

Reporting Diabetes on Death Certificates:
Physician Focus Group Report
Salt Lake and Utah Counties Physician Focus Group Findings

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Executive Summary

Diabetes is a significant health concern for people in the United States. According to the American Diabetes Association, over 29 million people in the United States have diabetes and it is the 7th leading cause of death. It has been estimated that diabetes costs the United States about \$176 billion in direct medical costs each year, and an additional \$69 billion in lost productivity. Hospitalization rates are higher for stroke and heart attack patients who have been diagnosed with diabetes than those who have not. Despite the prevalence of diabetes and the known complicating factor of the disease on other conditions, only 10-15% of those individuals who have diabetes that pass away have it listed as an underlying cause of death on their death certificate.¹

A study by the Utah Department of Health and Intermountain Healthcare provides evidence that diabetes is underreported on death certificates despite efforts in Utah to make it easier for physicians to report diabetes on a patient's death certificate. The study found that recent development of the HELP2 electronic medical record (EMR) interface with EDEN (Utah's online death certificate program) improved the timeliness and descriptiveness of death reporting, but did not significantly increase the reporting of diabetes and other chronic diseases on death certificates.²

The Kem C. Gardner Policy Institute was contracted by the Utah Department of Health's Center for Health Data and Informatics to identify and examine the possible barriers that exist to physicians indicating diabetes and other chronic illnesses on death certificates accessed by the HELP2 interface by facilitating two physician focus groups, providing two full transcripts, and reporting on the results. The study was funded by The National Association of Chronic Disease Directors. This report summarizes the findings of the two physician focus group discussions - consisting of a total of eight physicians.

Key Findings

- All participating physicians had positive experiences with the HELP2 EDEN interface.
- Physicians prefer using the HELP2 interface to both paper death certificates and the EDEN web login option, noting the timeliness and convenience of the tool as well as the benefits of having access to the patient medical record.
- Most physicians were unaware of national interest in listing diabetes and other chronic conditions on death certificates for surveillance purposes.
- Most physicians did not have a clear understanding of how the health information on death certificates is used at the national level.
- Most physicians believed physician training regarding how to correctly fill out different sections of death certificates was needed.
- In order to increase the listing of diabetes and other chronic conditions on death certificates, physicians believed that the HELP2 tool could be amended to include prompts in the form of pop-up checkboxes or a new co-morbidity section.

Key Recommendations

- Provide an automatic pop-up list of a limited number of chronic condition checkboxes for physicians to consider when filling out a death certificate.
- Provide an additional co-morbidities section in the death certificate, possibly using a prompt.
- Provide training opportunities and reference materials for physicians, both at the beginning of their practice and as elements of the EMR interface tool.
- If the impact of diabetes on patient health is determined to be more significant than other chronic diseases and conditions, provide an automatic EMR death certificate interface prompt asking if the patient has diabetes.

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Overview of the Project

The Kem C. Gardner Policy Institute at the University of Utah was contracted by the Utah Department of Health's Center for Health Data and Informatics to conduct two physician focus groups to identify and examine what barriers exist to physicians indicating diabetes and other chronic illnesses on death certificates accessed through the HELP2 electronic medical record (EMR) interface. The Utah Department of Health asked the Policy Institute to create a moderator guide, facilitate two physician focus groups, and provide full transcripts for both focus groups along with a report on the results.

This report summarizes the findings of the two physician focus group discussions. The Department of Health partnered with Intermountain Healthcare to recruit physicians who were familiar with the HELP2 death certificate interface tool. One focus group brought together physicians from the Salt Lake City area and the other focus group brought together

physicians working in Provo, Utah. Physicians in each focus group discussed their experiences with the HELP2 and other death certificate options as well as what barriers they thought existed that might prevent or dissuade them from listing chronic conditions such as diabetes on the death certificate. The information gained from the physician focus groups will inform future changes to EMR interfaces such as HELP2.

Evaluation Method

As noted above, the Utah Department of Health requested that two physician focus groups be held. Each focus group was defined by the geographic area in which the physicians worked in order to increase convenience for participating physicians. Focus groups provide qualitative data on individual experiences and perceptions. Focus groups are designed to collect input that helps to better describe or shed light on a situation by providing participants with a chance to respond to open ended questions based on their personal experience. The opinions expressed by participants are enhanced by group interaction: individuals respond to others' comments and elaborate on their own perspectives, offering a more detailed view than would be possible through one-on-one interviews or survey questions.

The Utah Health Department recruited physician participants through email invitations and email follow up. Physician invitations focused on involving physicians with the most experience with filling out death certificates on the HELP2 EDEN interface tool. Invitations were sent to about 10-12 physicians in each of the two areas (Salt Lake City and Provo) who had completed the most death certificates using HELP2.

After initial responses fell short of the eight person per focus group goal, additional invitations were emailed to the next physicians on the list with the most experience filling out death certificates. Ultimately, 16-20 physicians were invited to each focus group. Email reminders were sent to those who indicated that they planned to attend. Due to the small sample size, the results in this report should not be thought of as a representative sample of physician opinion of, or experience with, death certificate reporting. The range of physician specialties participating in the panel provide for a varied perspective on patient assessment and death certificate completion, however, there may be other concerns or experiences that were not expressed in these focus group discussions.

Evaluation Procedures

Policy Institute staff met with Utah Health Department staff to discuss and design the introductory information and moderator questions that were used for both focus groups.

Both focus groups were held in the evening and provided dinner for participants. The Salt Lake focus group was held in

Murray on October 14, 2015. The Provo physician focus group was held in Provo on October 21, 2015. Both met in evening hours from 5:00 to 6:30 p.m. and were held at Intermountain Healthcare hospitals.

Participants filled out a W-9 forms and received \$150 stipends for taking the time to participate in the focus groups.

Two Policy Institute research associates attended each focus group. One research associate facilitated the discussion and the other took notes during each group. All participants were given an opportunity to respond to each of the questions posed. Transcripts are based on a combination of note taking and transcription from two recording devices that were used during each focus group. Participants were told that the focus groups would be recorded for the purposes of creating transcripts before the recording began.

The following summarizes the key discussion points for each of the two focus groups, broken down by focus group moderator discussion guide question. For ease of review, each question is included in a bolded font and followed by a discussion of the key findings relating to that question. Analysis of key findings and recommendations follows the question-based discussion.

The discussion began with research associate facilitator providing a brief overview of the project and of the impact that diabetes has on national health. The introduction was followed by participants having the opportunity to introduce themselves by providing information on their medical specialty and their experience with death certificates. Following introductions, the facilitator began asking the question provided in the moderator's guide.

In addition to physician participants and Policy Institute research associates, a few people working with sponsoring parties attended each focus group and introduced themselves after the participant introduction. In the Salt Lake group, the manager of the Utah Health Department's Health Informatics program, the HELP2 tool developer from Intermountain Healthcare, the epidemiologist for the Healthy Living through Environment, Policy, and Improved Clinical Care Program, and another member of the Utah Department of Health's Health Informatics program attended. In the Provo discussion, the manager of the Utah Health Department's Health Informatics program, the HELP2 tool developer from Intermountain Healthcare, and the Coordinator for EDEN attended. These attendees answered some technical and research-specific questions as they arose during each discussion, but otherwise acted as observers.

Key Findings - Participant Introduction

Participants were asked to introduce themselves, their medical specialty, and the extent of their experience in filling

out death certificates whether that was with paper, the EDEN web interface, or the Intermountain interface tool within the electronic medical record used to access EDEN (HELP2). The discussion of physician specialty and general familiarity with death certificates is contained in this participant introduction section and the discussion of specific experience with paper.

Each focus group was comprised of four physicians and there was a mix of physician specialties in each group. In the Salt Lake focus group, there were physicians with specialties in pediatric critical/intensive care, pediatric hematology, neurology, and hospitalist/hospice. In the Provo focus group, there were physicians with specialties in neonatology, pulmonary critical care, hospitalist, and critical care.

Participant familiarity with death certificates varied based upon physician specialty and duration of medical practice. In the Salt Lake focus group, the physician specializing in hospice worked with death certificates practically every day. Comparatively, the pediatric hematologist working with adult patients at the LDS Hospital bone marrow transplant leukemia program filled out about 15 death certificates a year; and the pediatric/intensive care physician filled out about two death certificates each month. The IHC neurologist had experience with inpatient care for two years and with outpatient care for three years prior to that. She had only used the HELP2 tool for reporting deaths, had not received training for EDEN, and became aware of it only after receiving a call from a funeral home.

In the Provo focus group, the neonatologist had filled out about 7 or 8 death certificates for babies who had a fatal anomaly (birth defects) and babies that had lived for several weeks and then passed away. This neonatologist filled out three or four death certificates using the HELP2 tool. In comparison, the critical care physician had the most experience with death certificates, having worked for 30 years. Just during the week of the focus group, he had completed four death certificates using the HELP2. The hospitalist had just moved from Colorado two years ago and mostly had experience with paper death certificates.

1. Tell me what your thoughts are about the process of using the EMR tool through HELP2 to fill out death certificates.

In both groups, all of the physician feedback on the HELP2 tool in the EMR was positive. Multiple physicians mentioned their appreciation for the way the HELP2 tool allowed them to complete death certificates in a timely fashion with easy access to the medical record.

In the Salt Lake group, all of the responses to this question were positive. The hematologist reported enjoying using the HELP2 tool ever since she became aware of it because it allowed for immediate completion of the certificate and relieved concerns about people needing to track her down to complete the certificate. The hospitalist who worked with hospice had no complaints about the HELP2 tool, but usually used EDEN and liked working with EDEN. Other physicians discussed how much easier it was to complete death certificates in a timely fashion using HELP2 because it allowed them to access the death certificate and patient data immediately.

Each of the Provo group physicians mentioned a positive experience with the HELP2 interface. Two physicians specifically mentioned how it allowed them to complete death certificates immediately. One physician who filled out death certificates most frequently also had Virtual Private Network (VPN) access and expressed an appreciation for the ability to access the system online from home or travel. The other physicians noted that when they needed remote access, they had to use the EDEN web interface because they didn't have this VPN access.

2. How does that experience compare to completing death certificates directly on EDEN or on the paper form?

All of the physicians who had experience with the paper system preferred the HELP2 tool for a variety of reasons, but particularly because it allowed physicians to complete death certificates immediately.

In the Salt Lake group, one physician said that she had not worked with EDEN but preferred HELP2 to the paper form because it was immediately available and it provided patient information. Another concurred, and added that she liked the ability to complete death certificates when she was not at the hospital. The physician from Primary Children's hospital was particularly glad to have switched from paper to HELP2, noting that they had security issues with paper death certificates because physicians were asked to fill out death certificates in pencil but sign them in pen, with someone penning the remainder later. EDEN and HELP2 eliminated this problem.

Most physicians in the Provo group mainly use the HELP2 tool now, but a few of them had experiences with earlier EDEN and/or paper systems. The HELP2 tool was universally viewed as a better system than both EDEN or the paper system. One physician liked that it auto-populated the data.¹ Another physician appreciated that HELP2 did not require an additional login like the EDEN system did. One physician discussed how he thought that the HELP2 tool was more self-explanatory. The pulmonary critical care physician stated that paper was the worst system, EDEN was good, and HELP2 was

1. The HELP2 tool auto-populates patient demographic fields as well as physician-specific information such as name and license number.

best. He appreciated being able to use HELP2 immediately and not having to remember a password. There was some discussion in this group that contained information pertaining to future questions. For instance, they noted that although there is a section to put co-morbidities on a death certificate using the HELP2 tool, you have to populate it and the time it takes to do that can be prohibitive. A checkbox system was suggested as an alternative and is discussed later during the recommendation section.

3. Have any of you heard comments from colleagues regarding using death certificate reporting linked to an EMR tool that leads you to believe their experience has been different than what we have been discussing? If so, in what way is it different?

None of the physicians indicated that they had heard of other physicians having different experiences with the HELP2 EMR tool than were being discussed in their group.

In the Salt Lake group, none of the physicians indicated they had heard anything but positive things about the HELP2 tool. Instead, a discussion built off of one physician's observation that while he thought

"All of my partners are grateful to have this, I don't know if we have ever been told that chronic problems were important. I think a lot of times we are just labeling the cause of death. And I think my group will be surprised, as I kind of am, that we should be doing that."

The other physicians agreed that there had not been education regarding the need to report chronic conditions on death certificates. The pediatric hematologist noted that she was not even sure that there were even enough lines in the form for her to get to underlying conditions such as diabetes since in her specialty there are so many other factors leading up to the patient's death. This observation led to an exchange between two other physicians who confirmed confusion surrounding the issue of what to put as the immediate cause of death in the first line of the section. While they agreed that cardiopulmonary arrest did not provide the needed information, it wasn't clear whether another diagnosis such as stroke should be in the first line or whether that would be considered a secondary cause of death. Moreover, it was unclear to both how far to go back in the patient's medical history in terms of listing other contributing conditions. These ideas are revisited in the recommendations section.

The physicians in the Provo focus group agreed that the information they hear about the HELP2 tool is almost universally positive. Two physicians exchanged examples of how physicians used to have to be nagged to complete the

form when there was a paper certificate system and now they were able to complete the form even from travel destination (via EDEN online) or assist one another in these duties for a physician who is traveling. Another physician related how he thought that the feature noting time of death was useful to physicians who hadn't been in the room at that exact moment.

4. Does having an electronic interface increase, decrease, or make no difference in the likelihood of you listing a chronic disease such as diabetes to a death certificate?

None of the physicians thought that the electronic interface would decrease the likelihood of listing a chronic disease such as diabetes on a death certificate and several indicated it would increase the likelihood.

Most of the physicians in the Salt Lake focus group did not believe that having an electronic interface made a difference in the likelihood of listing a chronic disease such as diabetes on a death certificate, although one did suggest that if the electronic interface had a category specifically for chronic disease that feature would help.

The physicians in the Provo discussion group believed that, if anything, the electronic interface would make it more likely that they would list a chronic disease such as diabetes on the death certificate. The ease of referring to the patient's medical record was the main reason for the increased likelihood. One physician also mentioned that the ease of using the electronic interface meant that physicians could complete the certificate in a more timely manner and subsequently increased the chances of reporting chronic diseases because it is "fresh in your mind." However, two physicians noted that a prompt like those used for smoking and pregnancy would be more useful in increasing the likelihood of reporting chronic disease because it would serve to jog their memory that chronic disease was a point of interest.

5. How do you determine a causal sequence for the purposes of filling out a death certificates? What are your considerations and resources?

Both groups described varying levels of confusion regarding how to properly fill in the different sections of the death certificate. Confusion regarding whether cardiac arrest should be considered the immediate cause of death, and how to separate the cause and secondary causes when a patient has multiple problems, were the focus of the discussions.

Each physician in the Salt Lake group described slightly different concerns about the determining the causal sequence for the purposes of filling out death certificates, but there was a pervasive level of uncertainty about the process. The hospice

physician noted that in many cases he had not seen the patient, so he would call a nurse to get the record and then focus generally on the heart – heart failure, cardiac disease, coronary disease, and possibly hypertension. He noted that because of his focus on heart-related issues, he usually does not think about diabetes. The Salt Lake group’s discussion of question three also related to this question - the physicians in the Salt Lake group believed that there is a lack of clarity regarding how to correctly indicate immediate cause of death, secondary cause of death, and the extent to which contributing factors should be noted. Physicians built on this earlier discussion, noting “As far as right now, we have not been recording any medical co-morbidity that is contributing to [the patient’s death] whether we think it is or not.” Another physician added that she had always been advised against indicating that the patient died of cardiac arrest, because although that is what a patient dies of, it is not the cause of their death. Since she dealt with patients with leukemia, she usually entered something like sepsis for the first cause, and then entered a secondary cause such as immuno-suppression to graft or leukemia. The physician dealing with critical and intensive pediatric care noted that the physicians she worked with argued about what they should put in the top line of the form. She said they sometimes indicated cardiac arrest on the first line and then under “due to” or “result of” put something such as congenital heart disease. Other physicians she works with put congenital heart disease in the first line. The discussion of this question concluded with a physician stating “You are right...there is no education as to what is expected, so everybody just makes it up.”

One of the problems that the physicians in the Provo group discussed in answering this question was determining the cause of death when people have a large number of ailments at the end of life. The two physicians who deal with the largest number of older patients in their practice shared examples of the wide range of conditions a patient can have, and how sometimes it is necessary to guess which condition led to death. They also discussed different pressures they encounter from the family and other outside forces. For instance, families may prefer that a death be due to an accident if there are insurance repercussions or a doctor may prefer not to say that a patient died of sepsis when the hospital has a strong record on treating this condition.

Overall, the discussion in both groups indicated that because physicians lack training or resources to learn best-practices in accurately reporting cause(s) of death, informal rules and practices develop which are not consistent across Intermountain Healthcare or even within departments. One physician reported that when a disagreement in her department about how to fill out certificates led them to the CDC website to find an authoritative answer, they found the

website unhelpful and are still confused about how to report the condition. The physicians in these focus groups expressed an interest in training and a desire to have more consistent standards by which to improve cause of death reporting.

6. Are you aware of what happens with the data, how the data is used, after it has been submitted via death certificate?

Neither group had a clear understanding of how the data from death certificates was used. After physicians expressed a lack of knowledge, the Utah Health Department’s Health Informatics Program Manager provided an overview of the way that data is collected at the state level and then used by the Center for Disease Control’s (CDC) National Center for Health Statistics for national public health statistics and other purposes.

In the Salt Lake group, one physician ventured a guess, but none had a firm grasp on how the data was used. In the Provo meeting, there was one physician who noted a general sense that state health certificate data was used nationally to determine death rates related to different conditions; that the primary causes of death were heart disease and cancer; that poor habits such as smoking contributed to these conditions; and that diabetes was an increasing health concern in our country. However, no one in the group had a definite sense of how state death certificate information was compiled for national data purposes. At least one physician expressed that had he been aware of an interest in chronic disease reporting, he would have been motivated to improve such reporting as causal factors. In both groups, the Utah Health Department’s Health Informatics Program Manager provided a brief discussion of the complexities of the process the data collection process.

7. Can you think of any situational factors that influence the likelihood of you indicating diabetes and other chronic diseases on death certificates? Follow up questions: Would the time of day make a difference? Would your location when filling out the record make a difference? Would it make a difference if the patient was new to you? Would it make a difference if History and Physical Information was available?

Each of the focus group discussions were different in terms of the details discussed, but both discussions led to recommendations for a prompt to inform and remind physicians that listing chronic conditions such as diabetes is a priority, and that such a listing is needed and expected.

Even though this question was designed to identify daily situational factors that could be influencing physicians’ actions, it prompted a physician in the Salt Lake group to think of an

EMR reform idea. She suggested that having a prompt labeled “co-morbidities” would increase the likelihood of indicating diabetes and other chronic diseases on death certificates. Another physician built on this comment, stating, “Maybe we could have one line that is direct risk factors for whatever cause of death is and then additional co-morbidities that the patient has that decreases the general conditioning and performance.” She noted that her suggestion was meant to capture situations where a patient, “who is healthy otherwise would have survived bone marrow transplant, whereas someone who has diabetes would not.”

In the Provo group discussion, the initial response was that diabetes would be a consideration for inclusion on a death certificate if the problems the patient was exhibiting were obviously related to diabetes. This physician noted that conditions such as DKA, pancreatitis caused by diabetes, a 5000 triglyceride reading, or “blood that looks like cream” would indicate that diabetes was a factor in what the physician was observing. In comparison, he noted that he had not indicated diabetes for a 76 year old type I diabetic who died by colliding with a tree while skiing because he felt the cause of death was clearly the accident and not related at all to the diabetes.

Another Provo group physician confirmed this perspective, noting that he would not include diabetes on the certificate unless he was asked about it specifically. He added that he does try to include ailments such as diabetes in the significant conditions section of the death certificate but he believes that in many cases he and other doctors skip that section because of hurried schedules. Two physicians continued this discussion, noting that diabetes could be one of several conditions that a physician might choose to include based upon personal preference – other options included high blood pressure and anemia. However, they believed that even these conditions would not be included unless the death had a clear relationship to the ailment considered, such as a hypertension stroke.

The Provo group concluded this portion of the discussion by noting that by the end of life, many patients have a large number of ailments and chronic conditions that could be considered as possible contributors to death from a long-term perspective. They were not sure which of these conditions merited special attention or how to determine which conditions merited special attention from a societal health perspective. However, if a determination is made that diabetes or other chronic conditions are of particular concern, one physician recommended a two-part prompt in the EMR that asked first “did the patient have a chronic condition?” and second “did this chronic condition contribute to the patient’s death?”

When follow up questions were posed, none of the Salt Lake focus group physicians thought that time of day, location when filling out the record, or being busy would influence the

likelihood of indicating diabetes and other chronic diseases on death certificates. When asked about whether the patient being new to the physician would make a difference, one physician indicated that it would not, one noted that the patient’s medical record would be available through the EMR, and one noted that unless the physician is the primary care doctor, the patient is new to the physician in that the physician does not know the intensity of prior ailments.

This exchange prompted additional discussion about how the existing boxes on a death certificate seemed insufficient to filling in chronic conditions such as diabetes. The hospice physician suggested that the area on the death certificate for “other significant conditions” would be a good place to indicate that a patient had diabetes. However, he also cautioned that he sometimes does not know his patients, and since some of them do not go to the hospital before they die, and are not in HELP2, he has no knowledge of their chronic conditions through an EMR medical history.

A physician who joined the Provo group and answered questions later indicated that factors such as the time of day and how busy he is *do* make a difference in whether he lists diabetes and other chronic conditions on death certificates. When the other Provo group physicians were asked about this they indicated that the most important factor was whether HELP2 was available rather than a paper record. They agreed that HELP2 also increases the timeliness of filling out the record. A paper record made it much less likely that a physician would include additional information on a death certificate. One physician also noted that even with the additional information available, he has tended to focus on the acute cause of death and then base which conditions should be considered secondary factors based on their relationship to the acute cause of death rather than from a perspective of what types of influence chronic conditions have on the patient generally. Several physicians agreed that it is difficult to ascertain what conditions were the most influential leading up to the end of life, particularly in instances when there is a lot of turnover of medical staff and physicians in the time leading up to a patient’s death due to the nature of shift-work.

8. What patient health data would make you more likely to report diabetes on a death certificate? Follow Up: Would a patient’s blood sugar control status make a difference? Would the patient’s weight make a difference? Would a patient’s blood pressure make a difference?

Salt Lake group physicians gave a mix of answers to this question and follow up questions. Provo group physicians focused on the possibility of creating EMR interface prompts to address these conditions.

The initial question about the influence of patient health data on the likelihood of reporting diabetes on a death certificate did not immediately lead to much feedback from the Salt Lake group. One physician noted that many of her patients had diabetes and she wasn't sure what the purpose of the question was. The pediatric hematologist (who is currently treating mainly adult patients with blood-related ailments) noted that although a lot of her patients had diabetes, it was so far down the list in terms of potential things that caused patients' death that she could not see herself indicating diabetes on a death certificate unless the certificate asked her to list co-morbidities. Another physician said that if the patient's record indicated that he or she had complications from diabetes he would be likely to consider the influence of diabetes.

The answers to the follow up question were largely positive. The Salt Lake focus group physicians all indicated that the patient's blood sugar control status would make them more likely to report diabetes on the death certificate with the exception of the pediatric intensive care physician who was unable to remember if she had ever had a child who died of diabetes. When asked the follow up regarding whether the patient's weight would ever make a difference in whether they would be likely to report diabetes on a death certificate, the hospice physician said that it would make a difference in his practice. Two other physicians did not feel that a patient's weight in and of itself would be enough of a factor to merit considering reporting diabetes on the death certificate but that it could be considered a problem for the patient's health. None of the Salt Lake group physicians indicated that they would consider reporting diabetes on a death certificate because of the patient's blood pressure.

Physicians in the Provo group answered this by focusing on the possibility of adding a prompt or checkboxes to the EMR interface tool that would note high blood sugar levels, high BMIs, or even a list of the chronic conditions themselves in order to focus physicians' attention on these possibilities. One physician noted that such an addition would work like the smoking prompt does now.

9. Does the patient's primary cause of death influence whether you are likely to record diabetes as a contributing factor? Follow Up: If the patient had a stroke, heart attack, or kidney failure, would it make you more likely to consider reporting diabetes as a contributing factor?

Physicians in both groups indicated that kidney failure, and to a lesser extent stroke, would prompt consideration of whether diabetes was a factor, but the diabetes diagnosis must already exist.

For the Salt Lake group, the discussion for this question on the primary cause of death built upon some of the ideas shared

during discussion of the previous question that addressed patient health data. One physician said that diabetes would have to be listed as a pre-existing condition in order for her to consider it as a factor in one of these causes of death. Another said that she would include that poorly controlled diabetes contributed to the patient's death in the death summary (a separate note internal to the hospital, but not part of the submitted death certificate), but that it wouldn't make one of the top three contributors or causes given her hematology specialty. The hospice physician indicated that he always thinks of diabetes when someone dies of kidney failure, and sometimes when there is an MI (myocardial infarction) or a stroke. He explained that if a patient on hospice has kidney failure it is usually due to poorly controlled diabetes, but that even then he would rely upon an earlier diagnosis of diabetes before including it on the death certificate.

Except for a physician who arrived late, the Provo group had addressed these concerns earlier in their discussion. The physician who had not had an opportunity to discuss whether primary cause of death would make a difference in the likelihood of recording diabetes as a contributing factor on a death certificate said that it may have an effect - for instance if the patient had died of kidney failure.

At a different point in the discussion, physicians indicated that they would think of diabetes when filling out the death certificate if there was an obvious relationship between the patient's death and diabetes. However, in many cases - especially for physicians treating patients in older populations - it is difficult to determine which of the many ailments a patient had actually led to the his or her death. Even with the patient's history available through the HELP2 system, the physicians in the Provo group believed that a prompt in the EMR interface to remind physicians to consider certain factors about a patient or the possibility of patients having certain chronic conditions that are deemed worthy of national consideration

10. What do you think would make you more likely to report diabetes on a death certificate? How would you rank the ideas we just discussed in terms of usefulness?

Both groups emphasized the importance of an electronic prompt within the EMR interface tool and the need for new doctor training on how to properly fill out a death certificate.

For this question, participants were asked to brainstorm and the facilitator wrote ideas on a whiteboard that everyone could see. After participants had given their ideas, they were asked to rank the ideas in terms of usefulness. In both groups, there was a lot of agreement between physicians regarding the ideas and rankings.

The Salt Lake group discussed and ranked the following ideas: 1) Create a section titled “co-morbidities” for chronic conditions and include parenthetical prompts for ailments such as diabetes or hypertension, depending upon which specific co-morbidities are deemed useful and important for data collection. 2) Provide training for physicians on how to properly fill out death certificates (possibilities include a two-minute module real time training in HELP2 or on YouTube that provides specific instructions and examples such as “do not put cardiac arrest.”) This group suggested that a training video could pop up for first time users and not allow physicians to submit a death certificate until it had been viewed. The video would remain available to physicians who needed a periodic refresher on proper procedure. This suggestion is further developed in the Salt Lake group’s answer to Question 14. 3) Provide education regarding how to fill out death certificates to new doctors and in medical school.

The Salt Lake group agreed that the CDC website information is confusing, that it should not be used as a template, and that HELP2 should provide examples.

The Provo group had a shorter list: 1) Have an automatic pop-up list of a limited number of chronic condition checkboxes for the physician’s consideration when filling out a death certificate, and ideally, have the EMR provide the option for the physician to populate the death certificate with the patient problems that the physician determines were a contributing factor to the patient’s death. 2) Provide training for doctors on how to properly fill out a death certificate that includes mention of the need for chronic disease data.

The Provo group also had some discussion of a need to develop or improve upon the pop-up instructions currently provided in HELP2.

11. Do you think it is equally likely that you would think of including diabetes as a contributing factor as other chronic diseases? If not, what makes it more or less likely?

The two group discussions diverged for this question, with physicians from the Salt Lake group generally indicating that they would be more likely to think of including diabetes on death certificates than other chronic diseases, and the Provo group indicating that they considered listing diabetes or other chronic diseases based upon whether there was a relationship between the chronic disease and the ailment that was most likely to have caused the patient’s death.

Physicians in the Salt Lake group all agreed that they were more likely to include diabetes than other chronic diseases as a contributing factor on a death certificate. One physician indicated that she would be more likely to include diabetes

than conditions such as hypothyroidism or Vitamin D deficiency because the manifestations of diabetes included organ damage and were more life threatening. Other physicians concurred.

The Provo group discussion focused on the relationship between the chronic disease and the ailment that was most likely to have caused the patient’s death. The group agreed that it was more likely that they would indicate diabetes if the patient had died of kidney disease, but less likely if they died of something like stroke or cancer. The physicians in the Provo group shared a number of examples of how chronic conditions may or may not relate to the cause of death diagnosis. For instance, they noted that a patient can come into the hospital because of a stroke and eventually die of pneumonia, but may have actually died with hypertension as the cause of death because it was the condition that the patient had left untreated for fifty years.

12. What changes would you make to the current electronic medical record system to encourage physicians to report diabetes on death certificates?

Both groups used this question to further examine or develop the ideas they had expressed in question 10.

The Salt Lake group emphasized the importance of the changes they recommended in question 10, urging the creation of a co-morbidity section. One physician noted that the changes included in a new EMR tool called iCentra would include a button that allows the physician to see the patient’s chronic problems. The physician familiar with these changes thought they would be more user-friendly than having to review the patient record. Another physician maintained the need for the second section in addition to the iCentra changes, including a prompt asking if the patient had chronic conditions because otherwise there would still be confusion regarding where to list certain information.

During this portion of the discussion, the Provo group explored several aspects of how the EDEN record works, including how the time of death can sometimes differ on different portions of the record and whether it is possible to use HELP2 if the death certificate is requested for a patient who dies at home.² Earlier discussion in question 10 involved detailed recommendations for altering the HELP2 EMR interface to remind physicians of potential contributing chronic conditions and to provide physician training.

13. Would an electronic clinical decision support prompt influence the likelihood that you would report diabetes or other chronic illnesses as secondary or contributing factors on death certificates?

2. HELP2 can be used for any patient in the Intermountain System, regardless of where they die.

Both groups had already expressed support for the concept of a prompt earlier in the discussion and they maintained that perspective with their answers to this question.

The Salt Lake group maintained the pro-prompt position that they had just expressed in their answer to questions 12, with the same physician again emphasizing the need for a separate co-morbidity section even with the prompt.

The main Question 10 proposal for the Provo group was an automatic pop-up list of a limited number of chronic condition checkboxes for the physician's consideration when filling out death certificate. Ideally the interface would also eventually include an EMR option for the physician to populate the death certificate with the patient problems that the physician determines were a contributing factor to the patient's death. The physicians in the Provo group strongly believed that a prompt would make a difference and they mentioned it at various times throughout the focus group discussion.

14. Are there any aspects to the process of death certificate reporting that you feel we have missed in this conversation?

Only the Salt Lake group was asked this wrap up question.

In answering this question, the Salt Lake group further developed the third suggestion they provided in answering question 10. The physicians talked about the possibility of a new employee orientation on how to fill out death certificates that contained discussion of the national interest in documenting the pervasiveness of diabetes and the place where that information should be provided on a death certificate. The conversation renewed emphasis on how different people have different understandings of how to properly fill out death certificates, both in terms of what conditions should be indicated as the primary cause of death and in terms of how much information on secondary and contributing causes should be provided, and where it should be entered. A couple of physicians shared stories about how they filled out a death certificate differently than their co-workers would have. In fact, one physician remembered the commotion caused when she and another doctor inadvertently filled out the same death certificate with different wording and different assessments of which ailment was the ultimate cause of the patient's death. When one physician said that it was kind of scary to think that this data was being used for national level statistics, it led to a shared laugh. In addition to a training for new physician training, the group supported the idea of information and examples provided within EDEN's website.

Both this question and question 15 were considered optional wrap up questions in the moderator's guide. Based both on time and the fact that the Provo group had already

repeated their conclusions at this point in the conversation, they were not asked this question or question 15.

15. Are there specific examples that you can provide where the EMR tool made it easier or harder for you to complete a death certificate?

Only the Salt Lake group was asked this wrap up question.

The Salt Lake group confirmed their assertions from earlier in the discussion that the EMR tool (HELP2) made it easier to complete a death certificate.

Both this question and question 14 were considered optional wrap up questions in the moderator's guide. Based both on time and the fact that the Provo group had already repeated their conclusions at this point in the conversation, they were not asked this question or question 14.

Summary

Physicians far preferred their experience with HELP2 to their experience with paper death certificates and EDEN. The immediacy with which they could complete death certificates and the provision of patient data within the system were the most appreciated features of the system. Physician experience with death certificates varied based upon length of practice and type of medical specialty. From the most basic perspective, physicians who typically dealt with older patients near the end of life had more experience with filling out death certificates. In addition, certain specialties, like leukemia and NICU, also dealt with a certain type of death that does not usually lend itself to consideration of the possible influence of chronic diseases such as diabetes. Focus group participants outlined a number of updates to the EMR interface and possible physician training opportunities that they believed would promote inclusion of chronic diseases such as diabetes on death certificates. Both focus groups urged consideration of whether diabetes should be elevated for special consideration above other chronic diseases when designing changes.

Focus Group Recommendations

The main recommendations that emerged from the two focus group discussions involved amending the EMR interface tool to provide more guidance and information to physicians, and providing training opportunities for physicians.

Provide an automatic pop-up list of a limited number of chronic conditions checkboxes for the physician to consider when filling out a death certificate.

Physicians in the Provo group suggested pop-up checkboxes for physician consideration of a limited number of chronic conditions when filling out a death certificate. Ideally,

the pop-up check box system would interact with patient data from the EMR and provide the option for physicians to populate the death certificate with the patient's problems that the physician determines were a contributing factor to the patient's death.

Provide an additional section on the death certificate for co-morbidities, possibly using a prompt.

Physicians in the Salt Lake group recommended a new co-morbidity section be created within death certificates that includes parenthetical considerations such as diabetes or hypertension as examples for physicians filling out death certificates, depending upon which specific co-morbidities are deemed useful and important for data collection.

Provide training opportunities for physicians, both at the beginning of their practice and as elements of the EMR interface tool.

Physicians reported observing significant variation in how death certificates are filled out by different physicians. Primary cause of death can be difficult to determine for patients with a large number of inter-related ailments, and physicians disagreed regarding whether a catch all such as multiple organ failure or cardiac arrest should be listed instead of an ailment that led to that outcome. Due to this uncertainty, both groups supported physician training. Options discussed included providing training for medical school students; providing training for new physicians; and providing a two-minute module in HELP2 or on YouTube that physicians can reference as needed. The Salt lake group suggested that the training video could pop-up for first time users and would not allow physicians to submit a death certificate until it had been viewed. They recommended that the video would remain available to physicians who needed a periodic refresher on proper procedure. Moreover, they recommended that the video provide specific instructions and examples such as "do not put cardiac arrest as the primary cause of death." Both groups also recommended that the training highlight the importance of death certificate data to national health data.

Provide an automatic EMR death certificate interface prompt asking if the patient has diabetes.

Both groups agreed that if the impact of diabetes on patient health is determined to be more significant than other chronic diseases and conditions such as obesity or hypertension, then an EMR death certificate interface prompt (such as the one currently provided for smoking) is the easiest way to focus a physician's attention on the issue while filling out a death certificate.

Conclusion

Physicians from both focus groups expressed positive experiences with the HELP2 tool in comparison with both EDEN and paper death certificates. Each group also recommended similar pop-up EMR interface additions, with the caveat that consideration should first be given to whether diabetes should be elevated above other chronic illnesses and contributing conditions. The Provo group suggested a checkbox system, ideally one that prompts specific considerations based upon patient data. The Salt Lake group suggested a pop-up co-morbidity section with examples provided. Despite different specialties, physicians in both groups coalesced around an assessment that more physician training is needed to educate physicians both about the proper way to fill out death certificates and the national interest in using data from death certificates to establish national health trends. If diabetes is determined to be the only chronic condition meriting elevated consideration, physicians agreed that a prompt like the one used for smoking would be useful. However, if multiple chronic conditions need to be elevated, another format may be more efficient and useful.

Appendix A – Physician Focus Group Discussion Guide

Introduction and Purpose

I'd like to begin by introducing myself. My name is Samantha Ball. I am a research associate at the Kem Gardner Policy Institute at the University of Utah. Anna Bergevin is also a research associate at the Policy Institute. She will be at taking notes on our discussion tonight and we will be using those notes, plus recordings of the discussion, to create a complete transcript of our discussion. We are recording from two ends of the room tonight, just to make sure we capture everyone's input when we put together our findings.

The Utah Department of Health has contracted with the Policy Institute to hold and facilitate two focus groups that consist of physicians who are most familiar with Intermountain Healthcare's EMR death certificate tool. The focus group participants are divided into groups based upon geographic area. Tonight's group represents physicians from the Salt Lake Valley and next week we will have a group in Provo. The purpose of the focus groups is to assess what barriers exist to reporting diabetes and other chronic diseases on death certificates. The study is funded by The National Association of Chronic Disease Directors.

I know that everyone will be paid a stipend as a way to say thank you for attending and participating tonight. I am passing out these W-9 forms for each of you to fill out. They should include your name address and social security number. Since the stipend is going to you as individuals and not the organization you work for, everything that is asked for on the form refers to you personally and not Intermountain Healthcare. You will also need to sign and date the form before giving it back to me. Once the form is submitted, it will take about 10-20 business days for it to be processed and then it will be mailed to the home address that you provide on the form.

Prevalence and cost

First a bit of background on diabetes and diabetes reporting on death certificates: The American Diabetes Association notes that over 29 million people in the United States have diabetes and that it is the 7th leading cause of death. Data suggests that diabetes costs the United States about \$176 billion in direct medical costs each year, with an additional \$69 billion reduction in productivity. Hospitalization rates are higher for stroke and heart attack patients who have been diagnosed with diabetes than those who have not. Of people with diabetes, only 10-15% have it listed as an underlying cause of death on their death certificate.³ A study by the Utah Department of Health and Intermountain Healthcare provides evidence that diabetes is underreported. The study found that recent development of the HELP2 EMR interface with EDEN improved the timeliness and descriptiveness of death reporting, but did

not significantly increase the reporting of diabetes and other chronic diseases on death certificates.⁴

Physician introduction

Let's begin by having all of you introduce yourselves, your specialty, and the extent of their experience in filling out death certificates whether it is paper, EDEN or the Intermountain interface tool.

Questions

Death Certificate Experience

1. Tell me what your thoughts are about the process of using the EMR tool through HELP2 to fill out death certificates.
2. How does that experience compare to completing death certificates directly on the EDEN website or on the paper form?
3. Have any of you heard comments from colleagues regarding using death certificate reporting linked to an EMR tool that leads you to believe their experience has been different than what we have been discussing? If so, in what way is it different?
4. Does having an electronic interface increase, decrease, or make no difference in the likelihood of you listing a chronic disease such as diabetes to a death certificate?
5. How do you determine a causal sequence for the purposes of filling out a death certificates? What are your considerations and resources?
6. Are you aware of what happens with the data, or how the data is used, after it has been submitted via a death certificate?

Death certificates are the primary source of mortality information throughout the United States. Data compiled from death certificates are used to tabulate leading causes of death; to document trends in mortality over time; and to inform public policy, research allocation, and public health efforts.

A central death certificate registry is maintained by each state, typically in the state's public health department.

Factors that May Influence the Likelihood of Reporting Diabetes

Now we are going to discuss some factors that may influence the likelihood of reporting diabetes on a death certificate. For some of these questions, I will be giving you a chance to provide the answers that come to mind first and then

we will be following up with some specific examples of factors that may be influential.

7. Can you think of any situational factors that influence the likelihood of you indicating diabetes and other chronic diseases on death certificates?

Follow up questions:

- Would the time of day make a difference?
- Would your location when filling out the record make a difference?
- Would filling out the record at a busy time make a difference?
- Would it make a difference if the patient was new to you?
- Would it make a difference if History and Physical information was available?

8. What patient health data would make you more likely to report diabetes on a death certificate?

Follow up questions:

- Would the patient's blood sugar control status make a difference?
- Would the patient's weight make a difference?
- Would a patient's blood pressure make a difference?

9. Does the patient's primary cause of death influence whether you are likely to record diabetes as a contributing factor?

Follow up:

- If the patient had a stroke, heart attack, or kidney failure, would it make you more likely to consider reporting diabetes as a contributing factor?

10. What do you think would make you more likely to report diabetes on a death certificate?

How would you rank the ideas we just discussed in terms of usefulness?

11. Do you think it is equally likely that you would think of including diabetes as a contributing factor as other chronic diseases? If not, what makes it more or less likely?

12. What changes would you make to the current electronic medical record system to encourage physicians to report diabetes on death certificates?

13. Would an electronic clinical decision support prompt influence the likelihood that you would report diabetes or other chronic illnesses as secondary or contributing factors on a death certificates?

Wrap Up

14. Are there any aspects to the process of death certificate reporting that you feel we have missed in this conversation?

15. Are there specific examples that you can provide where the EMR tool made it easier or harder for you to complete a death certificate?

Conclusion

I'd like to thank all of you for participating tonight. The results of this discussion will be used to inform efforts to increase reporting of diabetes on death certificates in order to more accurately reflect the prevalence of diabetes as a contributing factor in deaths in the United States. Thank you for taking the time to give your input. Please make sure that you give me your W-9 forms before you leave so that you can receive your stipend.

(Endnotes)

- 1 <http://www.diabetes.org/diabetes-basics/statistics/?loc=db-slabnav>, accessed August 17, 2015.
- 2 Utah Department of Health and Intermountain Health Care. *Improving Reporting of Diabetes in Utah, An Evaluation of the Quantity, Quality, and Timeliness of Death Information Received from HER Compared to Electronic Death Registration or Paper*. Salt Lake City, UT; 2013.
- 3 <http://www.diabetes.org/diabetes-basics/statistics/?loc=db-slabnav>, accessed August 17, 2015.
- 4 Utah Department of Health and Intermountain Health Care. *Improving Reporting of Diabetes Deaths in Utah, An Evaluation of the Quantity, Quality, and Timeliness of Death Information Received from EHR Compared to Electronic Death Registration or Paper*. Salt Lake City, UT; 2013.