ENVIRONMENTAL PUBLIC HEALTH TRACKING ASTHO FELLOWSHIP REPORT

Submitted by

Colleen Kaelin, MSPH, RS Epidemiologist II

Kentucky Department for Public Health Division of Public Health Protection and Safety 275 East Main Street Mail Stop HS1E-B Frankfort, KY 40601

Submitted to

Association of State and Territorial Health Officials Environmental Public Health Tracking: State-to-State Peer Fellowship Program 2231 Crystal Drive, Suite 450 Arlington, VA 22202

07-15-14

INTRODUCTION

In February 2014, the Association of State and Territorial Health Officials awarded funds to several state health agencies to acquire and submit hospital discharge data for four health outcomes (asthma, carbon monoxide poisoning, heart attacks, and heat stress illness) to the National Environmental Public Health Tracking Network. The Environmental Public Health Tracking Network was initiated by the Centers for Disease Control and Prevention in 2009 to provide a web-based system of integrated health, exposure, and hazard information and data from a variety of national, state and city sources that would be accessible to the general public. Currently, 24 jurisdictions are funded by the CDC to transmit data to the national network and to build their own local tracking networks, which display Nationally Consistent Data and Measures along with any additional data the member states may choose.¹

The Association of State and Territorial Health Officials founded the Environmental Public Health Tracking State-to-State Peer Fellowship Program to increase the capacity for tracking in non-funded states, such as Kentucky, which became a fellowship member in 2010. In May 2013, Kentucky became the first non-funded state to submit data to national tracking network. The data sent by Kentucky was provided by the state Department for Environmental Protection Drinking Water Branch and processed by the Department for Public Health.² Submitting community Drinking Water Data allowed Kentucky staff to gain hands-on experience in the process of collecting, formatting and transmitting data to the national network and allowed us to assess our available resources along with the resources that we would need to build an environmental public health tracking program in Kentucky.

Providing hospital discharge data to key public health decision makers and the general public is important because Kentucky leads the nation in many common and preventable causes of death and in behaviors that contribute to preventable disease. According to Kentucky Health Facts, a website sponsored by the Foundation for a Healthy Kentucky, the current rate of premature death in our state is 9,271 years of potential life lost per 100,000 population, compared with the national rate of 7,562 for the same time period.³ In 2012, Kentucky had one of the highest adult asthma prevalence rates in the nation at 11.1%, compared to a rate of 8.9% for the entire United States, according to the Behavioral Risk Factor Surveillance System.⁴ According to America's Health Rankings, Kentucky ranks 45th in the nation in overall health outcomes.⁵ In addition, Kentucky is also home to many industries that have a potential impact on the environment and the public's health. The coal mining industry, particularly mountaintop removal mining, has been the subject of much concern and many studies regarding the potential impact on the incidence of cancer and birth defects in nearby residents. There are

numerous industries in Kentucky that can impact the health of workers and surrounding communities including, but not limited to, chemical plants, agriculture, and distilleries. Despite Kentucky's array of environmental health hazards and poor health outcomes, there is no comprehensive system in place to effectively track and connect state health and environmental data sources to health outcomes for key decision makers and the general public. By submitting hospitalization data to the Environmental Public Health Tracking Network, we can help community leaders and the public examine the impact of the environment on our state's health.

The objective of National Environmental Public Health Tracking Program is to expand to all 50 states. This project will help the program reach that goal by making data on inpatient and outpatient hospital visits accessible for jurisdictions where this information is not currently available. The project will also help promote contact between national tracking program staff and unfunded state health departments, and will provide the participating jurisdictions invaluable experience in environmental public health tracking by helping to build partnerships both within state health agencies, between fellowship members and tracking mentor programs and with external data shareholders. The national tracking program staff will learn from the participants what resources in personnel and IT infrastructure are needed by unfunded states to transmit data to the tracking program, and the tracking staff will gain experience in guiding unfunded states through the data submission process. The project will mutually benefit the participating health departments and the national tracking program.

REPORT ON PROJECT ACTIVITIES

The primary tasks associated with the Hospital Discharge Data Submission Project include Data Acquisition, Metadata Creation, Data Formatting and Data Submission. The project was first proposed during a meeting of the ASTHO Fellowship Members at the Centers for Disease Control and Prevention in Atlanta, Georgia in August 2013. Fellowship members reported on their activities in building environmental public health tracking capacity. Colleen Kaelin reported on Kentucky's experience in partnering with the state Department of Environmental Protection to exchange, format, and transmit community drinking water data to the national tracking network. Other capacity-building activities in Kentucky up to that time included the formation of a state Environmental Public Health Tracking Workgroup/Technical Advisory Group and the completion of two data linkage projects which examined the possible connection between environmental conditions, such as priority air pollutants and flooding, with respiratory conditions, primarily asthma. Kentucky maintained a strong relationship with the mentor tracking program in the state of Florida throughout this period. The Florida tracking staff conducted a webinar with the Kentucky TAG on September 13, 2013, which updated the Kentucky TAG members on Florida's tracking activities, including new content areas on the national and state tracking portals, and new visualization tools. Slides and a recording of the webinar were saved on the Kentucky EPHT Workgroup's SharePoint website. Kentucky was accepted into the Non-Funded State/Territorial Health Agency Participation in the Submission of Hospital Discharge Data to the CDC National Environmental Public Health Tracking Network project in February 2014.

Data Partnerships and Collaboration

In Kentucky, Hospital Discharge Data is collected and maintained by the Office of Health Policy in the Cabinet for Health and Family Services. Before the Office of Health Policy would agree to provide access to the hospital discharge data for completion of the project, there was some discussion as to whether it would be necessary for the Kentucky Cabinet for Health and Family Service Institutional Review Board (IRB) to approve the hospital discharge data submission project in order to satisfy regulatory requirements regarding the confidentiality of patient information. It was determined by the IRB administrator that the project would not be considered research involving human subjects as specified in 45 CFR 46.102 and therefore no submission to the IRB would be necessary.

The first project activity was the kickoff web meeting on February 25th, 2014. Colleen Kaelin, the epidemiologist for the Department for Public Health Division of Public Health Protection and Safety and the project lead, was joined by Allison Lile, the Office of Health Policy representative, on the call. The topics discussed at the kick-off meeting included gaining access to the national tracking program's SharePoint website, the process of metadata creation and submission, and a two-phase timetable for the project. On March 12th, 2014, ASTHO hosted a webinar guiding the Fellowship members through the SharePoint website. On March 13th, both Kentucky representatives participated in the Spring Data Submission Webinar as an orientation to the data submission process. A request to grant Allison Lile access to the SharePoint website was sent to the national tracking program so that she could review the relevant documents for the project. A new tab was added to the SharePoint website with information and documents specifically for ASTHO fellowship members with a checklist of scheduled activities and a list of resources and tools for the SharePoint site. Kentucky submitted several documents to be published on the ASTHO Fellows Project tab as a reference for other project members. These documents included the Memorandum of Understanding between the Department for Public Health and the Department for Environmental Protection that was used for the submission of the drinking water data along with a draft Data Sharing Agreement between DPH and the Office of Health Policy and an Agreement to Staff Access to Florida Center Data document provided by the mentor program.

Other collaboration activities of the project included check-in conference calls between ASTHO representatives and national tracking program staff with project participants. These calls took place on April 8th, May 6th and June 11th, 2014. Kentucky was represented in all the scheduled check-in calls to give updates on the progress of the project and, whenever possible, to give insight on the process of applying for and gaining access to the Secure Access Management System, metadata creation, and formatting the hospital discharge data. During this time, the usual activities of the Kentucky Environmental Public Health Tracking Pilot Project continued, including conference calls and updates to the Kentucky tracking SharePoint.

Drinking water data for the year 2013 was exchanged between the Department for Environmental Protection and the Department for Public Health, then formatted and submitted to the national tracking program on April 22nd, 2014. The Kentucky EPHT Workgroup/Technical Advisory Group maintained contact through listserv messages and conference calls. In addition, several outreach activities took place during this period. On March 27th, Colleen Kaelin presented a demonstration of the Environmental Public Health Tracking Network and an overview of the ASTHO Fellowship program at the Eastern Kentucky University Environmental Health Symposium. A poster describing Environmental Public Health Tracking was presented at the annual Kentucky Public Health Association Conference on April 16th, 2014. A second presentation demonstrating the tracking network took place at the University Of Kentucky School Of Public Health on May 29th, 2014. On May 28th, the Centers for Disease Control and Prevention released a new Request for Applications with the intention of adding four new jurisdictions to the Environmental Public Health Tracking Network. An application for the Commonwealth of Kentucky was composed and submitted within the grant deadline, and the response from CDC is eagerly anticipated.

Data Acquisition

In order to access the hospital discharge data, the Data Sharing Agreement between the Office of Health Policy and the Division of Public Health Protection and Safety had to be reviewed by Counsel in the Office of Legal Services to ensure that all issues involving the confidentiality of the information and compliance with HIPPA regulations were addressed. The DSA specified the ICD-9 codes, E-codes, and other data elements that would be exchanged between the two agencies. Once the document was edited to include the statement that no patient names, addresses, or any other identifying information would be exchanged, the document was approved by the Office of Legal Services and was signed by the project lead and the Executive Director of the Office of Health Policy on June 30th, 2014. Files containing the unformatted data elements in SPSS format were transferred from the Office of Health Policy to the Division of Public Health Protection and Safety on the same day.

Metadata Creation and Submission

Metadata for the Asthma Hospitalization content area for the years 2000-2012 was created using the SAMS Metadata Creation Tool and submitted on June 26th, 2014. Metadata for Carbon Monoxide, Heat Stress, and Myocardial Infarction Hospitalization for the years 2000-2012 were created and submitted on the following day. On June 30th, metadata for the Asthma, Carbon Monoxide, and Heat Stress Emergency Department content areas was created and submitted. While acquiring the raw data from the Office of Health Policy, the agency representative pointed out that emergency department data was collected beginning in 2008. Unfortunately, due to an oversight on the part of the project lead, metadata files for Asthma Emergency Department visits were created for the years 2000-2007. The project lead, Colleen Kaelin, immediately corrected the data intention spreadsheet and resubmitted this information to ASTHO and the national tracking staff. The metadata files for the three Emergency Department content areas for 2008-2012 were successfully submitted by the project deadline on June 30th. The initial review of the metadata files has been completed, the necessary edits will be made and the files will be resubmitted as soon as possible.

Data Formatting

The IP-NCDM and ED-NCDM SAS files were downloaded by the project lead on May 7th after permission was obtained from the Commonwealth Office of Technology. The project lead ran the SAS programs using the sample data provided in the files, and successfully created XML files for some content areas that were validated by the DIVE tool. However, due to the delay in obtaining the hospital discharge data from the Office of Health Policy, the raw data for Kentucky has not yet been formatted. The process of formatting and validating the raw data into the Hospitalization/Emergency Department Indicators and Measures will begin once the metadata has been edited and accepted by the national tracking program and Metadata Creation Numbers have been issued for each file.

CONCLUSION

Summary of Project

The first phase of the Submission of Hospital Discharge Data to the CDC National Environmental Public Health Tracking Network project has been concluded successfully by the Kentucky Environmental Public Health Tracking Pilot Program. The primary tasks of the project scheduled for completion by the end of the first phase; data acquisition, metadata creation, and data formatting; have either been completed or will soon be completed, and the data upload and submission tasks scheduled for the second phase of the project should be completed within the time frame specified by the project check list. However, there are still some corrections and adjustments that must be made before for the second phase tasks can begin. Most importantly, the metadata files must be edited, resubmitted and accepted by the national tracking program and metadata creation numbers must be issued before the data submission process can begin. The project lead must use the SAS program provided by the SharePoint website to format the data, adding the metadata creation numbers, validating the files using the DIVE tool, and submitting the validated output files to national tracking program via the Secure Access Management System. Over the next few weeks, the project lead will focus on completing the process of metadata creation and data formatting.

Fortunately, most of the contacts and collaborations that were needed for this project were already in place through the pre-existing Kentucky Environmental Public Health Tracking Workgroup/ Technical Advisory Group. There was a designated contact with the data steward agency that was familiar with the Environmental Public Health Tracking Network and the hospital and emergency department indicators and measures. The project lead already had extensive contact with staff at the national tracking program as well as staff in the mentor state of Florida. The project lead also had access to the national program's SharePoint website and the Secure Access Management System prior to the start of the project. Finally, the project lead had experience with the Metadata Creation Tool, the tools and SAS programs available on the SharePoint Website, the DIVE validation tool, and the Secure Access Management System through the submission of community drinking water for two previous data calls. The outreach activities of the Kentucky EPHT Pilot Program and submission of drinking water data during the Spring 2014 data call continued during the project period, as well as the submission of a federal grant application for Kentucky to become one of four new jurisdictions funded by the tracking network.

In spite of the extensive prior experience of the Kentucky EPHT Pilot program, there were significant challenges to completing the primary tasks of this project. Time and resources were stretched very thin, as tracking outreach activities and the submission of another year of drinking water data were the primary responsibility of the project lead, sometimes leaving insufficient time to devote to the hospital discharge data submission project. The data steward representatives expressed concern about the security and confidentiality of the data, and the cooperation of the Cabinet for Health and Family Services' Institutional Review Board and the Office of Legal Services was crucial to assure the data stewards that: (1) the submission of de-identified aggregated data to the national tracking network did not constitute research and (2) the submission of de-identified aggregated data to the network was acceptable under state and federal regulations. Because of these concerns, the project lead did not access the raw data

until the very end of Phase 1 of the project period. The result is that the data formatting process is behind schedule. Insufficient communication between the project lead and the data steward representative in the Office of Health Policy caused an error in the data intentions for the outpatient data; therefore it was necessary to resubmit the data intentions to ASTHO and the national tracking staff. Although welcome, the announcement by CDC of the proposal to add four new jurisdictions to the tracking program and the decision by Kentucky to compose and submit a grant application within a very short frame significantly impacted the amount of time that could be devoted to the data submission project.

Although the previous experience of the project lead in creating metadata and transmitting community drinking water data was helpful in many ways, the specifics of each content area are very different. Attention to detail is necessary in creating correct and acceptable metadata files and in formatting the data. Access to the Data Dictionaries and How-To Guides are crucial. Some method of formatting the raw data into the indicators and measures must be completely planned before a public health agency takes on the tasks of submitting data to the national tracking network. The experience of the mentor tracking program should be sought to as often as necessary in each step of the data collection, formatting and submission process.

The primary lessons learned from the first phase of the hospital discharge data submission project are the necessity of complete and clear communication between data shareholders and tracking staff and to be realistic in terms of the activities that can be accomplished by nonfunded states with no staff or resources officially designated specifically to environmental public health tracking. The cooperation of data steward agencies is crucial, and with health outcome content areas, concerns about the security and confidentiality of the data, and the legality of displaying the indicators and measures must be addressed to the complete satisfaction of all parties before a data submission project can even be considered. The development of a data sharing and data release policy is beneficial to any public health agency considering involvement in environmental public health tracking. Familiarizing data shareholder representatives with the technical details of metadata creation, data formatting, and data exchange with the national tracking network is time consuming, but their participation in the process prevents surprises and miscommunication that will delay or derail the intended data exchange. Above all, environmental public health tracking is a collaborative effort, and adequate time must be given to include and communicate with all the relevant agencies to address legal concerns and administrative issues such as data sharing agreements, downloading computer programs and tools from external websites, and the sharing of data, personnel and resources between agencies.

Recommendations

A hypothetical toolkit for non-funded states that were to consider sending data to the Environmental Public Health Tracking Network might include:

1. An orientation list of Frequently Asked Questions such as:

-What is Environmental Public Health Tracking and what is the Tracking Network?

- -Where does the data in the tracking network come from?
- -What are Nationally Consistent Data and Measures?
- -Who is involved in the tracking network at the local, state and federal level?
- -Who uses the data in the tracking network and what do they use it for?
- -How does the tracking program work in funded states?
- -What are the steps in submitting data to the network?
- -Contact information for national tracking staff

2. A Letter of Introduction to the State-to-State Peer Fellowship Program

3. Instructions on requesting access to the national tracking program's SharePoint website and the Secure Access Management System

4. The Metadata Creation Field Guide

5. Pamphlets on relevant computer programs such as SAS and ArcGIS and other related tools

6. A spreadsheet for states to complete listing potential shareholders for each content area, IT and Communication contacts, academic contacts and other possible TAG members for their jurisdiction

7. A checklist of potential resources, such as IT/GIS infrastructure, existing surveillance programs, environmental public health capacity, data sharing and release policies, and other related resources

- 8. Documents from the National Tracking Program including:
 - -the Nationally Consistent Data and Measures Document
 - -the Guide to Building an Environmental Public Health Tracking Network
 - -the Technical Network Implementation Plan
 - -Grantee Portal Requirements
 - -Grantee Communications Standards and Recommendations
 - -Links and information to the Environmental Public Health Tracking 101 online course

REFERENCES

1. National Environmental Public Health Tracking Network

http://ephtracking.cdc.gov/showHome.action.

Page created on: April 17, 2012 Updated on: October 17, 2013

Content Source: National Center for Environmental Health, Environmental Health Tracking Branch

2. Environmental Public Health Tracking Fellowship Fuels Major Milestone for Kentucky and CDC. <u>http://ephtracking.cdc.gov/trackingfellows.action</u>.

Page created on: September 19, 2013Updated on: September 20, 2013Content Source: National Center for Environmental Health, Environmental Health TrackingBranch

3. Foundation for a Healthy Kentucky http://kentuckyhealthfacts.org/ Data Sources: Data by Topic: Premature Death.

4. Kentucky Department for Public Health and the Centers for Disease Control and Prevention. Kentucky Behavioral Risk Factor Survey Data. <u>http://chfs.ky.gov/NR/rdonlyres/B83944D8-A64F-4C6E-B9AC-303C89313FE5/0/2012KyBRFSAnnualReport.pdf</u>

5. America's Health Rankings: "State Data, Kentucky". http://www.americashealthrankings.org/KY