RELEASE OF INFORMATION FROM THE EMS DATABASE

PURPOSE

To set the standards for providing quality EMS data to health professionals, researchers and the general public from the EMS Database while preserving confidentiality and protecting the privacy of patients and patient records. This Policy creates the procedure to release both confidential and non-confidential information.

POLICY

All requests for EMS data will be evaluated and performed according to the procedures described herein as well as the policies set forth by governing agencies.

AUTHORITY

A.R.S. § 36-2204, Medical Control.
A.R.S. § 36-2220, Records; confidentiality; definition
A.R.S. § 36-2221, Requirements: confidentiality: violation: classification.
A.R.S. § 36-2401, Definitions.

APPLICABILITY

EMS Database
Bureau of Emergency Medical Services and Trauma System (BEMSTS)

DEFINITIONS

Confidential data and information – Any form of data and information (case reports, computer records, computer printouts, etc.) from which an individual patient, the patient's family, or the patient's health care provider or facility might be identified that is not considered public information. Confidential data and information is also known as protected health information (PHI).

Data Linkage – Process whereby it is determined if a record in a file matches to one or several records in another file.

Public Use Data Files – Dataset available to the public with permission.

Researcher – Individual or group that is requesting confidential data and information from the EMS Database, including, but is not limited to, entities such as research groups, educational institutions, and government agencies.

Summary data and information – Data that is aggregated and displayed so that Confidential data and information, as defined above, cannot be identified.

DIVISION OF PRIMARY RESPONSIBILITY

Arizona Department of Health Services (ADHS)
BEMSTS

PROVISIONS AND GUIDELINES

A.   General Data Confidentiality Policies

1.   Under no circumstances shall confidential data and information be released to the public in any form.

B.   Request for Confidential Data and Information

1.   Confidential data and information required by Researchers for research purposes will only be released upon approval of the BEMSTS Bureau Chief, BEMSTS Medical Director, BEMSTS Data & Quality Assurance Section Chief, the EMS Data Manager. Researchers seeking confidential data and information must submit a request to the EMS Data Manager in writing in accordance with established procedures as outlined in Procedure B of this Policy.

2.   Inquiries from the press/media shall be referred to the ADHS Public Information Office (PIO). The PIO can be contacted at (602)542-1094. Only aggregate non-confidential information may be given to the media but the EMS Data Manager must first inform the PIO of the inquiry.

C.   Inappropriate Uses of Confidential Data or Information

1.   Confidential data and information contained in the EMS Database shall not be made available to the following:

   a. Businesses trying to market a product to EMS patients
   b. Insurance companies trying to determine the medical status of a patient
   c. Next-of-kin of reported patients, without proper authorization

D.   Disclosure of Summary Data and Information

1.   Summary data and information shall be disclosed in the following manner:

   a. Summary data and information contained in published reports by the EMS Database will be available upon request.

    b. Requests for summary data and information not available in EMS Database reports must be made to the BEMSTS Data & Quality Assurance Section Chief or the EMS Data Manager. The requestor may be required to cover the costs of obtaining the data.

    c. A comment, analysis, or interpretation of the data may be provided by the EMS Database.

2. To eliminate the possibility that individuals might be identifiable from tables containing cells with very small values, cell counts may be suppressed in the case of tables with cell counts less than 5 for <=1 year of data if the geographic area is smaller than the county level.

3. Users of EMS Database Public-Use Data Files will be required to sign an EMS Database Public-Use Data Agreement prohibiting the use of data for purposes of identifying an individual patient, a patient's family, or the patient's health care provider or facility, or for statistical publications that may result in identifying an individual patient, a patient's family, or the patient's health care provider or facility. These stipulations are outlined in further detail in the agreement. See Exhibit 1.

E. Re-Disclosure of Confidential Data and Information

1. Authorized recipients of confidential data and information shall not disclose the data and information to any other person or organization.

F. Releasing Confidential Data and Information to Other ADHS Programs

1. Confidential data and information may be released to another ADHS program upon completion of the ADHS Internal Data Request Form and approval by the EMS Data Manager, BEMSTS Data & Quality Assurance Section Chief as well as the BEMSTS Bureau Chief. See Exhibit 2.

G. Releasing Data to Independent Researchers.

1. Summary data and information may be released upon request.

2. Requests for confidential data and information intended for research purposes must be approved by the HSRB. (See Procedure B)

PROCEDURE

A.   Preserving Confidentiality of the EMS Database

1.   All documents identifying a specific individual, health care provider or health care facility are considered confidential data and information and, as such, are safeguarded to the maximum possible extent. Every employee having access to the EMS Database also has access to confidential data and information regarding persons and health care institutions interacting with EMS agencies. Employees have an express responsibility to protect the privacy of the persons and EMS agencies whose records are in the EMS Database. This is a moral and legal obligation; therefore, statutes and rules of confidentiality must be observed at all times.

2.   Data and information that identifies a patient, a patient's family, or a patient's health care provider or facility is not disclosed or discussed with anyone other than employees having access to the EMS Database or staff from the specific reporting source(s). All employees are informed of their responsibility regarding confidential data and information. Breach of confidentiality will be grounds for immediate disciplinary action, up to and including dismissal and criminal prosecution. All employees are required to sign a pledge to maintain confidentiality of all information.

B.   Submitting a Request for Confidential Data and Information for Research Purposes

1.   The researcher may contact the EMS Data Manager by e-mail or by phone to announce his/her intent to submit a formal request. The EMS Data Manager will fax or e-mail the "Public Records Request Form" See ADM-020 (Exhibit 1) and the "EMS Database Data Request Form" (See Exhibit 3).

2.   The researcher must complete the "Public Records Request Form" and the "EMS Database Data Request Form" and fax or e-mail the forms to the The EMS Data Manager.

3.   The researcher must submit a request to the ADHS Human Subject Review Board (HSRB) for approval. No confidential data and information will be released to the researcher without prior approval of the HSRB. The HSRB application and instructions are available at http://www.azdhs.gov/diro/legal/hsrb.htm.

4.   A copy of the formal request to the ADHS Human Subject Review Board must be forwarded to the EMS Data Manager. The formal request protocol should include:

a.   A brief outline of the proposed research
b.   A justification of the need for confidential data and information
c.   A list of requested data variables

d.   The preferred format of the data
e.   Needed frequency of the data (i.e., One-time data linkage vs. a continuous data pull for a survey)
f.   Description of how the data will be stored

g.   A list of who will have access to the data and how it will be safeguarded from unauthorized access

h.   A description of how and when the data will be destroyed upon completion of the research project.

5.   The checklist form "Checklist for Releasing Confidential EMS Data" (See Exhibit 4) will be initiated to track progress of the request from submission to fulfillment or disapproval.

6.   After HSRB review and approval the EMS Data Manager will be sent a copy of the approval letter from the HSRB. Upon receipt of the approval the request will be processed.

   a. No data will be released to Researchers if the HSRB disapproves of the research project.

   b. Upon approval of the HSRB the Bureau Chief of BEMSTS, the Data & Quality Assurance Section Chief and the EMS Data Manager will make the final decision concerning the appropriateness of releasing the data.

7.   Upon completion of the request, the EMS Data Manager will provide the researcher the confidential data file, a letter describing the data, and a data dictionary produced by the EMS Data Manager. These will be delivered via one of the following ways:

   a. The requested variables in a password-protected CD-R in an ASCII fixed field length data file or agreed upon format through Fed Ex in an envelope marked "confidential".

   b. The requested variables in a password-protected ASCII fixed field length data file or agreed upon format through encrypted e-mail using Secure Messenger by following the procedures in the Secure Messenger manual provided by Information Technology Services at ADHS.

   c. The requested variables in a password-protected ASCII fixed field length data file or agreed upon format through encrypted secure File Transfer Protocol (FTP).

   8. The password will be sent separately via an encrypted e-mail using Secure Messenger by following the procedures described in the Secure Messenger manual provided by Information Technology Services at ADHS.

   9. The EMS Data Manager will maintain a patient listing of the data sent to the Researcher. This will allow the EMS Data Manager to answer any questions after the data file has been sent to the researcher. This also allows the EMS Data Manager to identify or track data used for research.

   10. The EMS Data Manager will maintain all files related to the research project and will update the Data Request Log immediately upon receiving a project completion notice from the researcher

Responsible Position: Data & Quality Assurance Section Chief

C. **Procedure for Data Linkage Using Confidential Data and Information**

1. Follow Procedure B.1-8 above, then proceed below.

2. The EMS Data Manager or designated BEMSTS staff will be responsible for conducting the data linkage, providing the results to the researcher, and ensuring the confidentiality of the researcher's dataset.

3. The EMS Data Manager or designated BEMSTS staff will make arrangements with the researcher to perform the data linkage, including obtaining the data format and data variables that the researcher requires for the linkage. In most instances, it is preferred that the researcher provide the BEMSTS with a dataset with which the BEMSTS can conduct the match; this method will restrict access to the EMS Database records as much as possible. Some researchers may require the BEMSTS to provide them with a dataset to which they can match their data.

4. The data file should be submitted on a CD-R in an ASCII fixed field length file or in an agreed upon format and exchange. The following variables should be included: first name, last name, social security number, date of birth, and sex.

    a. Additional personal identifying information should also be included if available.

5. The data linkage will be completed using automated linkage:

    a. For automated linkages, the EMS Database will conduct a probabilistic match using LinkPlus. The match will be conducted on the fields listed in C.3. using a match probability of 95% or greater; a cut-off ratio will be determined at the time of linkage. The BEMSTS will make any necessary judgment calls as to whether possible matches contain enough information to be considered a match.

    b. Matching records will be randomly reviewed to verify the records were matched correctly.

6. The requested data on the matched cases will then be pulled from EMS Database using the following process:

    a. An export file of the matches is created in LinkPlus and MUST include the "Patient Name" in addition to the fields that are being matched.

    b. The Patient Name will be used to pull from the EMS Database. An export file will be created containing the necessary patient identifiers, including the Patient Name, and the requested variables. The procedure will be further defined in a separate Linkage procedure.

7. Upon completion of the data linkage and extract, the EMS Data Manager will provide to the researcher the data, a letter describing the data linkage procedures and criteria of release of EMS data and a data dictionary. These will be delivered via one of the following ways:

    a. The requested variables in a password-protected CD-R in an ASCII fixed field length data file or agreed upon format through Fed Ex in an envelope marked "confidential".

    b. The requested variables in a password-protected ASCII fixed field length data file or agreed upon format through encrypted e-mail using Secure Messenger by following the procedures in the Secure Messenger manual provided by Information Technology Services at ADHS.

    c. The requested variables in a password-protected ASCII fixed field length data file or agreed upon format through encrypted secure File Transfer Protocol (FTP).

8. The password will be sent separately via an encrypted e-mail using Secure Messenger by following the procedures described in the Secure Messenger manual provided by Information Technology Services at ADHS.

9. It is anticipated that the linkage process described above will be completed within 4 weeks of receipt of the researcher's data by the BEMSTS. The BEMSTS will notify the researchers of any delay in achieving this target date.

10. Data provided to the BEMSTS will be deleted from the Bureau's computer system (and all copies and any derivatives files destroyed) as soon as the researcher notifies the BEMSTS in writing that the work scope has been completed.

11. The BEMSTS will maintain all forms, etc. related to research project. The EMS Data Manager will update the Data Request Log immediately upon receiving a project completion notice from the researcher that the project has been completed.

Responsible Position: Data & Quality Assurance Section Chief

D. Request for Non-Confidential Aggregate Data

1. The person requesting the data will contact the EMS Data Manager by e-mail or by phone to announce his/her intent to submit a request. The EMS Data Manager will fax or e-mail the ADHS form "Public Records Request Form" (See ADM-020 Exhibit 1) and the "EMS Database Data Request Form" (See Exhibit 3) as well as the "Public Use Data Agreement".

    a. The EMS Data Manager will ask the requestor to specify on the request form what data is requested and to include his/her name, address, phone or e-mail information so that the BEMSTS staff can contact the researcher if necessary to complete the request.

2. The EMS Data Manager will contact the requestor when the request form is received and gather any additional information needed to fulfill the request.

    a. The EMS Data Manager will estimate to the requestor when the data request may be

completed.

3.   The EMS Data Manager runs the data query from the EMS Database. The EMS Data Manager will create summary data tables to send to the requestor. The EMS Data Manager will include the appropriate footnotes for the data query such as citing the EMS Database as the data source, the date of the data query, and any other information specific to that data query.

4.   The EMS Data Manager will e-mail or fax the completed data request to the requestor. The EMS Data Manager fills out a data request cover sheet that includes the requestor's information, the data requested, and what information the EMS Data Manager gave the requestor, including the filenames and file locations of the data query. The data request cover sheet and any information related to this data request are stapled together and put in the data request file drawer. The EMS Data Manager will update the Data Request Log immediately upon completion of fulfilling the request.

5.   When fulfilling data requests, the EMS Data Manager must use discretion and best judgment to determine how much detailed information the EMS Database can provide to the requestor. The EMS Data Manager must, if appropriate to the data request, follow the Arizona Department of Health Services confidentiality guidelines and the small numbers policy set by the Bureau of Public Health Statistics. The EMS Data Manager is not permitted to release any data that could lead to the identification of an individual patient, a patient's family, a patient's health care provider or facility.

Responsible Position: Data & Quality Assurance Section Chief

E.   Request for Non-Confidential Patient Level Data

1.   The person requesting the data will contact the BEMSTS by e-mail or by phone to announce his/her intent to submit a request. The EMS Data Manager will fax or e-mail the ADHS form "Public Records Request Form" See ADM-020 (Exhibit 1) and the "EMS Database Data Request Form" (See Exhibit 3) as well as the "Public Use Data Agreement".

a.   The EMS Data Manager will ask the requestor to specify on the request form what data is being requested and his/her name, address, phone or e-mail information so that the BEMSTS staff can contact the researcher if necessary to complete the request.

2.   The EMS Data Manager will contact the requestor when the request form is received and gather any additional information needed to fulfill the request.

a.   The EMS Data Manager will determine if this request can be done and that it does not violate confidentiality procedures. If there is any question related to appropriateness of releasing patient level data, the EMS Data Manager will meet with the BEMSTS Data & Quality Assurance Section Chief for direction.

b.   The EMS Data Manager will estimate to the requestor when the data request may be completed.

3.   If an agreement is made to proceed with the release of patient-level non-confidential data, the EMS Data Manager will write a short memo documenting the decision to proceed or not. If the request is disapproved, the EMS Data Manager will notify the requestor.

4.   The EMS Data Manager will process the request.

5.   Upon completion of the data request, the BEMSTS will send the data to the requestor with the requested variables and a data dictionary. These will be delivered via one of the following ways:

a.   The requested variables in a password-protected CD-R in an ASCII fixed field length data file or agreed upon format through Fed-Ex in an envelope marked "confidential".

b.   In a password-protected ASCII fixed field length data file or agreed upon format through encrypted e-mail using Secure Messenger by following the procedures in the Secure Messenger manual provided by Information Technology Services at ADHS.

c.   In a password-protected ASCII fixed field length data file or agreed upon format through encrypted secure File Transfer Protocol (FTP).

6.   The password will be sent separately via an encrypted e-mail using Secure Messenger by following the procedures described in the Secure Messenger manual provided by Information Technology Services at ADHS.

7.   The EMS Data Manager will maintain all forms , etc. related to the data request. The EMS Data Manager will update the Data Request Log immediately upon receiving a project completion notice from the researcher.

Responsible Position: Data & Quality Assurance Section Chief

 F.   Request for Non-Confidential Public Use File for Research Purposes

1.   The researcher requesting the data will contact the BEMSTS by e-mail or by phone to announce his/her intent to submit a request. The EMS Data Manager will fax or e-mail the ADHS form "Public Records Request Form" (See ADM-020 Exhibit 1) and the "EMS Database Request Form" (See Exhibit 3) as well as the "Public Use Data Agreement".

    a. The EMS Data Manager will ask the researcher to specify on the request form what data is being requested and his/her name, address, phone or e-mail information so that the BEMSTS staff can contact the researcher if necessary to complete the request.

2.   The researcher must submit a formal request protocol to the BEMSTS. The request should include:

    a. A brief outline of the proposed research

    b. A justification of the need for the Public Use File

    c. A list of necessary data variables for the research

    d. The preferred format of the data

    e. Needed frequency of the data (i.e., One-time data linkage vs. a continuous data pull for a survey)

    f. Description of how the data will be stored

    g. A list of who will have access to the data and how it will be safeguarded from unauthorized access

    h. A description of how and when the data will be destroyed upon completion of the research project.

3. The EMS Data Manager will contact the requestor when the request form is received and obtain any additional information needed to fulfill the request.

4. The EMS Data Manager or the designated BEMSTS staff will process the request.

a. The EMS Data Manager or the designated BEMSTS staff will estimate to the researcher when the data request may be completed.

5. Upon completion of creating the Public Use File, the EMS Data Manager will provide to the researcher the data and a data dictionary. These will be delivered via one of the following ways:

    a. The requested variables in a password-protected CD-R in an ASCII fixed field length data file or agreed upon format through Fed Ex in an envelope marked "confidential".

    b. In a password-protected ASCII fixed field length data file or agreed upon format through encrypted e-mail using Secure Messenger by following the procedures in the Secure Messenger manual provided by Information Technology Services at ADHS.

    c. In a password-protected ASCII fixed field length data file or agreed upon format through encrypted secure File Transfer Protocol (FTP).

    6. The password will be sent separately via an encrypted e-mail using Secure Messenger by following the procedures described in the Secure Messenger manual provided by Information Technology Services at ADHS.

7. The EMS Data Manager will maintain all forms, etc. related to data request. The EMS Data Manager will update the Data Request Log immediately upon receiving a project completion notice from the researcher.

Responsible Position: EMS Data Manager

G.   Request for Non-confidential Patient Level Data by ADHS Staff

1. To submit a formal request for non-confidential patient data, the ADHS staff member must fill out a Release of Data Internal Request form (See Exhibit 2) and send it to the EMS Data Manager. The request should include:

   a. The preferred format of the data, the frequency that the internal staff member needs this data (i.e. a one-time data linkage vs. a continuous data pull for a survey) needs to be stated on the form.

   b. A brief outline of the proposed use of the data

   c. A justification of need for patient level data

   d. A list of data variables requested.

2. The request will be reviewed by the EMS Data Manager, BEMSTS Bureau Chief, and the BEMSTS Data & Quality Assurance Section Chief.

3. If the request is approved, the EMS Data Manager will process the data query from the EMS Database and export all records meeting the requestor's criteria with requested data fields into an ASCII fixed field length text file or agreed upon format.

4. The data will be sent to the internal staff by either intranet e-mail or a CD.

5. If the request is rejected, the EMS Data Manager will e-mail the requestor stating reason(s) for the request's rejection and specify any changes needed for the request to be approved.

6. The EMS Data Manager will maintain all forms, etc. related to data request. The EMS Data Manager will update the Data Request Log immediately upon receiving a project completion notice from the researcher.