NASEMSO Data Managers Council

Ebola Exposure

QUESTION: (asked by Anne Vossbrink, AZ)

Do you have a de-identified public data set available for your State on an individual patient level?
If so, what data elements (variables) do you include?
Also, any tips or points I should know based on your experience developing one would be great.

State	Respondent	Data Set	Variables	Tips/Comments
FL	Steve McCoy	No		Have considered it but our legal is on par with Paul's legal in Virginia. We too have complete discretion on the data release. We have requestors complete a data sharing agreement that will either be approve or deny based on their proposals ability to reduce mortality and/or morbidity and not be linked to any political hot topics. I'll send that to you. It's not online yet. We brought the subject up with our state EMS council and there was a lot of concern about how far someone could drill down in the dataset to determine where the record was derived. Things like incident zip and even county were opposed.
IL	Dan Lee	Yes		We are just in the process of ramping up a site that provides exactly what you describe, i.e., a de-identified public dataset on an individual patient-record level. Here's a link: https://webdata.emsdata.com/IllinoisEMSData/Login.aspx?ReturnUrl=%2fIllinoisEMSData%2fPublic.aspx
MA	Ridgley Ficks	No		Our privacy rules prevent this type of data set be publicly available, everything must be aggregated with at least 6 instances.
ND	Lindsey Narloch	No		I am in the phase of what to include, what not to include, how often to put it out, how to automate it, what de-identified really means etc.
NM	Stuart	No		We never created a public data set. However, the data NM submits to NEMSIS (via ImageTrend) is de-identified, but it is not publically available on an individual record level. Personally I didn't see a need for a public data set on an individual level, and I don't remember ever being asked for one.

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UT	Shari Hunsaker	No		Utah prepares a public release data set for Emergency Department discharges. No other public data sets are prepared; however, the Department of Health does have a publicly accessible data query system that includes trauma and pre-hospital as well as ED. The product is called IBIS (Indicator Based Information System). Various programs within the DOH send files to the IBIS team or update their own indicator reports. Anyone can build a simple query that returns a cross-tab report. You can visit the site at http://ibis.health.utah.gov/about/Welcome.html
VA	Paul Sharpe	No		Virginia does not have a public dataset. Because our EMS and Trauma registries are exempted from the Freedom of Information Act, so our attorneys general rep has advised us not to create one any release of information policies. We share our data liberally, but we do have complete discretion on giving it out. We have considered doing something similar to NEMSIS and having a standard research dataset, but we would be careful not to define it publicly.