VITAL RECORDS IMPROVEMENT FUND ADVISORY COMMITTEE

-MINUTES-

Thursday March 21, 2002

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Vital Records Improvement Fund Advisory Committee Meeting

March 21, 2002

Health & Human Services Building 1st Floor Conference Rooms 6 Hazen Drive Concord, New Hampshire 03301

COMMITTEE MEMBERS PRESENT:

Patricia Little, City Clerk Appointment
William R. Bolton, Jr., State Registrar
Patricia Seskes, Hospital Association Appointment
Jane Ireland, Town Clerk Appointment
William Armstrong, IT Manager, DITM Appointment
Tom Janosz, Funeral Director Appointment
David Kruger, Public Member Appointment
Linda Hartson, City Clerk Appointment
Dr. Frank Mevers, State Archivist Appointment
Paul Bergeron, Nashua City Clerk, City Clerk Appointment

COMMITTEE MEMBERS EXCUSED:

Thomas A. Andrew, MD, Office of the State Medical Examiner Appointment

GUESTS:

Dr. Jesse Greenblatt, Director, Division of Epidemiology and Vital Statistics, OCPH Melanie A. Orman, Program Specialist, DEVS John O'Neal, Office of Information Systems
Mark Parris, Office of Information Systems
Mark Andrew, Administrator
Barbara Kostka, Executive Secretary
Don Gerow, Networking, OIS
Kathy Bizarro, NHHA
Jennifer Taylor, DEVS
Steve Norton, Director of Knowledge, DHHS

Vital Records Improvement Fund Advisory Committee Meeting

1. Approval of Minutes:

Ms. Little welcomed guests, called the meeting to order and suggested those persons in attendance introduce themselves to the guests. The first order of business was to approve the minutes of the November 15, 2001 and January 10, 2002 meetings. Ms. Little pointed out that there were two references to parties by their first names. Mr. Kruger made a motion to approve the minutes with corrections. Ms. Ireland seconded, and hearing no objections, Ms. Little accepted the minutes with corrections.

2. Web Enabled Health Initiative Presentation:

Ms. Little turned the floor over to Ms. Taylor and Mr. Norton. Mr. Norton began the presentation by explaining some of the history behind their presentation. He is responsible for the Enterprise Data Warehouse and because of confusion over what that entails, he wanted to explain to the committee what it is that they do and who they are partnered with in the department. He explained that warehousing is a technique in which you can bring a lot of information together and use it more efficiently. People often ask why they do this, as it tends to be somewhat expensive. It is a capital outlay and an ongoing operational cost.

Mr. Norton asserted that the reason is really quite simple. First, it takes the use of information out of the operational day-to-day activities and puts it somewhere else where you can focus a little differently on it. Anyone who has any responsibility for line activities knows that there is barely time to think about the future or strategic planning unless you make time. A warehouse often provides that opportunity. The second reason to do data warehousing, particularly from the department's perspective is to begin setting up an environment where they could look at the department as a whole. Not just Vital Records, Medicaid or DCYF. In fact, what the department does is serve families and individuals across a variety of programs throughout the state. It could be looked at as a big business with a whole bunch of books of business, serving often times the same people. Currently there is no cohesive way to look at them as one family or individual.

Warehousing, by putting information into a centralized area and linking that information up would allow the department to look at things like fragile children. How many children does the department have that are touched by different programs. The child may be receiving Medicaid and their family may be receiving "Child Abuse" services and/or temporary "Needy Families" Assistance. What can the department do to make the services provided to families more efficient from a global perspective? Mr. Norton also explained that there are some operational reasons to do this as well. One of the problems this department currently faces is that there are seventy-five different databases using different standards and supported in different ways. He added that the OIS people in the room would all agree that is not a good environment for ongoing operations.

A warehouse, by putting information in a central area with consistent standards helps to make their jobs easier. It also makes change easier. Mr. Norton pointed out that the

department often goes through a "change" every four years. A lot of knowledge is often lost during those transitions because of the lack of consistency. He explained that in the department there is literally "a ton" of information. It is his responsibility to collect that data and structure it in a way that the information can be used. It can be reports, data requests or developing measures that can be looked at. He stated that he used the term "information" on purpose. Information is like the number of low birth weight babies in New Hampshire. It doesn't tell us anything that we need to know about low birth rate babies. It is just a measure.

Mr. Norton's office is partnering with other divisions across the department to generate some knowledge. What does it mean that thirteen percent of our teens have low birth rate babies? What does it mean that DCYF has had a threefold increase in caseloads over the past three years? According to Mr. Norton, part of what his office does, is take the data, create some measures/reports, to help facilitate the development of knowledge about our business. They are then be able to disseminate that information to decision makers. What he finds interesting about the process is that is not the end of the process. Once the decision makers get those measures they may have questions or feedback and the whole process begins anew.

Mr. Norton explained that what he has done with a variety of people is set up in essence, decision support systems. They take the information structure it in such a way that it is useful to people and begin to generate some knowledge, and that knowledge is then disseminated to decision-makers and then the feedback process begins. Within the Medicaid system they are implementing a "Medicaid Decision Support System," a 1.7 million dollar initiative over four years. It is taking all the department's Medicaid information and putting it together in such a way as to be effective. It will make it possible to generate multiple Medicaid reports. They are also implementing a "Decision Support System" in the Division of Family Assistance. It will pull information from the New Heights software, place it in the warehouse and users will be able to query the information and generate reports.

This will generate some knowledge about the business and provide feedback into operations. He went on to say that they are doing the same thing with DCYF. With DEAS, they are carving out a small portion of their population. Only the OAA people and people in Financial and Human Resources were using EDW. Mr. Norton explained that they were at the meeting to discuss public health records. He stated that they were proposing the same methodology as they had used in the past to partner with other divisions to develop these systems. The purpose of implementing these partnerships is to increase access to information. Mr. Norton stated that there was an advantage to adding public health records to the warehouse, "Public health records in some sense, relate to much of the other work that we are doing."

As an example, Mr. Norton reported that within MDS nationally, it is of great concern, how many of our Medicaid clients have low birth weight babies. It is a big issue and there are ways that we could structure the program, which would affect low birth weight babies. So there is a natural relationship between those two pieces of information and there are other relationships that can certainly be discussed later. From the department's perspective it is critical to start looking across divisions so that we can start thinking about efficiencies and structuring our information that way is one source. Mr. Norton then turned the floor over to Ms. Taylor.

Ms. Taylor described the Health Statistics & Data Management office and its responsibilities to the committee. She explained that they are Epidemiologists, Bio-Statisticians, GIS people, who do mapping of the data and Data Analysts. They also do some programming in a variety of statistical software packages. Ms. Taylor explained to the committee that HSDM is the steward of many health population data sets in the department and those are the Vital Records data, State Cancer Registry, In-patient, Outpatient and specialty hospitalizations. A survey of adults in New Hampshire, looking at risk factors that would put them at risk for developing certain diseases. Though not the steward of it, they also work with the Office of State Planning on population data. They interface that data with their own. They are well versed in ICD-9 and Cancer coding (ICO). One of the ways that they use the data collected is through publishing an annual statistical reports on the state. Those reports can be found on their website.

Ms. Taylor assured the committee she would get the URL information to them before the next meeting so that they might look at the reports she spoke of. She added that they create ad hoc reports upon request. Anyone in the state can call and make a request for data for a specific area and her department will create a report. They also have a committee that reviews requests from academically affiliated researchers to get patient level data for their case control studies or maybe there is a cancer study and they want to enlist patients in those types of studies. They advise people internally and sometimes externally on sample design and survey design. The requester may call and say, "I want to survey my town about health risk behaviors. Can you help me set that up?"

Ms. Taylor told the committee that she wanted to explain to them, the needs of the public. She explained that Health Statistics is a service unit within the Department of Health & Human Services. They provide information to programs so that they are informed about what their priorities should be. Some of the questions might be "Is low birth weight an issue or is maternal smoking an issue?" Ms. Taylor's staff can determine that through data. Ms. Taylor referenced a document, The New Hampshire Healthcare System, The Guidelines for Change, which was a document published in October of 1998 It was a two year process in which numerous interviews were held with New Hampshire communities, towns, cities and other stakeholders in the public health community.

This project is one of the outcomes of that process. Ms. Taylor pointed out that the rest could be located in the materials she had distributed to the committee. The goal is to empower communities with information. Mr. Armstrong asked Ms. Taylor if there were any RSA s associated with that. Mr. Norton replied that there were. The Guidelines for Change were a function of law. He went on to say "We were required by law to do this two year process. We developed District Health Councils that were a part of this process and that document...we were required to bring that back to the legislature, which then they could act on as they saw fit."

Another recommendation of the report was that the state needed to have a better understanding of the uninsured. So, for the past several years they have implemented a random digit dial survey of New Hampshire residents to get a better sense of what is going on with the uninsured. The report also recommended, that children with special healthcare needs have to have better access to medical care. Another recommendation was that the state should provide better information to communities so that they might make better decisions, particularly around public health issues.

Mr. Armstrong stated that since there is a privacy task force in the legislature, obviously privacy is a big issue. Mr. Norton agreed. Mr. Armstrong added that it would be important, particularly as the state goes electronic. He asked if there is a published report anywhere that would have implications on either recommended changes to laws or is that feeding into the privacy task force. Mr. Norton said that it was, but he felt Dr. Greenblatt or Ms. Taylor could speak to the confidentiality issue surrounding Vital Records data. He did say that the department in general has a broad assessment process in place for its confidentiality and privacy rules. The rules developed by Dr. Greenblatt and Ms. Taylor are considered top notch, consistent with HIPPA regulations and in some respects, more stringent than what would be required under the emerging law that is likely to come out of the current subcommittee. Ms. Taylor added that privacy drives everything they do. Their goal is to get information out to communities, but the first cut is to protect the privacy of individuals whose information is released. She wants people to have access without being able to look at inappropriate information.

Ms. Taylor then explained how communities currently access health stats information. On the HSDM website there are annual reports and some tabulation of information. Ms. Taylor also explained that the problem with people only having access to the annual reports is that it is static information. While the department has an initiative underway to develop querying capacity so that people can actually ask questions, that will not be available until spring. Tables can be downloaded, but questions cannot be asked about the data. They also have hard copies of the annual reports and other publications that are produced by HSDM. Ms. Taylor added that people need more flexibility.

They may need it at the town level or an aggregate of towns. The reports HSDM create are on a state level. They are not broken down any further. People can call into HSDM and request ad hoc reports. Those requests range from simple requests to complicated requests that may take months to fulfill. HSDM handled 200 analysis requests for Vital Records information in the last year. That is about thirty-five percent of their new requests. In addition, there are more requests for help in understanding and using the data uncovered. Ms. Taylor explained that there are more requests than there are staff to fulfill them. There is generally a waiting period for the requester. She pointed out that people working on grants need the information in two days and they may have a very simple request, but if there are twelve requests ahead of them, there will be a wait.

What they hope to do with this project is develop tools that will handle the simple questions, so HSDM will be able to devote more time to the more in-depth analysis. Ms. Taylor gave the committee several examples of recent requests of her staff. Police departments often request information on deaths and hospitalizations due to drug (Heroin) overdose. HSDM probably receives two-dozen requests from police departments annually. Communities working on prevention programs will call and request data on falls in the elderly, for example. What HSDM does is use the death data related to falls and merge that with inpatient hospitalizations, emergency department visits, etc.

Ms. Taylor then advised the committee of the shortfalls of the current system. HSDM does not have adequate staff to handle all the data requests they receive to the extent that they would like. Over the years they received approximately ten to fifteen requests from academically affiliated researcher for this type of information. There have been fifty requests already this year. Ms. Taylor has been successful in reaching out to the research

community, but her staff is now overwhelmed. She told the committee that communities have become savvier and need the state to provide the data they require.

She advised that communities need instant access to information. Waiting two weeks for a data request is not satisfactory to some. She explained that many people call and say, "I need a data set." And what they really need is the analysis, not the data. That is what HSDM wants to provide. She mentioned the Regional Health Profiles Initiative that came about through a public-private partnership between Dartmouth Hitchcock and DHHS. People are using these regional reports, particularly for community benefit. They rely on this information and want it updated. Ms. Taylor told the committee that she wants a system to be in place where they can get the information without having to make requests and wait.

Mr. Armstrong asked if HSDM was getting information from Environmental Services regarding high cancer rates and environmental factors that might affect those rates. Dr. Greenblatt replied that they do get information from other agencies, but not specifically cancer related data from DES. He explained that his department handles most of that work. There are examples where those types of health issues are tackled across agencies.

Mr. Armstrong asked that if DES has information on hazardous waste sites and industries located close to them, is it Ms. Taylor's plan to take that data and integrate it so there is better understanding. He added that they had spoken of regional information so he thought it seemed appropriate. Ms. Taylor replied that the Office of Community and Public Health contains the Bureau of Health Risk Assessment, and when someone from the community calls in and says there are elevated levels of cancer in their area and they identify a business or entity they think may bear some responsibility. That goes to the Bureau of Health Risk Assessment.

HSDM supplies them with the cancer data and they collect additional data from other agencies. Health Risk Assessment could then take that information and go out in the field to do an assessment. If there is no environmental concern, HSDM handles the data request. Mr. Armstrong was surprised that HSDM did not collect or maintain that type of information. He felt that HSDM would be the experts the public would look to for that information. He added that maybe if they do not have to constantly be answering the phone, they would be able to go out and do more. He still was not clear as to the project's objectives.

Mr. Norton, in an effort to give the committee a better idea of what his office does, added that his office does is caseload projections for the department. Many things go into caseloads, changes in the economy, demographics, employment rates, etc. They take information from DES and the Office of State Planning. Based on that information they develop caseload trends. That is something that could easily be done within a system like they propose. You could take information from Environmental Services, link it with the Cancer Registry data and see if there is any relationship between the two. That would be a very sophisticated project and beyond what he and Ms. Taylor were proposing. HSDM would continue to do the normal analysis, but it would give DES or a community the opportunity to try and draw a correlation between illnesses and pollutants or contaminants. Mr. Armstrong asked if they would not be the integrator of that data. Mr. Norton replied that they could be. Mr. Armstrong explained that the reason he asked is that they are trying to put together E-Government to enable citizens take advantage of state services through a self-service type of system.

The other thing they are trying to accomplish is one stop shopping. Making the system such that a person does not have to retrieve information from multiple agencies to answer a question. He said that the ultimate goal should be that all the data would be available in one location. Ms. Taylor agreed that communities want that too. She explained that they are only talking about the data they are the stewards of currently, but added there is always the potential to expand that. She explained that communities will identify their needs, get the data and say, this is great, but we want more information. She felt that letting communities drive how the system develops is the way to go to ensure their needs are being met.

Ms. Bizarro told the committee that the Regional Health Profiles is an example of multiple data sets put into one report. It is mortality, birth, hospitalization, insurance, census information, etc. Before that report you had to go to hospital discharge file, the mortality file, etc, to get the information you needed. That report was seen as a great resource to have all that information in one place. Ms. Taylor went on to explain that their goal is to develop a web-based query system.

Essentially it will mean that New Hampshire residents will be able to access health information over the internet. Some of the information would remain static. They could also build their own reports. The requester could query anything they needed and a report could be generated. Then, based on community needs, additional functionality could be added to the system. The system could be flexible and modularized as needed.

Ms. Taylor then previewed what the web based query system looked like. It is a part of a public health decision support system. She pointed out that currently, HSDM warehouses it data in the EDW. Vital Records data, Hospital Association data, and Cancer Registry data also goes in. Then data goes out to certain places. A lot of the data goes out to health statistics to support their business process. Which right now is doing simple analysis requests, custom requests and the academic research files. The system also needs to support other departmental initiatives that Mr. Norton mentioned, like the Medicaid Decision Support System and the Electronic Disease Surveillance System, which is a reporting system being established in the department.

Ms. Taylor explained that all the things she had described were internal to the department. Functionalities that need to exist but are not what communities need. The goal is to have the information available to a web based query system. A tool would be developed to enable the public to expand on the information cities and towns receive through the reports they currently have available through VRV2000. Static reports could also be developed for cities and towns. The Regional Health Profiles were set up in a certain geographic aggregate. Ms. Taylor plans to set up regional profiles that the user can customize. The other enhancement would be the ability to build reports. What they would do is ask a question in a way that makes sense to them and the system would provide the answer.

Mr. Armstrong asked if the reports would all be summary reports. Mr. Norton replied that in some cases the reports would be interactive, but in others summary. Ms. Taylor explained to the committee that there would be suppression rules programmed into the system to protect the confidentiality of patients. The department has a data release policy for the office of Community and Public Health and it outlines when the department will not release information in order to protect direct identification or constructive

identification of individuals. Mr. Armstrong asked why any information that is not public information would be on that system anyway. Mr. Norton replied that, in order to only have summary information online would require them to produce summary information in every possible way that a community might want it. Doing it the way he and Ms. Taylor envisioned would allow HSDM to avoid doing that work. It would allow the user to summarize the data in the way they wanted it.

Mr. Armstrong asked that wouldn't that have to be a security tradeoff. Protecting confidential information and meeting eighty percent of the demand or meeting one-hundred percent of the demand and not protecting it completely. Mr. Norton and Ms. Taylor agreed. Mr. Norton stated that the thing that they have to worry about as they develop systems is that they must be flexible. Historically, the state has created monoliths that are good for only about four months. This system would be driven by the demand of the community and the people at this meeting rather than the circumstances the department finds itself in at any given time. It is somewhat more expensive than developing twenty-five different reports, but ultimately it is less expensive.

Mr. Armstrong mentioned that in the privacy issue is an area in which the state is a novice. Up to this point they have remained on the conservative side, generating twenty percent of reports manually to strictly maintain the confidentiality of the records. Still concerned, Mr. Armstrong said that he would speak with his Director regarding this project.

Ms. Taylor stated that she would move along so that the committee would be able to complete its agenda. She explained to the committee that they could help make this system a reality by helping with the funding. What she and Mr. Norton were looking for was seed money. She explained that the VRIFAC committee was the first group they had approached because it seemed linked. They also planned to approach other organizations around the state to see if they would contribute money. That would give them a pool of money with which to seek matching funds. Dr. Greenblatt stated that they had approached another group. That group was The Endowment for Health.

The Endowment for Health currently has a grant going on titled Empowering Communities with Data. One of the goals that this grant has established is to fund representatives from the New Hampshire Institute for Health Policy and Practice at the University of New Hampshire to go out and assess what communities need. They have already identified that they need a web based query system and now they are asking the communities what they want that system to look like. So now is the perfect time to actually start to think about this project. Dr. Greenblatt advised the committee that the Endowment for Health is a project that originated from break up of Matthew Thornton Healthcare and was a way for an insurance company to fund particular community initiatives. He believes it is headed by Jim Squires.

Ms. Taylor stated that in the two years she has been with the state, she has been really impressed with VRV2000 and the success it has had and would really like to see other systems developed in the department that gets the other data they need to do community health assessment in such a manner and with such quality as VRV2000 does. So one of the things she felt was "in it" for the committee was to expand on the success of VRV2000 and taking the lessons already learned about data acquisition and applying them to the new system.

Communities have been waiting years for this and if the department is going to do it, they need to deliver on it. The four data sets that HSDM gets from Vital Records, births, deaths, marriage and divorce will have a far greater field of end-users than before. She reiterated that they completed two hundred data requests last year. That did not include the three hundred requests for the annual report and the questions that arose from that. People will call and ask for their town to be broken out of the big picture. This system would definitely be able to give the cities and towns the information they want. She added that she had already explained what was "in it" for the state of New Hampshire.

According to Ms. Taylor, communities have been waiting many years for this and have heard many promises. Many have attended meetings where they have expressed their needs. They want a system where they have the ability to be independent and self-directed at least for the simple requests. If the VRIFAC offered some seed money, they would be known as the group that got this program off the ground. She was unsure if that meant anything to the committee, but added that if they interacted with the communities, they would know that they have been waiting for this for a long time. She went on to say that no one has been able to deliver for them before; the committee would be the first.

Ms. Little asked about the frequency in which HSDM would receive Vital Records data. Mr. Norton replied that there are currently over twenty-five data feeds to the warehouse and depending on the needs of their partners they update the data monthly, yearly, daily, or weekly. He explained that there is no need to update census data daily, but there may be a need to update Medicaid claims data weekly. They will update as frequently as their partner requires them to. More frequent updates generally require more maintenance and it is a constant maintenance. If you update less frequently the maintenance is completed all at once. Mr. O'Neal agreed. He stated that there is wide variety of data transfer time frames. New Heights is monthly, but it all depends on the data and the size of the data.

Mr. Gerow stated that if the VRV2000 data is moved too quickly it will be unverified data and the integrity cannot be guaranteed. A lot of the data is updated and corrected after it is initially entered. There is also the timing of machine utilization. If there is a machine running one hundred percent and you try to increase the workload, the machine will not be able to handle another request and either a new machine will be necessary or the request will need to be changed. Mr. Norton explained what they currently do with Vital Records. They take a lot of the fields from Vital Records and HSDM uses that information.

As the original partnership was described it was very limited partnership. They were only allowed to take a certain number of fields. What they are talking about here is expanding that relationship. He said that is important because they are familiar with the data, the speed in which they can move is much greater than if they were beginning from scratch. Because there are a lot of issues with ICD-9 and ICD-10 codes that are somewhat problematic and could take a lot of time. Those things are somewhat solved. The other reason is age standardization.

Mr. Armstrong stated that looking at the diagram it looks like Vital Records is already in a relational database based on their standard for data nomenclature. The two new entries are the hospitals and Cancer Registry. Mr. Norton agreed. Mr. Armstrong stated that it seems like all that Vital Records would have to do is chip in for a new server and another license if that is necessary. It looks like the majority of the data is there, so the cost

should be minimal. He said that the other two groups would be the ones that require the most work. Mr. Norton replied that it would all depend on what you wanted to do. One of the things he and Ms. Taylor discussed was whether or not they wanted to cost out something.

Mr. Norton stated that he could cost out a billion different things right now depending on the functionality that they feel the communities could engage. he explained that the cost is also in the integration of the data. Births, deaths, marriages and divorce, cancer incidence and hospitalizations are currently their own data stores. Do they want to automatically relate that information? That is one functionality that could be critical to communities accessing information. Mr. Norton felt that it is.

Mr. Gerow stated that this project would also affect technology. He said that it would be nice to have the nice new web based query system, with the data going to the Enterprise Data Warehouse. Depending on truly coming in on the web you have to take into consideration holes in the firewall, where is the data really going to go. Normally on a web page query system, all the information sits outside the firewall. In the case of populating this data set with every piece of equipment in there, that is not a feasible option. The alternative of leaving a massive hole that comes into the network so that the information can be retreived is not an acceptable alternative either. There is a lot of technology to be explored before you can just come up and hook this system up.

He stated that this kind of a query system would be great inside the DHHS system where anyone can sit down and retreive any information and it can be protected. Outside the firewall, then there is a different situation altogether. How much do you put outside, how much inside? Each one has different costs. Mr. Norton stated that the department had expended a great deal to find out a way that they can develop these web portals, so any cost estimate would not include that development work. He explained that as of April 16 or whenever the new website is launched, they will have a web portal system that has a defined firewall that will be able to support this type of activity. So the design cost for the web query cost could be considered completely separate from the development.

Mr. O'Neal agreed and further added that what is being asked here is that these are operational data storage and they make no attempt to relate the data. Many of their systems just dump their data into the warehouse and use it for reports. One of the difficulties is you have to know what the data is. If you want to ask a question you have to know where it is. What is being suggested here is the marriage of the data so that they do the background work. This is what we think the communities want to ask and here is how we relate the data so we can provide that answer. The warehouse is being used extensively for reports. It helps get all the data off the production machines, the data can be manipulated. Some systems manipulate the data before it gets to the warehouse, others after. Mr. O'Neal stated that he felt this was an exciting possibility.

Ms. Little told Mr. Norton and Ms. Taylor that she would like to have a better understanding of the ramifications for the committee's initiative with this new complexity from the technical perspective and also what other resources will the committee need to give more money to our own initiative. She said she wanted the IT perspective on this. How much more complicated will this make our initiative. Mr. O'Neal replied that from a purely Vital Records standpoint this will have little or no impact because it is the capture of data which they already know how to do. He stated

that what he though Mr.Norton and Ms. Taylor brought to the table was the marriage of that data outside of our operational data storage.

Mr. Armstrong asked Mr. O'Neal asked if it wouldn't negate all other reporting. Mr. O'Neal replied that it could. He said that was actually a very good question. One of the biggest questions they have in the warehousing environment is what is operational reporting vs. non-operational reporting. Taking the information out of the operational environment allows people to think about the information differently. Analytically in a way that they don't have the time or the energy for even the responsibility to look at as part of the operational system.

Mr. Armstrong told the committee that it seemed that we were talking to the wrong people. If communities want to pay for this then they would say they want it paid for through their Vital Records collection. It seems like the issue is not being addressed squarely. He asked if MDSS or anyone else accessing it wouldn't be responsible to chip in since they would be using the data as well? Mr. Norton replied that they do.

He distributed a hand out to the committee. Mr. Norton explained to the committee that he calls this discussion "proof of concept." He said that he has spent a majority of his career spinning his wheels waiting for funding. He then displayed what a pretty basic functionality would look like for a Public Health Decision Support System. He stressed that the point is not to fund the entire Public Health Decision Support System. Ms. Taylor agreed, they were only seeking seed money to fund the areas highlighted in red on the handout. Mr. Norton said that they need to rethink the data store that they have developed. What are the relationships they need to develop between the data sets, how often will they have to update them, what kind of editing will be needed. What kind of functionality will be needed to identify changes in the data, because data changes as it is validated and verified.

Those are the questions from a development perspective that they have to answer. Six months ago Mr. Norton did a cost estimation process to come up with an estimate of how much it would cost to completely restructure, develop all the relational pieces necessary to do the Vital Records portion of this project. The total he came up with at that time was \$380,000. That was a different time period. A time when he could hire who he wanted, before the freeze. From the internal perspective we need a business intelligence tool like SASS, Excel or Access which allows you to mine the data more effectively. That is something they would need to be able to do their own analysis and prepare themselves for external assessment. They have received cost estimates from \$450,000. to \$1,200,000 depending on whether or not the state wants to buy an entire one or if it is just DHHS.

Because Ms. Taylor does a lot of analytical work, there is also an additional requirement that with this increased information, she is going to have increased questions of increasing complexity. Additional resources in the SASS area would be necessary to think about. Mr. Norton informed the committee that if it was interested in thinking about this particular functionality as critical to their mission, he would take the time to draw out a good cost estimate of what that little component would look like. He apologized that he did not do it previously, but didn't want to invest the time if the committee was not interested in it.

Dr. Greenblatt asked Mr. Norton if the cost of doing those items would be around the totals on the page or a portion. Mr. Norton replied that the cost would be a portion. He stated that if he had to guess for just that component, the data work associated with it and with the current hiring situation, he assumed they would have to go ITS07 and guessed it would be in the ballpark of \$250,000 – \$300,000. Dr. Greenblatt asked about the other figures on the sheet. Mr. Norton explained that they were going to go forward with the business intelligence tool either way and some of those figures dealt with that. They intend to have a number of businesses chip in on that. A lot of the work has already been done to develop the web-based query system. They already have the portal and would now need to develop screens.

Mr. Norton felt that some of that work may be able to be done internally, but he was not certain. He said that internal operational costs were an issue. Between his office and OIS, they often have a penchant to build something they cannot afford to support down the line. He has decided that he will not do that anymore. If he cannot get definite support he will not go through with planning a project. Dr. Greenblatt asked if the estimate he had provided included matching funds. Mr. Norton replied that it did not. Dr. Greenblatt asked if the committee agreed that they were interested in hearing more and would like a cost estimate, would Mr. Norton include potential matching funds in that. Mr. Norton replied that he would. He added that he would immediately amend a contract with MDSS and might be able to get almost 90/10 matching funds to develop a data store around low birth weight. He would have to discuss with the feds, what kind of funding would be available. Mr. Armstrong asked if it was fair to say that he (Mr. Norton) is the report control point to make sure that we are not paying for the same report twice. Mr. Norton replied that he was.

Mr. Kruger stated that he would like to ask the city and town clerks and maybe the funeral directors what kind of demand is being put on them from the public. Is that where the requests are coming from. Ms. Little mentioned that she thought it was more for the city than for the public. Mr. Kruger, hearing that requests were not coming through the town or city clerk, asked Mr. Janosz if the funeral directors are ever approached for this type of data. Mr. Janosz replied that the only inquiries they receive are of a genealogical nature. Mr. Norton asked if there was anyone from Franklin or Manchester at the meeting. Seeing no one, he mentioned that he receives multiple requests weekly from cities. He passes those on to Ms. Taylor. He explained to the committee that their challenge was to decide if this was something where they would gain something. Mr. Kruger asked about hospitals and asked Mr. Bolton and Mr. Wurtz if they see these types of requests. Mr. Bolton replied that any requests for statistical reports are referred to Ms. Taylor's staff. Ms. Taylor added that the hospitals may not be asking for the information, but health leaders in the community would use this information. She said that what she and Mr. Norton were proposing would meet these needs.

Mr. Kruger stated that his personal concern was that we would create a query system that was way beyond what was needed. Ms. Taylor stated that what this system would not do, is handle the academic researcher requests. Mr. Kruger replied that he wanted to make sure that we were not "making work." Ms. Taylor replied that HSDM handled eight hundred requests last year with only eight staff members, of which, one is not an analyst and four of them were only recently hired. This system would give her department the luxury of time to help those with complex data requests. She stated that the Vital Records birth data is the most requested data. It is timely and available. She

wanted the committee to understand it is not just their data that the communities need. That data is included with data collected elsewhere. Ms. Ireland asked if HSDM charged for data. Ms. Taylor replied that they do not, they do not have the capacity to follow through. In the past if a company or a profit making entity asked for data they were usually denied. If they were a valid profit making company there would be a small charge. She estimated that her unit generates about \$3,000 a year.

Ms. Taylor said that she was aware the Utah brings in \$700,000 a year with their statistical information, but her unit does not have the capacity to do that at this time. Mr. Kruger replied that Utah has made a conscious effort to make it a money making enterprise and Ms. Taylor had not. He then asked Ms. Taylor how many of the eight-hundred requests had come from the feds. Ms. Taylor replied that approximately forty percent of the requests were internal requests and sixty percent were from communities. She added that more than fifty percent of the community requests were from individuals. Her office does not do a lot for the feds. Vital Records transmits a great deal of data to the feds, but they do not usually call and ask for specific reports.

Mr. Kruger asked that if Ms. Taylor did develop this system, would the feds then approach her unit for data rather than Vital Records. She replied that they would not. Ms. Little asked if anyone had the text regarding the use of Vital Records funds. Mr. Bergeron replied that he did. Ms. Little asked him to read it. Mr. Bergeron read "the sole purpose of the fund shall be to provide revenues for the improvement of the registration, certification, preservation and management of the state's Vital Records, and said money shall not be used for any other purpose." Mr. Norton stated that it was "suitably vague." Ms. Little asked if this project would fall under that. Ms. Little and Mr. Kruger both agreed that if it did it would be under the "management" of Vital Records.

Mr. Armstrong stated that if this project would help to ensure healthier citizens it would probably be money well spent. He added that just because people aren't asking for it, doesn't mean it isn't needed. Mr. Kruger added that it could be considered improving or maintaining. Ms. Bizarro pointed out that the slide Ms. Taylor had displayed about the state's health plan report that said there is a need for health information at the community level, is heard all the time in health care circles. When District Councils meet, data is at the top of the list of things needed. It is always a priority.

Ms. Taylor added that many of the members of the committee may not have heard it because people are appropriately being forwarded to her unit, but there is a demand for this data. Ms. Bizarro asked if the funding request was a one time request or would it be an annual request. Mr. Norton replied that it would be a one time request. Ms. Bizarro asked what other funding avenues they were examining. Mr. Norton told her that they were approaching Medicaid, Endowment for Health, General Commissioner Funds. He told the committee that the Commissioner is a very strong believer in consumer directed choice. He is very interested in making sure that communities and not the state are driving the care they receive. He believes that providing this service to the communities would empower them. He told the committee that he had spoken with a variety of people regarding seed money and felt that he was in about the same place with them as he was with this committee.

Ms. Little asked about how the confidentiality issue would be handled with all the new users that will have access to the data. Mr. Norton asked if she was referring to internal

or external users. Ms. Little replied that she meant internal. Mr. Norton explained that everyone who is employed by DHHS is held by the same statutes as external people. They have a whole series of confidentiality and privacy requirements that everyone must sign. They have done a security and confidentiality audit in the department and are aware of some areas that are in need of work, but in general, they have a good handle on it. He added, whether they have the resources to deal with that or not, is unclear. He stated that there are ways to protect confidentiality of data by developing rules. According to Mr. Norton, those rules dictate that Mr. Bolton is allowed to see everything and he is able to see nothing. Those rules apply to internal and external people. Their primary tool to manage that confidentiality are those roles.

As the data owner, Vital Records would be responsible for who has access to what. Mr. Armstrong mentioned the privacy issue again. He explained that working on the Governors Information Technology Commission report it was decided that policies have to be established and people identified as having access. It then has to be audited periodically to make sure it is being adhered to. Ms. Taylor told Mr. Armstrong that he made a very important point. She has investigated a lot of other web-based query systems in other states and from a very close technical level, there are software programs/algorithms that work through this data to make sure it is protected.

In New Hampshire there is a cell suppression rule. If the number of events in a town are between one and four the information is suppressed. If the requester is a researcher, they must go through hoops, but they will have access to the information. She questioned what a person in the community would do with kind of information anyway. There are also ways to track when people are using the website and using these types of tools. Mr. Armstrong added that he was also talking about internal users. He said that as a DHHS employee he doesn't have the right to go in and look at Ms. Taylor's records. Mr. O'Neal told him that as a matter of fact, he did. He said that outside Vital Records and some very important HIV data, most data is subject to the Right to Know laws.

Mr. Armstrong stated that the state has to have a way to prove to people that they have logs and can see who accesses the information. Mr. O'Neal replied that all their production systems log who touches what, but in this case people are not being given access to an operational register, let alone a production system. Mr. Armstrong replied that that was the danger of a data warehouse. It has the potential of being opened up to people that have no business being in it. Mr. O'Neal replied that right now there is raw data sitting in the warehouse, and this is the next level up. It is a selected view of the raw data.

Ms. Taylor wanted to make it clear that the information she was discussing was to be made available to the public. Mr. Armstrong replied that he was referring to internal users. Ms. Little told Ms. Taylor that the committee would just like some understanding of their policy regarding internal users. Mr. Norton replied that the policy that they adopt is the policy that is held by their partners. If the committee says that no one has access to the data, then no one does. They would have to request data sets to use.

Mr. Armstrong asked that if MDSS needs a piece of data, why not just answer any questions they might have and not send any data. Ms. Bizarro asked if Ms. Little was asking if the VRIFAC had control over the confidentiality policies pertaining to Vital Records data sets. Ms. Little replied in the affirmative and said she felt that she was given the answer that they were. Ms. Bizarro stated that she felt that was incorrect. Mr.

Bergeron added that Mr. Bolton, as State Registrar had that control. Mr. Norton stated that the Commissioner has the ultimate say over who can have the data and who cannot. Directors often don't want to disseminate their information, but the Commissioner is the final arbitor of all disputes. Mr. Armstrong stated that this is a statewide issue. Someone from outside the state could come in and ask to see what we do and it is the state's responsibility to show that what we say we do, we are actually doing.

Ms. Little stated that she was encouraged. Initially she had been a little concerned whether or not the committee wanted to be involved with this project. She said that there would need to be further discussion and better understanding of the costs associated. She certainly believes in leveraging the data, but is concerned with the confidentiality issue. Her main concern centered around the committee's ability to financially support its own initiative in addition to donating this seed money. She pointed out that the VRIF is not making millions. She also stated that she believed that the web enablement project is going to be a bigger strain on the budget, during development and maintaining it after launch. She wants to be sure that the fund could support both if that is what the committee decided to go forward with providing seed money.

Mr. Norton had to leave and explained to Ms.Little that he will come up with a better estimate of cost and provide documentation of confidentiality associated with the data warehouse. Mr. Bolton asked Mr. Norton if this was for a full blown development or one of another state's current solutions. Mr. Norton said that was a good question. They have discussed trying to touch base with Utah or Missouri. His sense is that they have a product they would probably like to sell and we would likely "get killed by it." Mr. Bolton replied that it was not to sell, but to maintain. Mr.Kruger said they should at least talk with them. Mr. Norton replied that they intended to. Ms. Taylor thanked the committee for their time and told them she would forward the HSDM web address and data release policy shortly. She encouraged all members to visit their website and take a look at the reports.

3. VPN Concentrator:

Mr. Gerow stated that before he left the Vital Records project, Vitts Corporation went out of business. Their demise delayed the Department's VPN solution and left Manchester with only one dial-up account and Nashua with two. Manchester came up with a dial-up multi-plexer, which allowed all four of their terminals to be up at the same time. Because each of those offices has internet access it was decided that the use of a VPN Concentrator would solve many issues. It is put out there and it is given an internet address. The users are given that address, usernames and passwords. The concentrator determines they are legitimate and allows access to VRV2000. Using this concentrator will eliminate the six and a half cent per minute telephone charges for the dial-ups.

There is a unit that goes in the offices and it is between five and eight hundred dollars. The concentrator with built in redundancy is \$20,000. There is a cheaper concentrator for \$13,000. There is charge of \$1,000, for power, \$2,000, for one year's maintenance. So for, \$25,000-\$30,000, we could get the concentrator with redundancy, power supply, maintenance and the two hybrid devices needed for Manchester and Nashua so they would operate in a firewall type situation like Keene. Mr. Gerow stated that in phone charges alone, the fund would be paying \$29,000, per year. The equipment would be paid for within the first year. He added that there is potential for other cities to be brought on. Any city with internet access could be brought on.

Ms. Little asked if they were looking for permission to purchase the concentrator. Mr. Gerow replied that he was. Mr. Armstrong asked to see a write-up on actual costs and how did we know what the performance was going to be? Mr. Bolton replied that this is the same kind of communication that is going to be offered by NHSUN. Mr. Armstrong felt that there was not a well-articulated plan on how they wanted to do this. He said that DITM had a meeting with NHSUN that afternoon and he would bring it up. The statewide plan calls for collapsing LANs and that will be a core service that Administrative Services will offer, but he was unsure when.

Mr. Kruger asked Mr. Gerow and Mr. Bolton if there are capacity restraints. Mr. Bolton replied that it could handle fifteen hundred concurrent users. Ms. Little stated that she felt there would be a substantial financial benefit to purchasing the concentrator and with NH Sun's approval she would certainly recommend the committee approve the expenditure. She asked Mr. Bolton to do a white paper on the concentrator issue.

4. Records Preservation & Maintenance:

Dr. Mevers distributed a handout to the committee. It was a listing of additional projects to get started with the preservation of vital records. He stated that the State Archives received an Administrative Support grant last year to hire a part-time person. This person has been a great help and is very interested in the work. Dr. Mevers proposed that the VRIFAC fund another part-time person to act as his coordinator for the grants program. He hopes to make some grants like the ones in the past to some of the cities and towns mentioned in Mr. Parker's report in 1996.

There would be an application process that would be time consuming. The applications would have to be received, decisions as to who gets money and how much. Dr. Mevers also wanted to hire a full time records clerk to work in the Vital Records reference library in this building and stop relying on volunteer staff only. Apparently volunteer numbers are dwindling. This would fall under the management and preservation of the records. We could begin to put the records into strict alphabetical order, acid-free folders, flatten them, etc. Another thing the committee might want to begin doing is to send some of the manuscript volumes out for conservation treatment. Additionally, he had a whole list of goals that have been discussed at one time or another and could eventually be done.

He was unsure of the exact cost, but it was confident it would be much less than the previous proposals. The full-time clerk would not have to have professional library experience, but an appreciation of genealogy and the maintenance of the records. Mr. Kruger suggested that if the main role of the new person were to alphabetize the records, the bureau would have to change the way it does things. Other states just provide microfilm of records to the public. They are not given the card copy to handle. He mentioned that there has also been discussion with the LDS church the possibility of making all the old records available online. Once that happens, the library at the bureau will be obsolete. He would definitely support the hiring of a full-time person for the library. Maybe organized a little differently than he saw on the handout. Mr. Armstrong suggested that a business plan would be helpful. Mr. Kruger agreed.

Dr. Mevers went back to his original proposal to hire a part-time coordinator to help him. Ms. Hartson asked who would be responsible for overseeing the person. Would

they fall under the state and require benefits. In the past she remembers the committee funding a position and that person was essentially taken over by the state and not doing what had originally been agreed to. The committee decided to hire a consultant and use some of the documentation used when hiring Mr. Parker as a guide. Mr. Bergeron suggested that the committee at least authorize the part-time person to help Dr. Mevers coordinate all these projects. Dr. Mevers current part-time Program Specialist could supervise this person. Mr. Armstrong questioned what needed to be coordinated. Mr. Bergeron replied that there is an RFP, creating and operating the grant program. Ms. Hartson asked how the committee how the hiring is handled. Ms. Bizarro asked if there wasn't a hiring freeze going on. Ms. Hartson stated her support for hiring a part-time person. Mr. Armstrong was not convinced. It was agreed a consultant would be hired and they would be asked to determine any manpower needs.

Ms. Hartson made a motion that the committee, direct Dr. Mevers and Mr. Bolton to go forward with the creation and issuance of an RFP to look into the hiring of a consultant. She also asked about the financial situation of the committee. Having been away for a long time she was unaware whether or not the committee could even afford \$250,000 or whatever the numbers are. She no longer knows where the committee is financially. With supplying computers to all the cities, towns and hospitals she wanted to be updated.

5. Financials:

Mr. Andrew passed out a handout and Mr. Bolton explained that the document was a modified plan that they had come up with several years ago. Some things have been added, some deleted and target dates have been added for some of the items. Some of the outstanding issues were web enabling the software and the Virtual Private Network are included on there. Ms. Hartson told the committee that she has received several calls from clerks, saying they were under the impression that more of them would be online by now. Mr. Bolton suggested they all look at the strategic plan.

Mr. O'Neal reported that a several clerks were added in November and now they are moving into the frame relay towns. Six more towns were being trained at the end of the month. Mr. Janosz asked what percentage of clerks were online now. Mr. Bolton replied that the percentage of automated clerks was about twenty percent. It was mentioned that it was likely that those twenty percent accounted for ninety percent of the vital events. Ms. Hartson asked if the support for adding more clerks was included in the budget before her. Mr. Bolton replied that it was.

Mr. Andrew reported that what he handed out was a moving target version of a Vital Records Improvement Fund budget, updated last week after discussions with Mr. Bolton and OIS. There were a couple of things he wanted to highlight. The anticipated revenue for this year is \$840,000. He felt that those numbers were on target, maybe even a little better than estimated. He pointed out the changes that had happened since the last update. One of these additions is a position that the Committee anticipates hiring for the Vital Records/EHDI/SDSS project. The VPN Concentrator has been budgeted in the amount of \$30,000. There is also a \$144,000 entry for new computers for next year. Mr. O'Neal mentioned that the Department had decided to go with Windows XP. The reaction was mixed. Mr. Andrew drew everyone's attention to Contractual Expenses. Under the advice of the OIS and Vital Records there has been a potential contribution of \$400,000 that might be needed for the RFP for web enabling VRV2000. There is also

an out year placeholder in the amount of \$51,000 for technical support. The committee has agreed that with the rollouts and new equipment, there might be a need for that. Mr. Andrew pointed out the \$1,320 in the preservation moneys placeholder. The budgeted amount would be \$50,000, but Mr. Andrew changed it to reflect what has been expended this year. That money went to tuition reimbursement at Dartmouth. There is a \$50,000 placeholder in out years. The last thing Mr. Andrew wanted to mention was the communication costs. For the last few years the department has paid those expenses, but they are going to transfer expenditure to VRIF. He annualized that amount as \$96,000.

Returning to page one of the report, Mr. Andrew pointed out the projected balance of the fund for the year. He estimated that at the end of this year the balance would be \$1,000,000. Next year, as spending is increased with the web enablement project, the balance is expected to be \$680,000. He concluded by telling the committee that the pages in front of them represented the current picture of the fund. He offered to answer any questions. Ms. Little asked where the other web enablement money was. Mr. Andrew replied that it was in the capital budget this year and next. He added that the Department might be asking the legislature to budget an additional \$500,000 for the following year as they had hinted that they might support.

Mr. Andrew also pointed out the \$200,000 slot in the budget was the money the legislature had appropriated from the fund. Ms. Little asked Mr. Andrew to confirm that they were not going to include that in their next budget proposal. Mr. Andrew pointed out that on the budget in front of them, that money was not in the out years. Their strategy was to go ahead with the budget without that money. The legislature will ask for the spreadsheet on the fund as they did last year. He explained to Ms. Hartson that when the legislature sees that the fund has \$1,000,000 this year and \$600,000 next year, it will be difficult to avoid them doing the same thing again.

Ms. Little adjourned the meeting.