Agenda Item: Garnering Support for ED Data.

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"The dark side." That is how the hospitals tend to view the state. We keep coming back for more data. We say, "If we had this next set of data, these are all the great things we can do." Given the likely reaction, government must spend a lot of time trying to garner support among hospitals and data users for new databases.

To garner support, you need to identify potential champions. Ask "who needs what?" "How do we get it to them?" "How do we present data in a useful way?" You need to identify the questions that the data can answer, so you can find the potential champions who may put together a coalition, a ground swell of support.

The usefulness of the information to particular customers will drive which potential champions you seek to enlist.

I am from a state data agency that is separate from the Medicaid department and also from public health. One of the interesting things about the ED data for us was really making the connection with public health and seeing them as a big customer and a big user of the data. The Massachusetts Department of Public Health became a real champion for us in the whole effort to collect ED data. They were helpful at every stage from initial consultations with ED physicians right through to the public hearing testimony.

Physicians were another group of key champions. At the time that we were moving forward, emergency department physicians were really interested in the data. Peer comparisons from one institution to another and looking at physician profiling were what the ED chiefs wanted from this kind of data. Physicians in the ED were a critical part of us building that coalition of support.

We have legal authority to collect data from providers, as do a number of the states. Just because we have the legal authority doesn't really mean that we can actually use it. To actually put a mandate on the industry is tough even without the need for a statutory change. We really did have to develop that groundswell of support, and we had to start off looking at our own agency as customers.

While a small agency, we have a number of competing priorities. We had to show our internal data customers why ED data would complement the information we have already. For our agency, having more information about access and ambulatory care-sensitive conditions was a real critical need. We had inpatient data, but we knew we were missing a good part of what was going on out there. So, the ED data basically closed the loop in terms of conducting our analysis.

While we were moving forward to meet these other needs, policy issues intervened to make ED data even more critical and timely. ED over-crowding started to really creep up, as did ambulance diversions. A gubernatorial health care task force was then meeting. The task force's concern about ambulance diversions and over-crowding gave us some of the political will to move forward in our state. We took advantage of the need for information to justify moving forward. The fact that there was also something "very bad going on", and there was not the information available to understand it, helped us garner support.

Win over government customers.

Integrated data was really what was needed for public health. ED data was a key component of information to allow for analysis of crash outcomes, trauma, the EMS system and injury prevalence.

I really found a champion in the EMS system at the department of public health. We worked on a CODES project together and saw that that ED data would make that CODES data that much more useful. Legislation to certify trauma centers was adopted in 2000 and the ED data would be useful for the trauma database.

The injury people were also certainly very interested in this data. They had been piloting data collection from EDs in our state. So, we looked to the experience of our injury surveillance partners' pilot as a jumping off point.

Bring in Physicians Early.

We also needed to really bring in emergency physicians. That was a group that the agency hadn't reached out to before. We needed to build some trust there. Our public health champion was also a real help in building that trust with physicians.

Beyond using data for their own purposes, there was a real tremendous interest among the ED physicians for research. They wanted to make sure this data was going to be public somehow. If this was just going to be something that was captured by a state agency and sit there for many years before a report came out, that was not going to be helpful for them. They wanted to not only use it for their internal improvement purposes, they also wanted to make sure that it would be available for research. In some appropriate manner, the data needed to be made available publicly, and that was a really key issue for the physicians.

As is appropriate, because many of these people were leaders in their institutions, the physicians were concerned about the burden of data collection on the hospital. This led to tempering some of the "ideal", in terms of data analysis, with questioning "what are the costs" of collection to the hospital and others. This was something that we had to work on.

Keep Talking/Build Consensus.

This really is all about process, but it is kind of nice to say, "keep talking" rather than saying "process"! Before we identified ED as the thing to do, we began by talking to some key decision-makers about the environment. We wanted to identify what was going on in health care delivery, and what we should be looking for in terms of information (nursing home data, pharmacy data, ED data, what have you).

Once we moved forward and decided ED was the thing for our agency to be focused on, we had a work group with all parties. This meant not only the physicians and the public health department, but also researchers, consumer groups, a number of different trade associations and certainly the hospitals. And we had to ensure representation of different types of people from within the hospital as they had a lot to contribute.

After we had a consultative session, where basically we went through a lot of implementation issues, we really hit a barrier with one of the major teaching hospitals in the state saying “no”. They really just weren't interested in this. Even as we were moving forward and getting a lot of support from a lot of different places, there are always some key players that you will have to deal with. At first, they just said “no”. And then, we met with them separately and we met with their ED physicians and with an organization that had a number of different hospitals. And we met with ED physicians from across their organization to listen to concerns.

After that, we held a full public hearing process.

And then, even after adoption of the regulation, we kept talking with the industry. Even in the last couple of months before the data rolled in, there were calls from hospitals with peculiar issues that come into play with the Emergency Department (that are different from inpatient data). So, we had to revise our specifications on the fly to deal with some of these situations that, even in an 18-month process, hadn't come up. It got down to the devil being in the details. The point is to “keep talking” so you implement your goals effectively- with the least burden and the most understanding of the data you will receive.

Strike the Right Balance.
To strike the right balance with an ED database, you need to consider the following:

- Meet the Specific Needs of Multiple Parties
  - Avoid duplicate collection
  - Avoid Single Stakeholder driving decisions
  - Balancing data Users vs. Producers
  - Ask Probing Questions
- Coded data vs. Real time data?
- Existing data vs. a Better Standard?
- Crucial data only vs. “nice” data?
- Already captured/electronic vs. New data ?

Issues we needed to address to “strike the right balance” included: integrating outpatient with inpatient ED data; submission of retrospective data; and the trade-off between speed and data “richness”.

Data Integration. Data integration is one of the issues that came up yesterday, as well. Billing systems “roll in” an ED claim into an inpatient claim, when a patient is admitted from the ED. Therefore, ED data collection reflects outpatients only. That certainly is a real issue for the analysis and presentation of information concerning the patients seen in an Emergency Department. Emergency physicians were concerned that, if you are collecting the outpatient ED data, how am I going to look? The most severe patients are admitted. We want to make sure there is a fair representation of the severity of the people that we are seeing in the ED. How is this outpatient ED data going to be tied to the inpatients-- those who are admitted from the ED and then their information is rolled into the inpatient data? Somehow that data needs to be tied together. Al Prysanka and others are touching on some of the solutions to this issue later in the panel.
Retrospective Data.

Another big issue with us, and yet a great opportunity, was retrospective data. One of the pieces of advice that Denise Love gave us was that, if you only had some retrospective data at the time you start collecting, then you will really be able to get a good jumping off point in terms of analysis. You will be able to start reporting right away.

We have experienced the model of waiting two or three years before you start putting information out, and that is not nearly as effective. If you can somehow get a "jump-start", and get reports out right away to the community and to the physicians that have been involved in this, it is much more beneficial.

We started off by saying we wanted three years of retrospective data. This was actually a real sticking point and a lightning rod in the whole public hearing debate. In some ways it is good to have a lightning rod. It was something that we could give some ground on without giving up retrospective data entirely.

With this issue, I was in trouble with everybody. Hospitals viewed any retrospective data as a burden. Researchers thought it was critical. That comes down to striking the right balance. The researchers on our committee were very sure they needed three years of data or more. ICD-10 is coming and there will be a break in the trending of coded diagnosis and procedure data. We need to understand what the trend looks like so that when that break happens we can assess the impact. We will be able to understand how things were coded pre-ICD-10 and post-ICD-10. The more years of data we have available, the better the assessment. Yet, certainly the hospitals were not interested in doing that. We had to strike the right balance. We got from January 1, 2000 forward, which is something close to two years of data.

Data Standards.

Some of the issues were looking at "how rich you want the data to be?" versus "how fast you want to get the data" in to the Division and get the data out to researchers? Do we use existing data as it is being used by the hospitals today? Do we look for some better standard? Within our work group we were looked at definitions for data elements, and compared DEEDS definitions to our existing inpatient definitions and to what is on the UB-92.

In many cases, we just had to struggle with the trade offs. That was one of the hard things for our public health folks, too, because we couldn't get in all the data elements that we wanted for surveillance activities. So, you have to sometimes say no.

Our Choices. We went with the use of existing data elements and definitions where they existed, if that met most of if not all of the needs. On balance, we were able to add in five new data elements that were new for the hospitals. That was asking more from them. However, by the time we had finished this process, we had really made the case for each and every data element that was somewhat different from existing data collection at the hospital.

Certain elements were crucial for our data champions. Among them "mode of transport" and "discharge time" were deemed critical, but hospitals were not collecting them at the time. They had the "admit time" but not the "discharge time". Some of the local hospitals had been working on an emergency severity index and wanted to really move it out to the rest of the industry. This was added as well. We had to build the case for each new data element because of the potential burden.

Funding.

We did try our best to look for grant funding, but we just really didn't find the support out there for infrastructure. There is a real unwillingness to invest in a data base, which surprises me. Our inpatient data base has been around for over 15 years, close to 20 years. Likewise with ED data, we anticipate a public health data set that has some utility and moves forward through time. Whether technology takes us in a direction where data collection changes dramatically, we are not sure. But comparable trend data will remain important.

In the end, we got no external funding or budgetary increase. Nevertheless, we somehow have built the case internally such that we have found the resources to move forward.

Current Status of the Database.

We adopted a regulation in August 2001. We keep tweaking our specifications here and there, as the hospitals contact us with issues peculiar to the ED. We do “keep talking”.

The deadline for the first submission was March 16, 2002. We have started to see data roll in. During the next couple of months we are in a testing phase. Most hospitals are getting the formatting right. A couple have passed our edit specifications. So, we think we are moving forward. We are excited about that. We can't wait to analyze the data! So that is our status.