES projects focus on victims of motor vehicle crashes, they demonstrate the significant
potential of linking multiple datasets, and the use of such information in the development,
implementation and ongoing evaluation of targeted interventions.

What remains to be seen is whether the successful example of multi-system data linkage provided by
CODES can be improved, broadened and implemented by the states. The data linkage enterprise
enabled by CODES was put in place with sufficient funding, guidance and infrastructure to assure every
opportunity of success. Such projects are inherently complex and costly. When costs and complexity are
weighed by states with limited resources against the criticality of such an approach, the implementation
of a comprehensive data linkage system can be met with difficulty.

The National Association of State EMS Officials (NASEMSO), with support from the National Highway
Traffic Safety Administration (NHTSA) investigated the extent to which emergency medical services
patient care records could be linked with other record systems in the states, what methodologies are
used, and how the linked data are used by the states. The survey instrument (see appendix) was
designed to facilitate the data linkage study. The purpose of this endeavor was neither to judge nor to
rank the various state systems. Neither was it the intent to provide specific recommendations, but
rather to contribute to a clearer understanding of what exists, so that both the challenges and the
opportunities of future system development can be more fully appreciated.

The survey population consisted of state EMS officials of the 50 states and six territories of the U.S. Of
the potential pool of 56 respondents, 48 surveys were returned, for an 86 percent rate of return. A copy
of the survey instrument is included in the appendix.
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1. EMS Data Linkage Status, Type, and Sharing

The CODES projects typically link data from five different data systems: motor vehicle crash; emergency medical services; trauma registry; hospital discharge; and death certificates. Ostensibly, the number and types of databases in various CODES projects may have varied, but the focus has traditionally been upon injury and death from motor vehicle crashes.

The National Association of State EMS Officials (NASEMSO) looked at 10 datasets (other than those that capture EMS responses), including those used in the CODES projects, and asked state EMS officials whether the EMS patient care reporting system was linked with one or more of these systems.

911 Dispatching Data

911 centers are the customary Public Safety Answering Points (PSAPs). Calls for police assistance represent the largest portion of all 911 dispatch traffic, followed by calls for EMS, and lastly calls for fire suppression representing the smallest portion of 911 dispatch traffic.

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<tr>
<th>Probabilistic</th>
<th>Deterministic</th>
<th>Deterministic &amp; Probabilistic</th>
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<td>90%</td>
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2 respondents stated 911 dispatch data are shared with a national database

**Opportunity:** The call center is often, but not always, the earliest point of contact with the patient or someone calling on a patient’s behalf, and the ability to link this subset of data with EMS patient care data would be beneficial.

**Opportunity:** Linking identified 911 call center data elements, such as pre-arrival dispatcher-assisted CPR instruction, dispatcher-poison center interaction, and dispatcher-assisted burn care with EMS data will provide comprehensive information on the full spectrum of caller-system-patient interaction and outcomes. Linkage will require EMS agencies, PSAP and 911 call centers, and state EMS and trauma system administrations to identify subsets of data elements.
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Motor Vehicle Crash Data
Not all motor vehicle crashes produce injuries. Some do not produce injuries serious enough to warrant an EMS response, so this database contains some information that would not be the target of linkage with EMS records. Linkage between EMS patient care data and motor vehicle crash data is part of CODES project efforts, so it is not surprising that the prevalence of reported linkage was somewhat higher with this database.

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</tr>
<tr>
<td>13%</td>
<td>6%</td>
<td>2%</td>
<td>2%</td>
<td>73%</td>
<td>4%</td>
<td>100%</td>
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5 respondents stated motor vehicle crash data are shared with a national database

The Safe, Accountable, Flexible, Efficient Transportation Equity Act: A Legacy for Users, 23 U.S.C. § 148 (SAFETEA-LU) of 2005 established the Highway Safety Improvement Program (HSIP), requiring states to implement a Strategic Highway Safety Plan (SHSP). An SHSP establishes statewide goals, objectives, and key emphasis areas and integrates the four E's (4Es) - Engineering, Education, Enforcement and Emergency Medical Services (EMS). The first three Es are factors in preventing or minimizing injury, and the fourth E (EMS) factors after injuries occur to improve patient care and health outcomes. An SHSP identifies emphasis areas (e.g., pedestrians, roadway departure, impaired driving, and seatbelt use) for each of the 4 Es.

**Opportunity:** Motor Vehicle Crashes are still a leading cause of death, disability, and injury. Motor vehicle crash datasets are mature and ubiquitous in the states. A sizable portion of EMS resources are directed at response to motor vehicle crashes. With proper funding and technical assistance, this linkage could provide important insights into the contribution of the SHSP “4th E” to post crash management.

**Opportunity:** Linking MVC data with EMS data can provide opportunities for post-crash retrospective research on prevention, injury severity and outcomes, and new or revised treatment guidelines/protocols. Linking MVC data with EMS data will require EMS and law enforcement agencies to jointly establish a subset of unique identifiers (e.g., crash record number, EMS patient care record number, name, date of birth, social security number), and promulgate inter-agency data sharing policies to facilitate deterministic linkage.
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Emergency Department Data
Where separate emergency department reporting systems exist, the universe of information collected would include EMS transported patients, but also a sizable cohort of patients other than those delivered to the emergency department by EMS.

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<th>Emergency Department Data &amp; EMS Data Linkage Survey Results</th>
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3 respondents stated emergency department data are shared with a national database

Opportunity: Linkage would facilitate measuring differences in patient outcomes, as well as establish and improve the efficacy of early treatment and medically supervised transportation of the sick and injured.

Opportunity: Linking Emergency Department Data (EDD) with EMS data will provide comprehensive information on the full spectrum of caller-system-patient interaction and outcomes, and enable patient tracking from system entry to final outcome. Linkage will require EDD to include a data element that identifies the mode of patient arrival to the emergency department by EMS v. privately owned vehicle or walk-in.

Trauma Registry Data
Where trauma registries exist, the total cohort of patients would represent a subset of EMS transported patients and a subset of trauma patients. Not all EMS patients are trauma patients, and not all trauma patients are delivered into the trauma system by EMS.

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<th>Trauma Registry Data &amp; EMS Data Linkage Survey Results</th>
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5 respondents stated trauma registry data are shared with a national database

Opportunity: Linkage would capture essential information on the patient population transported by EMS to a Trauma Center. This provides an objective and outcome-oriented approach to improving trauma care.

Opportunity: Linkage would facilitate research and publication in peer reviewed scientific journals that focus on trauma care, prehospital care highway safety.
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*Opportunity:* Linking EMS prehospital care data with trauma registry data will improve the completeness and accuracy of patient information in trauma registries. Data linkage will improve completeness and accuracy of EMS data by capturing patient outcomes (e.g., admission from ED, died after admission to hospital, died in ED, discharge alive from ED, transferred from ED to another facility).

**Burn Registry Data**
Burn care is highly specialized. Burn patients constitute a small fragment of EMS transported patients, but are likely to have very high acuity. Neither are all burn patients who might be included in a burn registry (where those registries exist) exclusively delivered to burn care by EMS.

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<th>Burn Registry Data &amp; EMS Data Linkage Survey Results</th>
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1 respondent stated burn registry data are shared with a national database

*Opportunity:* Linking burn registry data with EMS data can provide opportunities for retrospective research on prevention, burn assessment, outcomes, and promulgating treatment guidelines/protocols. Linkage of burn registry data will require states to identify if there is one state-managed registry or several registries managed by individual burn centers or a consortium of burn centers, and identifying common unique identifiers to aid in data completeness and accuracy.

**Reportable Disease Registry**
Linkage between EMS patient care data and reportable disease registry data is or is expected to be an emerging area of interest.

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<th>Reportable Disease Registry Data &amp; EMS Data Linkage Survey Results</th>
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0 respondents stated reportable disease registry data are shared with a national database

*Opportunity:* The ability to link these datasets to track patient movements and study disease outbreaks from an epidemiological perspective will be essential in dealing with pandemic outbreaks.
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Rehabilitation Registry Data
The duration and type of rehabilitation a patient receives can carry important implications in evaluating early treatment modalities and interventions. This is particularly true with the growing emphasis on stroke care as well as the focus on trauma. Linkage between EMS patient care data and rehabilitation registry data is completely lacking.

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<th>Rehabilitation Registry Data &amp; EMS Data Linkage Survey Results</th>
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0 respondents stated rehabilitation registry data are shared with a national database

**Opportunity:** Linkage would provide an opportunity to study the correlation between early intervention and recovery time, identify ways to shorten rehabilitation and decrease costs of care.

**Opportunity:** Linking rehabilitation registry data with EMS data can provide comprehensive information on the full spectrum of caller-system-patient interaction and outcomes that enable patient tracking from system entry to final outcome. Linkage can provide research opportunities to better measure the cost (i.e., public/private financial and patient/family quality of life) of injuries and disease events entering a health care system through the EMS and trauma system. Linkage of rehabilitation registry data will require states to identify if there is one state-managed rehabilitation registry or several managed by individual rehabilitation institutions or a consortium of rehabilitation institutions.

Hospital Discharge Data
Hospital discharge data is one of the more established of the patient databases, and is one of the databases relied upon in CODES linkage projects. Again, not all EMS patients end up being admitted to a hospital, and a small portion of hospitalized patients are delivered by EMS. In the area of overlap, much can be derived related to outcomes of care.

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<th>Hospital Discharge Data &amp; EMS Data Linkage Survey Results</th>
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3 respondents stated hospital discharge data are shared with a national database

**Opportunity:** Linking EMS patient care data and hospital discharge data could help identify ways to shorten hospital stays, decrease costs of care, and reduce medical costs.
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Death Certificate Data
A minority of EMS patients die as a result of the injury or illness triggering EMS response. A proportion of EMS patients succumb to their injuries or illness either at the scene, at the hospital, or after discharge to home or a non-acute care institution.

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</tr>
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<td>6.25%</td>
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<td>83.3%</td>
<td>6.25%</td>
<td>100%</td>
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0 respondents stated death certificate data are shared with a national database

**Opportunity:** The death certificate database is likely the most mature of the databases included in this study. Linkage between EMS patient care data and death certificate data represents an excellent opportunity to identify causality and to effect changes in care that will reduce preventable mortality in the patient population.

Cardiac Arrest Registry Data
Not every patient in such a registry will have been those transported by EMS, and many EMS patients will not suffer cardiac arrest. Further study of the areas of overlap is crucial to developing better strategies for survival and improved outcomes.

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<td>0%</td>
<td>85.4%</td>
<td>6.25%</td>
<td>100%</td>
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2 respondents stated cardiac arrest registry data are shared with a national database

**Opportunity:** Linkage between EMS patient care data and cardiac arrest registry data is important to improving treatment modalities and patient outcomes in prehospital care, in-hospital care and rehabilitation.
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2. Data Linkage History and Near-Future Plans

Whether a state has accomplished a data linkage project in the past is an indicator of its capacity to do so in the future and may help facilitate future endeavors, as the lessons learned from prior data linkage efforts may be partially or wholly transferrable to establishing and maintaining new linkage efforts.

Thirty-six percent of the respondents to this item indicated that emergency medical services patient care data has been successfully linked with other data systems in the past. Of those indicating prior data linkage involving EMS patient care data had occurred, 65% said those efforts had been part of a CODES project.

Another indicator of policy movement in the direction of data linkage would be the prevalence of state statutes requiring or enabling it. Three respondents reported having statutes that specifically set conditions for or require records linkage or that establish access to linked data sets for research purposes.

Whether states plan to incorporate EMS patient care data into linkage efforts in the near future is yet another indication of movement toward comprehensive data linkage efforts. Roughly half of the respondents reported data linkage efforts inclusive of EMS patient care data are planned within the next year.

Ongoing data linkage projects that do not incorporate EMS patient care data were reported by 18 respondents.
3. Data Linkage Challenges

Three factors that are taken into consideration in policy development and implementation are cost, complexity, and criticality.

1. **Cost:**

   Some investment costs are attendant with developing, implementing, and maintaining a data linkage program. As many states continue to struggle with tightening budgets and diminishing revenues, it may be difficult to advance on policy initiatives (such as data linkage) that have a potential savings on the back end of such investment.

   The great advantage of data linkage from a fiscal point of view is that more efficacious policies would mean fewer wasted resources. However, if the initial costs of developing, implementing, and maintaining the program are the only factors considered, these benefits may seem unjustifiable to state-level policymakers wrestling with finite resources and multiple priorities.

   To the extent that state-level data linkage projects occur at all, such efforts are largely associated with leadership, support and funding from the federal government through the CODES project.

   Eighty-five percent of respondents identified funding as a problem or challenge to accomplishing data linkage. Ninety-two percent of respondents indicated increased funding would help facilitate data linkage in their states or territories.

2. **Complexity:**

   Multiple factors can influence the difficulty of a challenge. Technical issues such as those involved in reconciling data definitions, data formats, and inclusion/exclusion criteria all contribute to making data linkage inherently complex. In addition, issues of custodial responsibility, data confidentiality, legal restrictions on usage, access to suitable hardware and software platforms, and access to personnel with adequate expertise may add layers of complexity to the challenge of implementing data linkage.

   Fifty percent of respondents identified inadequate hardware or software infrastructure as a problem or challenge to data linkage. Fifty-two percent of respondents indicated updated equipment or software would facilitate data linkage in their respective states or territories.

   Forty-eight percent of respondents indicated that inadequate access to expertise is a problem or challenge to data linkage. Fifty-eight percent indicated that increased access to expertise would facilitate data linkage.

   Only 42 percent of respondents reported that confidentiality issues represent a problem or challenge to data linkage. An additional 10 percent indicated that jurisdictional issues were a
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problem or challenge. Thirty-three percent of respondents indicated that a change in state law or regulation would help facilitate data linkage. Only 21 percent of respondents indicated that a change in state law or regulation would be helpful.

Twenty-five percent of respondents reported that the lack of interest or willingness of partner organizations to collaborate is an impediment to data linkage. The same number also reported that a change in this would help facilitate data linkage.

3. Criticality:

The level of importance an issue is assigned has significant bearing on its ranking in priority. The survey instrument asked respondents about the level of priority assigned to data linkage by the Governor’s Highway Safety Representative/Traffic Records Coordinating Committee.

Nineteen percent of respondents reported the importance of data linkage is characterized as mission critical. Forty-four percent of respondents reported data linkage is seen as important. Fifteen percent indicated data linkage is seen as somewhat important. Eight percent reported data linkage is seen as low priority. Fifteen percent of respondents reported the importance of data linkage in their states as unknown or unsure.

Funding clearly predominates as an issue that is preventing states from moving forward with data linkage projects. This was the only obstacle identified by more than half of the respondents. Though other difficulties are acknowledged and represented, it is also clear that data linkage is seen as a relatively important issue, with 78 percent of respondents indicating it to be seen as at least somewhat important.
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4. Data Usage

The question of data usage has two elements: what kind of access to the merged data do the agencies that contribute information have; and ultimately, for what purposes are the data intended to be used?

Since this study examines the role of state EMS offices in data linkage, the instrument asked about the type of access the state EMS office has to the data from the merged datasets that include data from the EMS patient care data system.

Access to the individual record level represents the greatest level of access. Eighteen respondents indicated the state EMS office has this level of access to merged datasets.

Standardized reports represent a lesser level of access to merged information. In standardized reports, the level of detail provided is significantly less than at the individual record level, and the reports may be somewhat tailored to the needs of each requesting entity. Thirteen respondents indicated that the state EMS office has access to standardized reports from merged datasets.

Access to aggregated data is another lesser form of access. Aggregated data can be useful but often have limited application for any detailed analysis. Ten respondents indicated that the state EMS office has access to aggregated data from merged datasets.

Variable access means that the level of access changes depending on the specific datasets involved in the request for information and the clearance of the requesting entity to the various elements of the data. Eleven respondents reported that the state EMS office has variable access to information from merged datasets.

Seven respondents answered that the state EMS office has no access to information from merged datasets, and seven respondents indicated that the level of EMS office access to merged data was unknown.

The ways in which the linked data are used by various programs in the state speak to the purpose of creating and maintaining the linked data.

Twenty respondents indicated the linked data are used for research purposes. Nineteen respondents reported that the merged data are used to produce standard periodic reports. Sixteen respondents indicated the data are used for ad hoc reports. Ten respondents indicated the data are used to evaluate and refine existing policy and regulation.
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Conclusions and Recommendations

The survey found that most linkages with EMS patient care data systems are remnants or parts of contemporary CODES projects; and that funding is the predominant issue preventing states from moving forward with data linkage projects.

*Recommendation:* NHTSA should look at restoring CODES funding to previously participating states that discontinued their CODES projects after the 2009 NHTSA CODES funding restructuring.

Disparate hardware, software, and data standards in data collection amongst agencies that share a common public health and safety goals precludes reliable and cost-effective data export or exchange, and precludes these agencies from identifying trends throughout the continuum of care.

*Recommendation:* A data collection and reporting system standard should be adopted that facilitates reliable and cost-effective data linkage (e.g., NEMSIS, NTDB, and HL7, NFIRS), and a national body comprised of key national data stakeholders should be established with appropriate levels of funding allocation.

The inconsistency of statutes amongst the several states on data linkage is a combination of some mandating, some not mandating, and others setting conditions on data linkage. Promulgating consistent statutes that authorize intra-state agency data linkage without burdensome conditions will facilitate data linkage.

*Recommendation:* The data managers within their respective disciplines of the several states, in cooperation with NHTSA should establish a process to share their statutes and draft recommended statutory content and policy recommendations that facilitate intra-state agency data linkage.

While most state EMS offices see data linkage as important, it can sometimes be challenging to communicate the importance to other stakeholders, especially funding sources, unless they can show concrete examples of how the linked data is necessary to evaluate and monitor system performance.

*Recommendation:* NHTSA should commission the identification and development of EMS system performance measures that can only be measured using data from linked datasets.
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Appendix-1: 2011 NASEMSO EMS Data Linkage Survey Instrument

<table>
<thead>
<tr>
<th>Name of State/Territory</th>
<th>Name of Person Completing Survey</th>
<th>Title of Person Completing Survey</th>
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<tbody>
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<tr>
<td>Phone Number</td>
<td>Fax</td>
<td>E-mail address</td>
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### A. Data Systems Linkage Status

1. Please indicate which of the following data systems in your state are currently and routinely linked to the EMS patient care data system (PCDS), the type of linkage used (D = Deterministic, P = Probabilistic) and which systems transmit data to a national database (NDB):

<table>
<thead>
<tr>
<th>Data System</th>
<th>Linkage with EMS Data</th>
<th>Type of Linkage</th>
<th>Shared with NDB</th>
</tr>
</thead>
<tbody>
<tr>
<td>911 Dispatching Data</td>
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<tr>
<td>Motor Vehicle Crash Data</td>
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<tr>
<td>Emergency Department Data</td>
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<tr>
<td>Trauma Registry Data</td>
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<tr>
<td>Burn Registry Data</td>
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<td>Reportable Disease Registry</td>
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<tr>
<td>Rehabilitation Registry Data</td>
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<td>Hospital Discharge Data</td>
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<td>Death Certificate Data</td>
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<tr>
<td>Cardiac Arrest Registry (e.g., CARES)</td>
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<tr>
<td>Specific Other:</td>
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</tbody>
</table>

2. If EMS data are **not** currently and routinely linked to any other data systems:

   - Has the EMS PCDS been linked with other data systems in the past? [ ] Yes [ ] No [ ] Unknown
   - If so, was the previous effort part of the CODES project? [ ] Yes [ ] No [ ] Unknown
   - Are datasets other than EMS PCDS being successfully linked in your state? [ ] Yes [ ] No [ ] Unknown
   - Is data linkage inclusive of EMS PCDS being planned within the next year? [ ] Yes [ ] No [ ] Unknown

3. Does your state have statutes that specifically set conditions for or requires records linkage, or that establish access to linked data sets for research purposes?

   - [ ] Yes [ ] No

### B. Data Linkage Challenges:

1. Which (if any) of the following characterize problems or challenges your state faces in linking discrete datasets? *(check all that apply)*

   - Funding
   - Confidentiality issues
   - Data usage restrictions
   - Inadequate access to technical expertise
   - Interest/Willingness of partners to collaborate
   - Software/hardware infrastructure
   - Jurisdictional issues
   - State law prohibits data linkage
   - Other issues (specify: )

2. Which (if any) of the following would help facilitate the linkage of datasets in your state? *(check all that apply)*

   - Increased funding
   - Enabling legislation
   - Regulatory changes
   - Greater access to technical expertise
   - Interest/Willingness of partners to collaborate
   - Updated equipment/software
   - Other (specify: ) [ ] Unknown

3. Which of the following best characterizes the priority assigned to data linkage by the Governor’s Highway Safety Representative/Traffic Records Coordinating Committee in your state?

   - Mission-critical
   - Important
   - Somewhat important
   - Low priority
   - Unknown/unsure

### C. Data Usage:

1. What type of access does the EMS office have to the data from the merged datasets that include data from the EMS PCDS?

   - [ ] Individual record level (including identifiers)
   - [ ] Standard reports
   - [ ] Aggregated (no individual identifiers)
   - [ ] Varies with type of datasets merged
   - [ ] No access
   - [ ] Unknown

2. In what ways are the linked data used by various programs in your state? *(check all that apply)*

   - Research purposes
   - Generate periodic standardized reports
   - Generate ad hoc reports
   - Evaluate and refine existing policy and regulation
   - Other (specify: )
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Appendix-2: State Data Linkage Diagram Examples

Idaho Trauma Registry Data Flow
Courtesy of State of Idaho EMS Bureau and the Idaho Hospital Association

For questions regarding the Idaho Trauma Registry Data Flow, contact the Idaho EMS Bureau at:

- (877) 554-3367
- IdahoEMS@dhw.idaho.gov
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Kansas Emergency Medical Services Information System (KEMSIS) & Kansas Department of Health and Environment (KDHE) Data Integration

For questions regarding the KEMSIS & KDHS Data Integration Chart, contact the Kansas Board of EMS at:

- (785) 296-7296
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North Carolina Outcomes Data System

For questions regarding the North Carolina Outcomes Data System, contact the North Carolina Office of EMS at:

- (919) 855-3935