COACTION PUBLISHING

Data requests for research: best practices based on the North Carolina DETECT experience

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Objective

To describe the process by which researchers request access to data sets of emergency department data from NC DETECT, the history of this process and the resulting best practices and lessons learned.

Introduction

The North Carolina Division of Public Health (NC DPH) has been collecting emergency department data in collaboration with the Carolina Center for Health Informatics in the UNC Department of Emergency Medicine (CCHI) since 1999. As of August 2011, there are 113 of 115 emergency departments sending data electronically at least once daily to NC DETECT. Data elements include disposition, initial vital signs, up to 11 ICD-9-CM final diagnosis codes, up to five external causes of injury codes (E-codes), as well as the arrival date and time, patient sex and age, patient zip and county and chief complaint. As of January 2008, NC DETECT emergency department data covered 99% of the NC population and captures approximately 4.5 million ED visits each year. As a result, requests for data from researchers continue to increase. Use of the data for public health purposes is covered by the mandate requiring hospitals to submit their emergency department data to NC DPH.

Methods

Data requesters must use the ED data in NC DETECT for public health-focused studies. Data requests from commercial entities are not approved. The data request process occurs primarily via paper and e-mail, although we have implemented a centralized tracking system to store all documentation for data requests and track changes to them over time. To initiate the process, requesters view a presentation on https://www.ncdetect.org/ReportsPortal/public/dataRequest.do and then enter information on the study purpose, the researchers involved, any grants covering the research and the specific data requested—specifically the data elements, time frame and file format. Researchers must get approval from their home institution's Institutional Review Board and sign a Data Use Agreement (DUA) with NC DPH. The DUA outlines data use requirements such as securing the data during the study, presenting data in aggregate form only (in a manner in which an individual cannot be identified), sharing materials with NC DPH prior to presentation or publication and destroying data upon completion of the study. Data requests within NC DPH typically do not require a DUA and are exempt from this process. In addition, researchers who need to determine the feasibility of a study before submitting a full data request can go through an exploratory process that requires a DUA but no IRB. While data requests are ongoing, a small Data Oversight Committee (DOC) meets once monthly to review these requests and to discuss status and outstanding issues. The NC DETECT DOC includes representatives from the NCDPH, CCHI, NC Hospital Association (NCHA) and DPH legal personnel (as needed).

Results

We currently have 31 data requests in our online tracking system. Each data request represents multiple e-mails and phone calls, iterative revisions to the data request and multiple data pulls from the NC DETECT database. Requests can be delayed when researchers request data elements that are not collected by NC DETECT, submit unclear requirements, change requirements, do not understand the challenges of processing free text data and/or add/change researchers who will be accessing the data. Requesters have used NC DETECT data to publish manuscripts on topics including the health effects of wildfires, ED visits for cancer patients, tick-borne illness and asthma, and comparison of NC ED visit data to national data, among others. Because the ED visit data are collected under a state mandate and in collaboration with the NCHA, their release and use for research is thoroughly evaluated by the DOC. The complexity of the data requests over time has resulted in changing of data use restrictions, as well as revisions of the DUA wording. We do not have enough resources to closely monitor the use of the data once they are provided to researchers. However, researchers are expected to abide by all provisions detailed in their DUA and by signing acknowledge the potential penalties for violation of the terms the agreement.

Conclusions

Data requests can take a considerable amount of time and iterative discussions with the requester, even with a well-defined process and clear documentation. Understanding the administrative and technical time commitments involved is important when considering making syndromic surveillance data available to external users for research.

Keywords

Data sharing; data use agreements; data requests

References

1. N.C. GS § 130A 480.
2. www.ncdetect.org/pubs.html

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