Next Steps for the Inter-State Exchange of Non-resident Data Between State Health Data Organizations

NAHDO Summary of Findings and Proposed Next Steps

Prepared for the CDC Environment Public Health Tracking Program

By

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September 2009

Overview

Public health agencies maintain numerous data bases to support their mandates to improve and promote the public's health. Despite the rich sources of population health data, exchanging data resources across various agencies within a state is challenged by different laws governing each data set and the fragmentation of public health programs. These challenges are compounded when a program attempts to share health care data across-state jurisdictions. Public health applications, such as the Environmental Public Health Tracking Network (Tracking) will benefit from the cooperative exchange of health care data that is systematic across states, rather than the ad-hoc data exchange practices in place currently.

The National Association of Health Data Organizations (NAHDO) has been working to improve the quality, availability, and use of health care data for public health, research, market, and policy applications since 1986. Historically, states have focused on obtaining as complete of census of health care data in their states or jurisdictions, filling or adjusting for the gaps in information occurring within the states, such as Veterans Administration and other federal hospitals not subject to state reporting mandates. Once data collection is as comprehensive as possible, often a state will set its sights on obtaining resident data from neighboring/border states, which is more of priority in states with overlapping health care delivery markets and rural states in which residents often travel outside of state for acute care and hospital services.

Data gaps secondary to out-migration of residents can be significant in some markets. In the 2003 Healthcare Cost and Utilization Project's (HCUP) Statewide Inpatient Datasets[1], discharges of out-of-state residents in four states in which there were statistics ranged from 2.43 percent to 6.19 percent. These four states averaged 4.7 percent of annual resident discharges admitted to facilities in another state. For local markets, this out-migration could be higher. Even with missing data (non-reporting states and suppressed data), it is evident that there is a fair amount of border crossing to seek hospital care (Tables in Appendix I).

[1] [1] HCUP State Inpatient Databases (SID). Healthcare Cost and Utilization Project (HCUP). 2003-2004. Agency for Healthcare Research and Quality, Rockville, MD. www.hcup-us.ahrq.gov/sidoverview.jsp

Whether states are studying health care delivery patterns or rural health issues, the out-of-state data have long been an interest to states.[2] States have approached NAHDO in many venues over the years seeking guidance in streamlining and facilitating state-to-state data sharing arrangements. States already sharing data experience lengthy bureaucratic processes and delays in obtaining data from another state; states with no data exchange arrangement were seeking guidance on how to start data sharing activities.

Until recently, the data sharing activities were not a high priority for most states and with cutbacks in data agency budgets and staffing, the business case for pursuing the small amount of data was weak. Emerging applications, such as the Environmental Public Health Tracking Program and Measurement of Hospital Readmissions, have elevated the data sharing issue, because even small data gaps can affect indicator rates because of the small numbers and the sensitivity of the measures themselves.

Soon after NAHDO became a Tracking Partner to work with Tracking states to facilitate the acquisition and use of hospitalization data, the issue of exchanging de-identified non-resident discharge data across states was raised. The states identifying this issue were generally states that had (a) acquired their statewide hospitalization data for Tracking; and (b) were in states with higher cross-border migration patterns. States with an arrangement with a neighboring state, like New Mexico, reported that negotiating with a border state for their resident utilization data is time-consuming. The data request process can be onerous and could include an evaluation by the Institutional Review Board . Once an inter-state data exchange is negotiated, continuing the arrangement is dependent on staff in one or both of the state agencies for successive years, which could be jeopardized if one or both of these staff persons leave their position or the agency. In short, states may benefit from an institutionalized and more central approach to data exchange, facilitated by NAHDO. NAHDO explored whether this process can be streamlined and made uniform for Tracking states.

Exploration Process

As a part of its Tracking activities, NAHDO explored the significance and state's perceptions of need for a more formalized inter-state data exchange process. First NAHDO obtained HCUP

[2] The NAHDO-Stanford Building Research Infrastructure and Capacity Project, funded by the Agency for Healthcare Research and Quality, 2000-2006, Findings in five rural states.

data from AHRQ to identify the magnitude of data gaps as a result of out-of-state migration for care. Next, NAHDO conducted interviews with five of the six states in the Pilot Data Acquisition Project, also a NAHDO Tracking activity in Year One.

2003 SID Analysis

NAHDO requested and reviewed a worksheet developed by AHRQ from the 2003 HCUP State Inpatient Database (SID) that identifies discharged patients' reported state of residence. .[3] Analysis indicates that states experienced, on average, almost five percent of total discharges in 2003. It was useful to highlight the relevance of the issue to the state health care data organizations. (Note that some Tracking states, like New Mexico, are not HCUP partners, therefore no data were available and that Florida suppressed statistics with a numerator <500 records in 2003). The tables in Appendix I, prepared by NAHDO summarize the AHRQ worksheet for the pilot Tracking states. The first column identifies the number of residents from border states discharged in the state of interest in 2003 (and what percent they constitute of the state of interest's total discharges), and the second column identifies the number of residents from the state of interest discharged in one of their border states (and the percent they constitute of the border state's total discharges).

Interviews with Six Tracking State Hospital Data Stewards

Tracking partners had already identified obtaining discharge data from boarder states to be a slow and challenging process. Some states had indicated that they attempted to approach individual boarder hospitals for their data- this was not a feasible option for the long term. In order to determine data steward perceptions on out-of-state utilization data gaps, NAHDO developed a brief questionnaire and sent it to the six pilot Tracking states data stewards. The survey aimed to identify if acquiring data from boarder states was an issue for them, if they already receive data from border states and if so, what processes they have in place. The letter and questions (Appendix II) with the HCUP statistics (Appendix I) were sent to the data stewards in April 2009. Five of the six data stewards responded.

[3] HCUP State Inpatient Databases (SID). Healthcare Cost and Utilization Project (HCUP). 2003-2004. Agency for Healthcare Research and Quality, Rockville, MD. www.hcup-us.ahrq.gov/sidoverview.jsp

Summary of Findings

Five out of six states responded and indicated that accessing data on their residents discharged in border states was important for the following purposes:-

- To provide additional information regarding the health outcomes of patients
- To inform public health activities and policies.
- To provide more accurate measures, such as hospital readmissions.

All five states were interested in learning how other states solved cross-state data exchange. While all states expressed interest, most had not proceeded with data sharing with neighboring states due to lack of funding and staff to solve the legal and technical issues in order to implement data sharing. There was general interest in solutions to facilitate such sharing agreements.

Of the states surveyed only two states (Maine and New Mexico) had existing agreements with their border states (Maine: Massachusetts and New Hampshire and New Mexico: Texas). The Maine Memorandum of Understanding and Data Use Agreement is attached (Appendix III). The data Maine obtains from MA and NH is not used by Maine for any specific purpose other than making it available to authorized users by special request only.

Maine negotiated specific agreements with each state. While NH and ME share identical restricted data, MA will only share unrestricted data (de-identified) with Maine. Once ME receives the data they treat it like they would treat their own data, applying all the same rules and regulations to it that pertains to ME's hospitalization data. NAHDO assumes that NH reviewed the ME data policies and that these were consistent with NH's

A couple of states reported that they had been approached by neighboring states about exchanging hospital data, but that no formal process has been established. For example, Utah, Nevada, and Colorado have discussed the options for data exchange of each other's resident discharges in the past. Some agencies have exchanged data for specific projects, such as the Building Research Infrastructure and Capacity (BRIC) project (Utah and Nevada). States with fewer residents going across the border for care did not place this activity as a high priority.

Typically, state health data organizations code the out-of-state resident zip code to the state code in their public use files, releasing resident zip codes on the research files on a case-by-case basis through a review/Institutional Review Board process.

Tracking pilot states suggest that obtaining non-resident discharge data is likely to improve the specificity and quality of the indicators produced for environmental health outcomes. Data stewards seemed receptive to data exchange for other reasons, related to hospital readmission rates and other population-based studies, as well as market migration pattern analyses. From both standpoints, it appears that states are open to learning best practices and understanding the cost-benefit of such data exchanges. NAHDO recommends that prior to a large-scale data sharing project, it would be beneficial to work closely with two states as case studies to inform a larger, future project.

Based on the NAHDO interviews, considerations for the data stewards in participating in a data exchange process include the following:

- Needs of the PH community, including, but not limited to Tracking, should be considered. It would be important to serve as many data users in this process
- States mandated to track and report hospital readmission rates may find this project useful, as often the readmission of a heart patient occurs at a hospital other than the 'index' admission hospital. In the case of overlapping markets, readmissions in a different state confounds the measurement.
- Data stewards are likely to respond if there is specificity and clarity of the data elements to be shared
- States laws, rules and regulations differ, but most do accommodate data disclosure. Understanding the restrictions and permitted releases will facilitate the MOU development.
- Beyond the pilot, there will be a need to evaluate the price of data and the willingness of states to provide the data to eachother without cost, in a mutual agreement.
- Some states do not collect (or do not always release) hospital discharge data, or emergency department data
- How to share between state agencies (in one state) and hospital associations in another- is this feasible? This will take more exploration, as it may vary by association.
- What are the optimal time frames for sharing?

- States such as Florida that have many out of state residents- should they only share with their border or should they be sharing with the many states they have visitors from?

- States differ in their perception of the urgency of acquiring out-of-state data. In states like Utah, with minimal out-migration of residents seeking health care, the acquisition of out-of-state data may not be a high priority. States like Maryland, whose health care markets overlap with its neighboring states, with much border migration, have a high degree of interest in pursuing solutions for acquiring resident data from Delaware and West Virginia. Residents in Cumberland, MD and Morgan Town, WV, for example, seek care in health care facilities in both markets.

- Cooperation and trust between two states is essential, with assurance to participating agencies that the data they are responsible for are handled appropriately.

Proposed Next Steps

NAHDO proposes a feasibility project with two states. The aims of this project would include:

- Identification of the costs and benefits to inter-state data sharing for Tracking indicators;

- Documentation of the process and lessons learned, including the benefits, to obtaining resident data seeking care out-of-state, which would inform the design of a larger scale data sharing initiative.

Working with the two states, NAHDO proposes the following steps:

1. Recruit participants in two Tracking States, both the Tracking and the hospitalization data stewards must agree to participate in each state.

2. Determine the scope of data to be exchanged: Identification of the essential, minimum data elements needed by Tracking. For example, inpatient data only or ED; would de-identified data suffice, or is identifiable data needed to facilitate linkages?

3. Document the process: What is the data acquisition process for de-identified and identifiable data? Diagram this out, in conjunction with the hospital data stewards and Tracking staff. Include the timing of the data acquisition (e.g, annual, after data aggregation is complete, etc.)

4. Legal analysis: Even though states are geographically close we know this does not mean that laws, rules and regulations are the same. These need to be acknowledged in any MOU, and if a template is devised we need to have room for tweaking. The MOU must acknowledge that all laws, rules and regulations from the state where the data was received from will be adhered. (Without that acknowledgement states would likely not sign the agreement, given they must follow their specific statutes and rules.)

With two states, we could establish a pilot, to determine the scope and process that would best work in the real world of today's data agency. Data formats could be proposed and vetted with several NAHDO vendor members who aggregate multi-state hospitalization data, for feedback. This process would provide us with on-the-ground experience before data exchange is more broadly executed. Once the data scope, process, and generic/template MOU is prepared, NAHDO would facilitate direct state-to-state negotiations, NAHDO does not want to be an intermediary for the data, but rather assume a coordinator/facilitator role.

From a select NAHDO member base, we could form a small working group of data stewards to advise on developing a sample MOU and on how frequently this data exchange could feasibly occur (quarterly, annually?). This would assure more broad application of the MOU, beyond Tracking, if there is buy-in on the MOU content.

The time frame of the pilot once everything was in place would be 18 months, which would allow time for DUAs to be signed and an exchange of data to occur. The final step would be to evaluate, with the data stewards and Tracking states, if this adds to the robustness of their data and measures for public health research.

NAHDO would need support for staff time to coordinate teleconferences and activities, to begin a pilot exploration data sharing initiative.

What might also come out of this pilot, are general guidelines for the public health sharing of data, similar to those contained in a Public Library of Science online report, "Towards a Data Sharing Culture: Recommendations for Leadership from Academic Health Centers", the following table has been adapted for promoting a culture of data sharing within public health data organizations:

Recommendations for State Agencies to Encourage Data Sharing[4]

1. **Commit** to sharing data, given privacy constraints. Identify model data use agreements and opportunities to streamline the IRB review process.
2. **Recognize** data sharing contributions in improving health care delivery, quality, and population health.
3. **Educate** staff on responsible data sharing and reuse and promote a framework for deciding upon appropriate data sharing mechanisms.
4. **Fund** the costs of data sharing, support for repositories, adoption of sharing infrastructure and metrics, and identify best practices.
5. **Publish** experiences in data sharing to facilitate the exchange of best practices.

[4] http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0050183

APPENDIX I

APPENDIX I: HCUP 2003 SID STATISTICS FOR SIX STATES

/Citation: HCUP State Inpatient Databases (SID). Healthcare Cost and Utilization Project (HCUP). 2003-2004. Agency for Healthcare Research and Quality, Rockville, MD. www.hcup-us.ahrq.gov/sidoverview.jsp

FLORIDA

Total discharges in FL 2003 SID: 2,443,916

Discharges from in state residents: 2,361,850 (96.64%)

Discharges from out-of-state residents: ***unknown---cell suppression for cells*** <500

Missing/invalid/homes/foreign: 82,066 (3.35%)

	In FL SID	FL residents discharged in border states
Georgia	unknown/suppressed	4,442 (0.41%)
Alabama	unknown/suppresed	N/A—no statewide database

MAINE

Total discharges in ME 2003 SID: 165,410

Discharges from in state residents: 161,206 (97.45%)

Discharges from out-of-state residents: 4,028 (2.43%)

Missing/invalid/homes/foreign: 176 (0.10%)

	In ME SID	ME residents discharged in border states
New Hampshire	1,570 (0.94%)	2,585 (2.13%)
Massachusetts	682 (0.41)	2,631 (0.31%)

MARYLAND

Total discharges in MD 2003 SID: 707,375

Discharges from in state residents: 659,576 (93.77%)

Discharges from out-of-state residents: 40,818 (5.8%)

Missing/invalid/homes/foreign: 2981 (0.42%)

	In MD SID	MD residents discharged in border states
Pennsylvania	9,010 (1.28%)	3,338 (0.17%)
Delaware	5,927 (0.84%)	N/A—not an HCUP Partner
District of Columbia	5,702 (0.81%)	N/A—not an HCUP Partner
West Virginia	6,805 (0.96%)	1,565 (0.54%)
Virginia	6,366 (0.90%)	6,055 (0.70%)

NEW MEXICO

New Mexico does not submit data to HCUP.

	No NM SID	NM residents discharged in border states
Texas	N/A	12,538 (0.44%)
Utah	N/A	111 (0.04%)
Colorado	N/A	1,119 (0.23%)
Arizona	N/A	1,259 (0.18%)
Oklahoma	N/A	NA—not an HCUP Partner

PENNSYLVANIA

Total discharges in PA 2003 SID: 1,951,310

Discharges from in state residents: 1,862,650 (95.45%)

Discharges from out-of-state residents: 86,584 (4.43%)

Missing/invalid/homes/foreign: 2,076 (0.10%)

	In PA SID	PA residents discharged in border states
New York	11,765 (0.66%)	8,652 (0.34%)
New Jersey	43,581 (2.23%)	40,476 (0.89%)
Ohio	9,465 (0.48%)	3,568 (0.22%)
West Virginia	4,194 (0.21%)	3,614 (1.25%)
Maryland	3,338 (0.17%)	9,010 (1.28%)
Delaware	4,378 (0.22%)	N/A—not an HCUP Partner

UTAH

Total discharges in UT 2003 SID: 260,926

Discharges from in state residents: 244,449 (93.68%)

Discharges from out-of-state residents: 16,163 (6.19%)

Missing/invalid/homes/foreign: 314 (0.12%)

	In UT SID	UT residents discharged in boarder states
Colorado	540 (0.20%)	653 (0.13%)
New Mexico	111 (0.04%)	NA
Arizona	1,142 (0.43%)	531 (0.08%)
Nevada	3,189 (1.22%)	485 (0.02%)
Idaho	4,395 (1.68%)	NA
Wyoming	3,019 (1.55%)	NA

APPENDIX II

APPENDIX II---NAHDO INTERVIEW SURVEY SENT TO SIX TRACKING STATE HOSPITAL DATA STEWARDS

NAHDO

NATIONAL ASSOCIATION OF HEALTH DATA ORGANIZATIONS

Improving Health Care Data Collection and Use Since 1986

Dear Health Data Organization Representative:

The National Association of Health Data Organizations (NAHDO) is assessing the processes involved with and/or the feasibility of sharing de-identified non-resident hospital utilization data across states in order to supplement states' data sets. We would be grateful if you could complete the short survey below to assist us with this assessment.

Purpose

NAHDO is currently engaged with the Environmental Public Health Tracking Network (EPHTN) program being led by the Centers for Disease Controls (CDC) to provide technical assistance in the area of hospitalization data. This issue of cross boarder data sharing has been raised by several of the states funded by the program. Tracking states have reported that approaching a border state for their resident utilization data is time consuming and can be onerous and in some instances could include Institutional Review Board review. NAHDO is exploring whether this process can be streamlined and made uniform for Tracking states. To do this it is important for us to understand how data agencies manage/deal with this and if they have any existing processes in place. Before completing the survey please review the table below that NAHDO developed for your state based on a worksheet developed by AHRQ from the 2003 HCUP State Inpatient Database (SID) that identifies discharged patients' reported state of residence.

INSERT TABLE HERE

If you have any questions or concerns about the survey, or would rather we interview you contact Emily Sullivan on 801 532 2292 or by email at esullivan@nahdo.org

Please complete the survey imbedded in the email below and return via email to esullivan@nahdo.org

Sincerely

Denise Love

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Telephone: 801-532-2299 Fax: 801-532-2228 E-mail: nahdoinfo@nahdo.org Web: www.nahdo.org

Survey to assess the process involved with sharing de-identified non-resident hospital utilization data across states

- How important is accessing your states resident discharge records for patients that were discharged in another state?

- Do you have an existing cross border(s) or out-of-state data use agreement with another state; if yes, can we have a copy to review?

- If you receive resident data from another state, does your agency use these data? If yes please describe

- If your agency is currently exchanging non-resident data with another state:
  - What is the cost to share out-of-state resident data?
  - What data elements are shared?
  - What are the restrictions on the use of the data?
  - How are the non -resident data used?

Please provide any other information on the process involved or your ideas on sharing non-resident/out-of –state data that you think would be useful to NAHDO.

We will be writing a summary of the information gathered and will be sure you receive a copy of this.

Thank-you for your time.