

PA12-166

HB5038

House	4812-4998	187
Public Health	62, 64-66, 69-70, 105-108, 117-154, 345-348, 350- 351, 651-673, 1950, 1951- 1952, 2105	81
<u>Senate</u>	<u>4482-4483, 4497-4499</u>	<u>5</u>

H – 1136

**CONNECTICUT
GENERAL ASSEMBLY
HOUSE**

**PROCEEDINGS
2012**

**VOL.55
PART 14
4474 – 4836**

lg/cd/ed
HOUSE OF REPRESENTATIVES

243
May 2, 2012

Will the Clerk please take a tally, and will the Clerk please announce the tally.

THE CLERK:

House Bill 5496

Total number voting	148
Necessary for passage	75
Those voting Yea	145
Those voting Nay	3
Those absent and not voting	3

DEPUTY SPEAKER ALTOBELLO:

The bill passes.

Congratulations Representative Rowe.

Will the Clerk please call Calendar 335. That's 335 please.

THE CLERK:

On page 43, Calendar 335, Substitute for House Bill Number 5038, AN ACT IMPLEMENTING THE GOVERNOR'S BUDGET RECOMMENDATIONS CONCERNING THE ALL-PAYER CLAIMS DATABASE PROGRAM, favorable report by the Committee on Appropriations.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter of the 38th District, you have the floor, madam.

REP. RITTER (38th):

lg/cd/ed
HOUSE OF REPRESENTATIVES

244
May 2, 2012

Thank you very much, Mr. Speaker.

I move for acceptance of the joint committees' favorable report and passage of the bill.

DEPUTY SPEAKER ALTOBELLO:

The question before the Chamber is acceptance and passage. Please proceed, madam.

REP. RITTER (38th):

Thank you very much, Mr. Speaker.

Mr. Speaker, as the name implies this bill allows implementation of an all-payers claims database. Mr. Speaker, there is a strike-all amendment that I would like to call and discuss as the bill.

The Clerk is in possession of LCO 4170. I would ask that the Clerk to please call the amendment, and then I be granted leave of the Chamber to summarize.

DEPUTY SPEAKER ALTOBELLO:

Would the Clerk please call LCO 4170, which shall be designated House Amendment Schedule "A"?

THE CLERK:

LCO 4170, House "A" offered by Representative Ritter and Senator Gerratana.

DEPUTY SPEAKER ALTOBELLO:

Representative begs leave of the Chamber to summarize.

Without objection? Without objection?

Seeing none, please proceed, madam.

REP. RITTER (38th):

Thank you very much, Mr. Speaker.

Mr. Speaker, this amendment which will become the bill requires the Office of Health Reform and Innovation to oversee the planning, implementation, and administration of an all-payers claims database program for the purposes of receiving and storing data relating to medical and dental insurance claims, pharmacy claims, and information from enrollment and eligibility files from reporting entities.

It requires insurers and administrators of healthcare claims and payments to provide information for inclusion in the database and establishes civil penalties for the failure to do so.

The Office of Health Reform and Innovation, or OHRI, must make this data available for information relating to healthcare use, cost, quality, and services. In all cases, the data disclosure must protect the confidentiality of the individual health information.

The amendment further specifies how OHRI must utilize the data in the database, allows them to

independently hire consultants, as required to do this work, and specifies oversight by the all-payer claims database advisory group.

It further specifies that the Office of Policy and Management must adopt the appropriate regulations to do so.

One point, Mr. Speaker, I would like to make is that in the discussions on this bill, it's clear that it's incumbent upon the APCD Advisory Committee to develop additional clarity through regulations on the reporting process, including, specifically, how this information will be protected. And this will be, I think, a major focus of their work as once this bill becomes law.

The amendment directs the special advisor to the Governor on healthcare reform to seek the necessary funding from this effort for federal and other private sources. There is no fiscal note.

Mr. Speaker, in working with this, the original bill that we were presented with was fairly lengthy and initiated a lot of discussion among the committee, and I'm very pleased to thank, not only the committee, but a lot of our healthcare organizations for taking the time to work on this and to come on board. The

lg/cd/ed
HOUSE OF REPRESENTATIVES

247
May 2, 2012

efforts supported by the insurance industry, the
medical society, the business industry association,
the hospital association, and the healthcare advocate
community, and I urge its adoption.

DEPUTY SPEAKER ALTOBELLO:

Thank you, madam.

Further on House "A"?

Representative Perillo, you have the floor, sir.

REP. PERILLO (113th):

Thank you, Mr. Speaker.

If I may, through you, sir, a few questions the
proponent of the bill.

DEPUTY SPEAKER ALTOBELLO:

You surely may.

Please proceed, sir.

REP. PERILLO (113th):

Thank you.

Through you, Mr. Speaker, the Chair of the Public
Health Committee mentioned that in the amendment there
is no fiscal note, and I will notice that in the
original bill there was a fiscal note between 1 to 2
million dollars every year. I understand there is
some sort of reference in here to the ability to
attempt to access funds from the federal government in

lg/cd/ed
HOUSE OF REPRESENTATIVES

248
May 2, 2012

order to pay for this. I don't see anything in here that indicates that those the funds are clearly available.

So my question is if those funds are not available, in order to cover the full cost and in order to truly make this budget neutral, wouldn't we then have to go forth with this? Is this claims database dependent upon receipt of federal funds? Through you, sir.

DEPUTY SPEAKER ALTOBELLO:

Thank you, Representative Perillo.

You are the second speaker in a row to say there is no fiscal note regarding this amendment. I'm looking online, and I believe there is one filed and - - well, we can proceed from there, perhaps.

Thank you.

Representative Ritter.

REP. RITTER (38th):

Thank you very much, Mr. Speaker.

Mr. Speaker, I would direct the Representative's attention in the amendment to lines 24 for 26, where it states that the special advisor shall not incur costs or contract for services associated with said program for which funding has not been secured in

accordance with this subsection. Previously, in this subsection, beginning on line 16, it was stated that the special advisor is directed to seek funding from the federal government and other private sources to cover these costs.

So I would interpret that to mean there will be no cost to the State. I would further interpret that to mean that if, in the future, that funding was not available, there still would be no cost as directed by this amendment to the State. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker, and I think the lady for her answer.

So just to clarify, this isn't simply aimed a one-year effort to obtain funds. So if in any year, four years out, we fail to obtain federal or private funds, then, in fact, we would have to cease administration of that database, and that database would go away?

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

And I agree with that. Directing Representative's attention to the wording beginning on line 19, where it states that there will be an annual reporting and presentation of the budget from the special advisor to the secretary of the Office of Policy Management with the budget -- with that information so I would agree with Representative's statement. There's no contemplation of future state funding.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you very much, Mr. Speaker, and again I think the Chair of the Public Health Committee for clarifying that.

If I could, just direct Chair's attention to line 16. And this is something that refers throughout the amendment, refers to the special advisor to the governor on healthcare reform and states that she shall seek funding and do a number of other things throughout the course of the bill. But it comes to mind that the special advisor to the governor on

healthcare reform, I do not believe is stated in statute or created in statute in any way, shape, or form. This -- as I recognize it, unless I'm very much wrong. I believe this was position appointed by the Governor and created by the Governor which he has, of course, the full authority to do. But I don't believe there is anything creating this position in statute. In which case, I'd be very concerned that we're now putting power and authority into the hands of someone who, perhaps -- into the hands of a position that, perhaps, may not be here tomorrow. So I am wondering whether that's wise or, quite frankly, or, perhaps, maybe I'm misunderstanding this? Through you, sir.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

Well, I agree that Representative Perillo's concern is always a valid concern. Actually, when we're talking about any of us that are present here in state government -- and I would include myself in that as well as any of the administrative positions -- and this bill does nothing to change, perhaps, that uncertainty. I would like to point out, however, to

the Representative that beginning in section 3, which begins on line 174 of the amendment, reference made to the wording in section 19a-724a, which we passed last year and a session where we established the Office of Healthcare Reform and Innovation, and specifically give the power -- their direction to that office to convene a working group to work on this specific initiative and, perhaps, that may give some comfort to the Representative. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker. And I did note that in statute that office has been created but, of course, my concern was that this specific position had not.

If I could move on briefly to subsection D, lines 32 through 45. The amendment discusses that the special advisor to the Governor may engage in contracts for certain things. I'm wondering what those are and it's been enumerated to some degree, but it mentions in line 42 things, like the collection, management, or analysis of data.

Does the Chair have any sort of sense or idea of what sorts of companies or firms or private

contractors to be utilized for this. Are we talking about actuarial work? Are we talking about database management work? What exactly are we looking for? Through you, sir.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

Through you, Mr. Speaker, the State of Connecticut is not the first state to embark on the creation or use of an all-payers claims database, and indeed, several states -- we heard in testimony about a variety of other states that have done this.

The most commonly accepted method of doing this would be through third-party vendor arrangements of the type that the Representative has referred to. And while I cannot cite by name any of those companies, I can tell you that it was our information during the hearings that there are, indeed, a series of vendors out there for which this is their specific specialty, and that would be my understanding of the intent of this language.

Furthermore, I can point the Representative to the National Association of Health Data Organizations,

lg/cd/ed
HOUSE OF REPRESENTATIVES

254
May 2, 2012

which is an organization designed, specifically, to help, not only with the design of the architecture, but the encryption, protection, and our use of security protocols around this data. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker.

And to follow up on that and I understand the language in here is "may" and not "shall" in terms of engaging or contracting with a private entity. However, I do understand and I just would like to clarify, it does seem to be the intent of OHRI and the special advisor to the Governor to enter into a contract, even though in statute in the amendment that's before us, that is not required; is that correct, sir?

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, yes.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

lg/cd/ed
HOUSE OF REPRESENTATIVES

255
May 2, 2012

REP. PERILLO (113th):

Thank you very much.

And if I could direct the Chair's attention to lines 44. It does state that in any such contract, the -- it would expressly prohibit disclosure of such data. So that basically saying that anyone with whom we entered into a contract would not be able to disclose data that they gain or have access to in the course of providing their work.

I'm noticing, though, and I don't see it, is there any sort of penalty for disclosure? We state that they can't, but there doesn't seem to be a requirement that there must be a penalty. So I'm wondering if this is a requirement that has no teeth? Through you, sir.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker -- Mr. Speaker, there are disclosures throughout the statutes for -- I'm sorry. Excuse me, I misspoke -- there are penalties and sanctions throughout the statutes for these types of the disclosures, both in the state and the federal

lg/cd/ed
HOUSE OF REPRESENTATIVES

256
May 2, 2012

statutes, and there is nothing a specific in the statute.

There is a penalty mentioned in the statute, but it is for the failure to comply with report. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker.

So to clarify, federal guidelines and regulations, such as HIPAA, the Health Insurance Portability and Accountability Act, does have penalties in place with the discloser of information. Would those apply in this instance? Through you, sir.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, and the answer is yes. I would direct the Representative's attention to the words -- wording on lines 57 through 58 of the amendment where it refers, specifically, to the federal protection laws. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

lg/cd/ed
HOUSE OF REPRESENTATIVES

257
May 2, 2012

REP. PERILLO (113th):

Thank you, Mr. Speaker.

So to follow up to that, the Health Insurance Portability and Accountability Act refers to disclosure of individually identifiable health information. So am I to understand from that, through you, Mr. Speaker, that the goal of this is to have individually identifiable health information. The goal of this amendment and that potential disclosure of that individually identifiable health information would trigger the Health Insurance Portability and Accountability Act's penalties. Because HIPAA does not apply to nonidentifiable information? Through you, sir.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, that language is there to protect any, specifically, individually identifiable data that could indeed be used for this purpose. It is not specifically stated anywhere in this amendment that the data must fall under the category. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you very much, Mr. Speaker, and I appreciate the answer.

If I could direct the Chair's attention to lines 189 and 190. This section refers to the individuals who would comprise the all-payers claims database advisory group. Specifically, it makes reference to a representative of the Connecticut State Medical Society. I'm just curious as to why it was this one particular group that was identified and not others? Through you, sir.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, that request actually came to us from the Connecticut State Medical Society following the hearing and, actually, in the processes of discussing this bill. The Medical Society has agreed deal of expertise in this area and were very eager to provide their representative to serve on the advisory committee and allow us to take advantage of that expertise. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

lg/cd/ed
HOUSE OF REPRESENTATIVES

259
May 2, 2012

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker.

And a follow-up to that, through you. We have other types of providers in the state of Connecticut, not just the physicians that would be within the Connecticut State Medical Society. We, obviously, have large facilities, our hospitals, our nursing homes, pharmacy groups that would have relevant information as it pertains this and, perhaps, some expertise. I'm wondering why none of those other groups are included, such as Connecticut Hospital Association, and others. It would seem they would have some value? Through you, sir.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, a couple of points to that. The addition of the representative of the Connecticut State Medical Society is new language. I would point out that this particular section is -- I'm sorry -- is amending existing language. The further -- and it was at their specific request.

The existing language, where continues beginning in the line 190, does speak to representatives of various groups, including health insurance purchasers, insurance companies, hospitals, consumer advocates, and healthcare providers. That's existing language from the statute that we passed last year. I can also point out to the Representative that it goes on to specify that the special advisor may appoint additional members to said group, as necessary.

I will comment to that that was really an attempt to continue to gather as much expertise to this group as we possibly can. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you very much, Mr. Speaker.

If we could just backtrack briefly. Back into section 1, beginning on line 46. It states that the special advisor to the governor on healthcare reform shall utilize data and the all-payer claims database to provide healthcare consumers in the state with information concerning the cost and quality of healthcare services.

I'm -- I'm wondering how this database will be able to give consumers information as to the quality of healthcare services that would be provided? Through you, sir, if there could be some clarity there.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I can give a couple of examples to Representative Perillo of, perhaps, of some of the types of questions that could be either answered or the types of enlightenment that could be provided by this data and point out to him, also, that the -- the definition of "quality to consumer," I understand, perhaps, could indeed be individual or subjective but can only be enhanced by the addition of information.

And some those questions might be along the following lines: talking about the ability for emergency rooms to provide preventative primary care; issues with adequate or complete treatment; particular over or underutilization of services, say, imaging services that might need to be addressed; cost information; also, from the consumers' standpoint --

it's my opinion at least, is often part of that decision process, and there would be an opportunity for consumers if they chose to pursue this to learn the cost of specific individual procedures, say, an MRI or a back MRI by provider location or by payer; and a further useful piece of information that could be obtained might be about the average cost of a service, using a specific health plan as opposed to another specific health plan.

A lot of this really would be at their request and inventiveness, specifically of the consumer.

Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker.

And just to follow up, the Chair did mention one thing that, perhaps, could be available to individuals and it was about prevent -- whether or not emergency rooms were able to provide preventative primary care. That to me seems like a very, very specific question that one might ask and something that would probably be very, very difficult to ascertain through broad databases of information.

So I'm wondering in order to drill down to that level of detail, is the expectation that users would be able to, basically, freely utilize the database as one might use to access database or something much more complex, or is the expectation that the Office of Health Reform and Innovation, OHRI, would prepare specific reports with certain information. Because I can imagine, in that particular case, what types of services are provided in a specific emergency room, aren't going to be readily available from claims data that comes back from insurers. So are we expecting that the state of Connecticut is going to extrapolate data and prepare reports, or are we expecting that individuals are going to have the free ability to access information and utilize the database? Through you, sir.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, the expectation is that consumers or individuals will be able to obtain information that can help them make, not only medically appropriate decisions, but economically

sound ones when they are thinking about their healthcare.

The special advisor has provided plenty of information in her testimony and, specifically, talks about the availability of this information to be available through a type of user-friendly web portal at no cost to an individual or to a consumer. I understand that individuals, of course, have different abilities to look up and use that information. But I think, Mr. Speaker, in today's world for us to walk away from or fail to be able to take advantage of information that could be available in making these, for many people, very important and weighty decisions, without using all the resources available to them would be a shame.

I think that the vision -- and this has been happening -- it's my understanding in other places where these databases are starting to prove to be very effective tools, is that individuals can look up healthcare services by facility and determine a variety of information that can help them make their decisions, help them have informed discussions with their medical providers and be able to gain a better understanding of the implications to both, to them

lg/cd/ed
HOUSE OF REPRESENTATIVES

265
May 2, 2012

individually and to their families. Through you, Mr.
Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you very much, Mr. Speaker, and I
appreciate the answers the question.

Of course, it begets another. The Chair of
the Public Health Committee referenced the ability of
consumers to take this data and make medically
appropriate decisions. My concern with that is that
simple data available and aggregated in any way shape
or form through some sort of portal that the Chair
identified might be created, in the hands of somebody
who is not necessarily educated as to what the data
means, we could be sort of enabling bad decisions by
giving information that is not easy to understand or
that, quite frankly, if you don't have a sense of what
it really means, can actually lead people in different
directions.

So I have a very big concern about that, and I
know that the all-payer claims database has been
utilized in other states and has been implemented.
And of course, the goal of that has been to inform

consumers, and I would clearly state that, perhaps, informing them about the cost might be a little bit easier than informing them about medical appropriateness. But the simple fact that we're giving folks raw data and allowing them to interpret in any way they see fit is a concern. So I would imagine that in order to give meaningful data that is not confusing, that is not misleading, that does not send folks down the improper road in order to seek to their care that the State of Connecticut would have to aggregate that in some way, shape, or form.

It would seem in this case that judging one provider versus another in terms of their outcomes is very, very different and very, very difficult because, quite frankly the mortality -- or the morbidity of the patients that one provider versus another may see, might be very, very different. So outcomes from one provider in a certain part of the state -- outcomes from one provider that, perhaps, sees a less healthy populations than another, could conceivably indicate to the untrained eye that that provider who sees a more difficult population with higher morbidity and mortality rates, is less effective than the provider

that seeks -- sees a healthier population but that would be misleading.

And I'm worried that if we put this data out for consumers, while extraordinarily well intended, we could be in creating an unintended consequence, which is to enable folks poorly. Enable folks only halfway. Enable folks to make decisions that really aren't appropriate, despite the fact that they believe they are appropriate given the information that is before them.

And quite frankly, it one of the reasons why you don't want someone just going online to WebMD and diagnosing themselves and determining what they should be asking. That's why we have the benefit of a provider.

Which leads me to my next concern that, perhaps, we are taking away from the provider, the ability to determine what is medically appropriate? What is most cost-effective? And this something that we discussed a little bit in committee, but something that I believe deserves discussion further, is that are we trying, as a state, to create some sort of clinical pathway, a best practice, if you will, cookbook medicine, where we are outlining the proper approach

H – 1137

**CONNECTICUT
GENERAL ASSEMBLY
HOUSE**

**PROCEEDINGS
2012**

**VOL.55
PART 15
4837 – 5168**

to treat patients, the best medications to treat patients, the best tests, the right way to do it. When, in reality, most physicians will tell you -- and I'm sure some or one may tell you later on during this debate -- that every patient is indeed different. And what is medically appropriate and most cost-effective for one patient may not be medically appropriate or most cost-effective for another.

So -- if the -- if the Chair could give some sort of sense as to what the goal is as to determining medical appropriateness, what the goal of the State of Connecticut is as to how this data will be used to ensure that the highest quality of care is provided. I would appreciate it very much. Thank you, sir.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you very much, Mr. Speaker.

Through you, Mr. Speaker, the Representative expressed substantial concerns about the opportunity for the types of provider-to-provider comparisons that he felt, perhaps, would be inappropriate.

I'd like to point out a couple of things about this data and also a few of the things that we've

heard from providers when they were talking about it. The first is this is paid claims data. This data is not data of the type that would enable a patient to diagnose their problem. This is data of a type that comes from claims that have been paid. A large part of the evaluation, indeed, can be cost, and everyone in this chamber knows full well the hours and hours we spent here talking about cost and what happening in the healthcare system and the relationships between cost and quality and what we can best do to help control it or to help, at least, try to understand it.

In those conversations a couple things become apparent, the first this is to the average consumer, cost is a very big deal. And so I don't want to walk away from the value of having that information or let anybody think that it is not part of the considered valued information that could be available through this database.

But the options that are provided by the multitude of providers that we have had Connecticut is also valuable information for not -- for all those consumers that we so -- that we try so hard to represent and try to represent well. So I would not

like to eliminate, certainly, the value of that from the discussion either.

But remember we're talking about, we're talking about paid claims data. We are not diagnosing problems for an individual illness for patients. We are not determining treatment for a patient. What we are, perhaps, providing is an opportunity to bring more information to the professionals, to the providers that make those particular decisions for their patients.

Finally, I'd like to point out where a lot of the support for this initiative comes. It comes from the provider community. I don't think it's a reasonable expectation that that provider community would not have given -- would not have provided the thoughtful support and information to the committee, if it felt, indeed, that this is something that was not just detrimental to their practices but took away the opportunities for any providers to practice to the maximum of their knowledge and experience for the best benefit of their patient. That simply is just is not the case.

In addition, we heard from hospitals, as well as the business and insurance industry about this. And I

think again, there's -- the discussion is a discussion focusing on our ability to bring more information to the ever puzzling and constantly bothering issues that we've had here about providing health care, about supporting our providers, and about providing it in the most efficient and cost-effective manner that we can for the greatest number of people here in the state of Connecticut. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker. And again, I think the Chair of the Public Health Committee for her answer.

There is no doubt that having data available -- having information available can be of great benefit if used properly. But I can certainly see where this data could be misused, and one of those areas is actually as we help to identify cost. As Representative Ritter said, it becomes a little bit easier with paid claims data to determine which providers treat a specific illness, treat a specific diagnosis at a lower cost.

Now, I see here in line 52 that insurers will have access to this data. And in order for the data

to be meaningful, it would have to link patients to providers. So that begs the question -- and certainly raises a concern for me, that insurers who have a clear interest in keeping the cost of claims down, may be able to then cherry pick doctors who provide cost, who provide care at a higher cost irrespective of the quality of their outcomes.

So if I'm an insurance company and I have access to this data, perhaps, I may say this to myself, All right, I'm going to find the top 10 percent of my providers who treat illnesses -- I'll make this a very specific example. I'll find the top 10 percent of cardiologists who treat patients with high blood pressure at the highest cost, and I'm going to cut them out. I'm not going to renew my contracts with them because it's just too expensive.

So I could see where an insurer, in their own self-interest, appropriately so, might try and do that without regard to the fact that, perhaps, those 10 percent of doctors who do provide care at a higher cost, maybe they also have the best outcomes. And perhaps, the cost in relation to tests and drugs prescribed has led to those high outcomes.

So, through you, Mr. Speaker, I'm wondering if any thought has been given -- if any care is going to be taken to ensure that this data that available to insurers is not used in that manner and is not used in a way that could, perhaps, negatively impact patients here in the state of Connecticut.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

Through you, Mr. Speaker, and I'm searching for the right place in the bill -- one moment, one moment Mr. Speaker.

Thank you, Mr. Speaker.

Through you, Mr. Speaker, a couple of places in the bill to point the Representative to. First, I'd like to start with section 4, on lines 99 and the following, where discussions the appointment of the all-payers claims database advisory group. That advisory group will not just develop a plan to implement this and advise on its implementation, but it's also on its use and monitor the kinds of requests that are being made, and I think that, perhaps, speaks to Representative Perillo's concerns about

inappropriate requests from insurers. I believe he was talking about. But, also, it's -- the type of information that is contemplated for insurance companies to find to be interesting has to do with planned design and targeted populations that they might best be suited for marketing their insurance policies and not individual performed practice -- practice performance by practitioners and -- the testimony on information, certainly, that we received from them spoke very highly of the potential value of that information to them, and I think the opportunities for those types of analyses to strengthen, not just our individual provider healthcare system, but the offerings to consumers throughout the state with enhanced insurance offerings is enormous.

If we -- we often are frustrated by our inability to have that complete picture when we're talking about opportunities to encourage different kinds of insurance options for people in the state of Connecticut. And we hear from our insurers on a regular basis, as well, that -- that that's a frustration. So I hope that helps the Representative with this question.

lg/cd/ed
HOUSE OF REPRESENTATIVES

275
May 2, 2012

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you very much, Mr. Speaker.

And as we talk about organizations and types of individuals who might be interested in accessing this data, I also note on line 52 that employers would have access to this data. I imagine employers would most likely want information on their employees. And while I understand that, perhaps, they might not be able to gather specific information about specific employees. I could see where a small employer that only has half a dozen employees taking the health insurance that's offered by that employer, if that employer were able to get the full list of information, the full list of diagnoses, the full list of procedures and tests and drugs administered to their employees in a small employee -- employer environment where there's only so many people, I could see where an employer who is, perhaps, again, as I said before, seeking to use this data inappropriately, might use it in order to ascertain what specific illnesses their employees have, you know, whether or not, you know, Joe in accounting is seeing a psychiatrist, are on

lg/cd/ed
HOUSE OF REPRESENTATIVES

276
May 2, 2012

antidepressant medications, or number of other things that might be of interest.

So what steps might be taken to ensure that employers are using this data for the right reasons and that an employer, you know, under the guise of the right reasons could clearly do what I just outlined, clearly do what I just said. So what steps could possibly be taken to ensure that that doesn't happen? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

Mr. Speaker, the Representative's question raises a couple of interesting points. The first one, actually, is that that data, for employers, is available today. And an employer can find out from their insurance company, depending on -- I'm not sure how long it takes but can often get the information on its employees.

I would also like to point out that the -- the identification of that information is fully protected under federal law and it is -- while indeed as the Representative has suggested -- it would be possible

for employers to make guesses, that also is no different than they can do today.

But I'd like to talk to some of the advantages of having this information from employers when evaluating the decisions that they might have to make about the selection and modification of plans that they might be able to offer to their employees to improve both the quality of their employees' health but also the cost of the employer and the employee.

Often employers make different evaluations about the need to improve their healthcare results. What they can get out of the change in insurance plan design? Should they promote a patient's centered medical home model for their employees or shouldn't they promote that? How could it make a difference? And finally, in many cases, health enhancement programs are evaluated for specific employee populations.

And once again, I would like to come back to the point that in looking at these decisions, it's these days more of a guessing game and less of an informed decision. This is an opportunity to, perhaps, bring more and a higher-quality data into that decision-making. And I believe that is something that will be

lg/cd/ed
HOUSE OF REPRESENTATIVES

278
May 2, 2012

helpful to employers across the state. Through you,
Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you very much, Mr. Speaker, and again I
think the Chair of the Public Health Committee for her
answer to the question.

As we talk about the value of this data and the
ability to determine what leads to positive outcomes
and what cost of care is more expensive, I imagine
that in some -- in fact, I know in some way, shape, or
form, we must be able to follow a patient through the
full continuum of care as they're treated by multiple
providers and, perhaps, as they a shuttle from one
insurance plan to another, where, perhaps, their
patient identification number in one insurance plan
might be different from that in another.

So with those things going on, I would imagine
they would need to be some sort of number, some sort
of common field that would link that patient together,
that would aggregated into one so that you could
follow the patient through the full continuum of care.
So that leads the question, how are we going to ensure

lg/cd/ed
HOUSE OF REPRESENTATIVES

279
May 2, 2012

that this information that is tracked by individual,
is not available to others? Through you, sir.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, we talked at the beginning of this discussion about the contracting for these particular services that will happen by the special advisor to the governor on healthcare reform in order to manage this program. And I talked about the opportunity to contract through vendors who specialize in the -- in the security, the encryption, the security, and the use of the data specifically of this type, and that is what the bill contemplates.

I also discussed opportunities for additional consulting on these problems. It would -- particularly through different organizations, the National Association of Health Data Organizations being, I believe, the most commonly known.

Mr. Speaker, throughout the amendment which, perhaps, could become the bill, there are discussions of the need for the special advisor to ensure that the data is securely collected, compiled, and stored in

full conformance with both federal and state law, and these would be the methods that she would use.

I would point out, Mr. Speaker, that this data is not contemplated to reside, specifically, here with the state. It would be managed exclusively through a vendor with area professional experiences to do this. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you very much, Mr. Speaker, and I do again thank the Chair of the Public Health Committee for her answers to those questions.

This is a bill that I did support in committee. It is a bill I intend to support today, but I do have some very serious concerns about it, not the least of which are those which as discussed.

I do see where this data could be made available to consumers well intendedly so but be misused to those consumers leaving them to decisions that are not medically appropriate, leading them to decisions that are not in their own best interests. And I understand the intent is to do the opposite, but I am concerned that to the untrained eye, to the uneducated consumer

about what can be very, very scientifically detailed decisions, we could be steering folks in the wrong direction.

I'm concerned that insurers could use information about physicians and other providers inappropriate such that those positions regardless of the quality of care they provide, those physicians that provide more expensive care than others could be cut out and asked to no longer be participants in that health insurance program.

I'm concerned about employers and the ability of employers to access data about the healthcare habits of their employees, about the diagnoses of their employees, about the medication their employees are on, about the tests their employees have received. It is very clear to me that all of this data being sought in is all-payers claims database could be misused despite the fact this its use is so very well intended, and I think those are all things that we need to keep in mind.

The only thing that gives me some degree of solace and some degree of comfort as this moves on -- and I must say that they give an awful lot of credit to the special advisor to the governor on healthcare

reform and innovation, she has been very, very active in this process. She has clearly displayed an interest in ensuring that this data is used appropriately and that the data is secure. But I caution us all, decisions can't be made about a person who happens to work for the State of Connecticut at a point in time. She should be commended for her work, but she's probably not always going to be here.

So I vote for this bill with great pause and great concern because I think we do need to understand that where there is data, where there is healthcare data, where there is personal data, where it can be linked to individuals, there is always concern. There is always risk.

So with that, I do support the bill. I do thank the Chair of the Public Health Committee for her time in answering my questions and allowing me to express my concerns, but I do think we all need to take those concerns into account as we cast our vote today.

Thank you very much, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Thank you, Representative.

From 31st District, Representative Srinivasan,
you have the floor, sir.

lg/cd/ed
HOUSE OF REPRESENTATIVES

283
May 2, 2012

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker. Good evening, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Good evening, sir.

REP. SRINIVASAN (31st):

I, too, share a lot of concerns that were just brought to the floor by my esteemed Ranking Member. We definitely need an efficient healthcare system. A system that is much better, much, much better than what we have today. A system that has got to be cost-effective on the one hand; and on the other hand, make sure we have top notch service. Quality cannot be compromised either. So we have cost on the one, quality on the other, and a very important component that we can never lose track of -- sight of, is securing our privacy. That is equally important in this entire group of things that go into good medical care.

We all heard that this amendment, if it were to pass, which will then become the bill, that this does not have a fiscal note. It was made very clear. We do not have a fiscal note. But my concern is that we may not have a fiscal note today because this program

needs that amount of money to get started. But once we have the federal grant going forward, if those funds dry out, we have started a program, we are in the process year one, year two, and then what will happen is a concern that I have and will we, as a state, be left to hold the bag because on the one hand we have this all-payer system, which is then in effect for let us say, two years, three years and then we are short as far as the funding is concerned. Those are some of my general concerns with this bill. The security and, of course, the funding factor.

Through you, Mr. Speaker, if I can have a few questions to the esteemed member -- the esteemed Chairwoman of our Public Health Committee?

DEPUTY SPEAKER ALTOBELLO:

6

Please proceed, sir.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

Through you, Mr. Speaker, in subsection b, Line 24, you know, you made it clear in the earlier conversation with Representative Perillo that funding will come and it will come regardless of the years that we need to go through. Will that funding, through you, Mr. Speaker, always be a federal fund or

lg/cd/ed
HOUSE OF REPRESENTATIVES

285
May 2, 2012

would we also be looking at private sources in case we do not get private funding? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

Mr. Speaker, I'll direct the Representative to the preceding lines, beginning on line 16, where it states that the special advisor shall seek funding from the federal government and other private sources to cover these costs. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

And so through you, Mr. Speaker, the -- the special advisor will seek the funds, and in the event the funds, through the federal government, or the private enterprises are -- do not match up, are not there, dry up. Then, through you, Mr. Speaker, what happens to this all-payer program, which is already on board? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

Mr. Speaker, again, I would like to point the Chamber to the language in lines 24 through 26 where it states that the special advisor shall not incur costs or contract for services associated with this program for which funding has not been secured.

Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

So through you, Mr. Speaker, if the funding is not secured in year two or year three, what then happens, through you, Mr. Speaker, to this program which has already started, but now we do not have any funding? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

through you, Mr. Speaker, I would interpret those to mean that the special advisor cannot incur costs nor contract for services if there is no funding.

lg/cd/ed
HOUSE OF REPRESENTATIVES

287
May 2, 2012

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

So through you, Mr. Speaker, for my own clarification, in that case if no funding is available, the program that we have started comes to an abrupt halt? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I believe that is the correct interpretation.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

Proceeding further, Mr. Speaker, in lines -- in subsection C, lines 27 through 31, which have been alluded to by the Representative before. Some of my concerns, the -- the database that we are going to create, obviously, has to be de-identified and the de-identification of the name will be with a number. So somebody within the state, a group of people, will have that connection between the name on the one hand

lg/cd/ed
HOUSE OF REPRESENTATIVES

288
May 2, 2012

and the number on the other; is that true? Through
you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, as I said earlier, the
answer to the question is no. The data will not
reside somewhere in the state.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

Thank you for the clarification. The data may
not reside in the state. I do agree with that. But
will someone have that connection between, A, the
name, and, B, the number, so that the de-
identification is in the hands of somebody? Through
you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, as I said earlier, it
is anticipated that this will be done through a
contract relationship with a vendor whose professional

-- profession and business is the management, not an acquisition and management of this type of data.

There are quite a few different protocols for managing data and for managing the specific identifiers that are attached to data records and that would be the -- under the expertise and guidance and direction of that vendor, Mr. Speaker.

I can elaborate a little bit in that there are different -- a variety of different protocols available to scramble and to render blind various identifiers that are attached to individual data records. Obviously -- and it's my opinion, it probably would be a bit foolish to, specifically, identify the ones that would be used here on the floor and inappropriate since the protection of that data is indeed our highest goal here. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Through you, Mr. Speaker, I do think the proponent of the bill for the answers.

But my concern is when this very important information is in the hands of a professional, we all

know that we're always looking for the most reasonable, most cost effective way to do business, and in that process of trying to be careful of cost, my concern is the choice of how lenders could be in any way be compromising such an important component of our own security? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I don't see anything in this amendment that would encourage the State to do something irresponsible in its selection of a vendor for this.

I understand the concern of the Representative, and I -- it's my feeling that there are numerable places throughout this language that emphasize the need for us to take the security and -- of this data and the privacy of our residents in the State of Connecticut very, very seriously. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Through you, Mr. Speaker, in line 38, Subsection (d), where we talk about obtaining fee-for-service.

Through you, Mr. Speaker, who will be allowed to obtain this information and how we will make sure that that information, once again, is secure? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

Mr. Speaker, that answer is contained in the proceeding lines where it states that the special advisors responsible for making the contracts necessary to obtain this information, this -- these health claims information, not only to obtain -- to obtain it but enter into contract for the collection, management, and analysis of this data. That would be the special advisor to the governor for health care reform.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

Through you, Mr. Speaker, moving on to subsection (h), line 67, where we are talking about organizations that do not comply or failure to comply, and hence, maybe having to deal with civic penalty, which could be as much \$1,000 a day -- up to -- up to \$1,000 a day.

Through you, Mr. Speaker, what was the rationale or the thought process if we can -- if I can hear that as to come up with the huge fee of almost a \$1,000 a day? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker.

The seriousness and the intent of the amendment would be the rationale for the fee. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Through you, Mr. Speaker, would that day include weekends and holidays, as well? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker. The language in the amendment states \$1,000 per day. I would interpret that to mean weekends and holidays.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31ST):

Thank you, Mr. Speaker.

Through you, Mr. Speaker, businesses and municipalities are self-insured -- or can be self-insured, those businesses and municipalities that are self insured, would they have to comply with this all-payers program? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, the program obtains its information from reporting entities, and those reporting entities are defined in the language beginning in line 87. Should a plan fall -- a businesses or a municipality or plan fall under the definition of reporting entity, as defined here, they would indeed be required to report.

I would point out that in most cases it would not be the individual business or the municipality, but it is their insurance administrator who would be responsible under this language. And there is some lengthy language in those lines from 187 to 107.

Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Through you, Mr. Speaker, would that information that we are trying to gather here pertain specifically to public health, so that we can then come up with good, better, sound public health policies, or will it include and encompass all medical issues? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, the information that is required to report it -- to be reported is information that relates to medical insurance claims, dental insurance claims, pharmacy claims and other insurance claims and -- and their information from enrollment and eligibility files. That latter is usually is

lg/cd/ed
HOUSE OF REPRESENTATIVES

295
May 2, 2012

interpreted to mean associated with the state's medical assistance programs. That is the only information that is contemplated in this amendment.

Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

I do want to thank the proponent of the bill for answering the questions.

And through you, Mr. Speaker, there is a need for all of this information to be in one place, that definitely will help us, will make sure that our public policies -- public health policies are better geared having all that information in front of us but having said that that there -- my concern is once again, A, the cost, in terms of the continuation of a program. Because my worry is we could start something, a year or two could go by and the way we are right now, if we do not get the funding, yes, the -- the State will go out and ask for the funding. The State is not responsible. I'm well aware of that.

But if we've started a program where you have this information and two years down the line, three

lg/cd/ed
HOUSE OF REPRESENTATIVES

296
May 2, 2012

years down the line, when the funding drives -- dries out, my big concern is we have started something and at the end of that nothing is accomplished.

So for me the fiscal component is important because I do not see a guarantee. I mean, nothing is guaranteed in life. I'm well aware of that, but a reasonable amount of guarantee that this could be an ongoing program. Because this information that we collect is going to be useful not just in a month or two but we need to have the cumulative information for years to come for it to be an effective policy.

So that, Mr. Speaker is my primary concern and then attached to that is the significant concern of security and security breaches. If the security were to breach, were to occur, as Representative Perillo brought out, in terms of a small organization. A small business owner who has five employees, six employees, and through that is aware of what is happening in that person's life directly or indirectly, those security breaches are equally a concern to me.

And finally, my biggest worry is, is that State embarking on a kind of program by which we can create a standard of care. Is that what the goal will be

because we'll be collecting all this data and, as said, who would be the physician, who would be the group, which would be the hospital where that the services are rendered at the least price not taking into account the outcomes?

So when we do not match the outcomes and just look at one side of the equation, which is the cost factor, would then the interpretation of that be very different?

And those are my concerns, Mr. Speaker. I think it's a good bill. I will definitely be monitoring the debate as we go on in this evening to see what the thoughts are from the other speakers.

Thank you, Mr. Speaker.

And I want to thank the proponent of the bill for her kind answers.

Thank you.

DEPUTY SPEAKER ALTOBELLO:

Thank you, sir.

From the 16th District, Representative Schofield, you have the floor, madam

REP. SCHOFIELD (16th):

Thank you, Mr. Speaker.

I rise in enthusiastic support of this bill. As many of you know, I've worked in the healthcare field for a very long time prior to coming to the legislature, both as a consultant and in the payer world, both public and private. And, you know, we did a lot of work in a number of different companies that I worked with and in the public sector trying to improve data feedback, performance feedback to providers. But one of the big problems was that we never had enough data. Any one payer always has a small slice, even Medicaid, probably the biggest payer, has 11 percent of the population. So we would take our provider profiles back to physicians, hospitals, other groups and show them data about mostly things that were very quality oriented. Are you complying with clinical guidelines about the frequency of hemoglobin A1-C tests, the frequency of mammograms that you should be giving, et cetera. And the providers that were doing a great job would say, Yeah, I already knew I was good. And the providers that were not doing such a great job would say, Well, your data's not statistically significant because you don't have enough of a sample size. And they may well have been right.

The sample size is critical and so by pulling together the data across multiple payers, you'll finally have that critical mass of data to concatenate the patient files across health plans, across time, and across locations as people move from town to town. With a large sample size, you can really look at whether prevention is being done appropriately. You can look at outcomes because you know length of stay in hospitals, frequency of visits, readmission rates, lots of information that is very quality oriented. It's not all about just looking at the cost.

And physicians are acutely responsive to good data. They're competitive animals. They want to do a good job. And if you show them with irrefutable data that, hey, your -- your colleagues are doing a better job on these metrics than you are, they're going to change their behavior. And yes, sometimes payment is attached to that, pay for performance has resulted in improvements in outcome. Look at the change that's happened within hospitals once Medicare stopped paying for extra days that were a result of hospital acquired infections and other iatrogenic illness. Infection rates have plummeted since that change happened.

So we have access to data that we can and should use to improve the quality of healthcare markedly. And by improving quality, we will actually result in savings, as well, because better quality healthcare is, in fact, in the long run going to be less expensive.

There've been numerous studies. The Institute of Medicine study several years back said that there was as much as \$29 billion a year lost in medical errors. We can be doing a better job of preventing those errors by having health plans work collaboratively in the kind of organization that's proposed here with medical providers to identify what quality improvement initiatives as a state -- statewide should be pursued based on where are the problems in our healthcare system and what -- which of those problems are amenable to change based on better practices. We can really make everyone's lives a bit better.

Let's see what else did I want to talk about here. Error rates. We certainly -- sorry, I'm just looking down at my notes -- we can see error rates. There are huge frequency of physician and hospital and other clinician errors as they practice medicine and

by putting in place the kinds of data feedback that will help.

One of the prior speakers talked about cookbook medicine as though that were a pejorative term, and I must say not very many people are going to bake a very good cake without a cookbook. You wouldn't want your pilot flying an airplane without a checklist, and you don't want doctors or any other clinician doing things without clinical guidelines either.

Clinical guidelines, I think people have a misconception they tell you that you must do a certain thing on every patient and that's not true. They tell you what works with most patients, and they also, those guidelines, recognize that there are lots of exceptions and they usually give you guidelines about how to deal with the exceptional patient who doesn't fit the norm. Those clinical guidelines are developed by the best physicians in the country in order to help people make decisions.

The -- the best minds, folks, like Atu Guande, are promoting the use of checklists because they help improve medicine.

Just one last thing I want to say is that this kind of data is already collected in large databases

that are privately held and proprietary. I happened to have dinner recently with a friend who works for a big medical device company who was telling me that they -- they buy this data from existing places. We should have that data, as a state as well, and use it for the betterment of the quality of care of our citizenry not just have private companies using it to figure out how to better price their products.

So, again, my strong support -- and one last thing, this is actually very similar to a bill I introduced in 2008 and 2009, so I'm very happy that Representative Ritter has succeeded in moving it forward to this point.

Thank you.

Deputy Speaker Ryan in the Chair.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative Carter of the 2nd.

REP. CARTER (2nd):

Good evening, Mr. Speaker.

A few questions -- I rise for a few questions through you to the proponent of the bill?

lg/cd/ed
HOUSE OF REPRESENTATIVES

303
May 2, 2012

DEPUTY SPEAKER RYAN:

Please proceed, sir.

REP. CARTER (2nd):

Thank you, Mr. Speaker.

Through you, Mr. Speaker, as I -- as I go over the bill, I notice that the special advisor to the governor on healthcare reform will eventually appoint an advisory group and that's advisory is group line 177. Will that advisory group be able to incur any additional costs on their own? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, there's no allowance in this amendment for that to happen.

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Thank you, Mr. Speaker.

As we look at a -- there's been a lot of talk tonight about what kind of data would actually be forwarded up to the State and in lines 47 through 58,

there's a lot of information about how the payer data will be utilized.

Through you, Mr. Speaker, in -- in line 49, where they talk about the -- what -- what is going to be given up to the State for the quality of healthcare services. What exactly will that data be? Will that data be everything on healthcare claim, including diagnosis and what was paid and what was billed? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I don't have the list of requests in front of me. I only have the amendment that describes the data that will be in the database, so the availability of specific data probably would depend on the request.

I would like to point out, however, Mr. Speaker, that information that has also been provided to us about the management of these types of programs, this would be information from the special advisor points out that the as administrator of the all-patient claims database, the responsibility, of course, to take all and any measures necessary to appropriate use

of the data would call for a data review committee to be established. And that type of a committee, a data review committee, has been very successful in other states to make sure that data requests are not used for inappropriate purposes and would have the right and the ability to deny a request for data of the type that could be inappropriately used. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Thank you, Mr. Speaker.

Then the -- so I'm to understand the -- the data review committee determines the total appropriateness for every individual request? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, those are precisely the types of questions that I think would be answered through the establishment of a committee, which requests, how many of them would have to be individually evaluated?

I spoke earlier, Mr. Speaker, of the availability of information data to individual consumers through -- envisioned through something like a web portal and, again, which information would be available to them would also be determined as we go down the line with this. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Thank you, Mr. Speaker.

So as I understand -- understand this amendment, with respect to the insurance claims, that an individual who goes to their physician and is diagnosed with something, let's say, a rash for instance and that -- that patient now -- or I should the office submits a claim for that visit, which would include what the patient was diagnosed with and also what the patient was treated, what the provider billed, and eventually, I assume somewhere what the claim was reimbursed. That would go into a central database that the State will set up with a third-party vendor. Is -- do I understand that correctly?
Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

Mr. Speaker, the played -- the paid claim information would be information that is required to be reported, and it would come from the paid claims end of the process, not the initial diagnosis end of the process. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

So I understand, through you, Mr. Speaker, this is supposed to be a means so we can track a patient, and we can look at long-term health outcomes from a patient so that -- that paid claim would have to say what that patient was diagnosed for or with? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Mr. Speaker, that is entirely contemplated.

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Thank you very much, Mr. Speaker.

And you did -- you actually cleared up a very good question for me and that -- that is that this is not what the physician billed, that this will be actually what -- what was just paid on the claim; is that correct? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, that is my understanding.

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Mr. Speaker, through you, is there any opportunity for a patient to opt out of having their information given to the State? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, that -- two points: first, that information is already required to be given to all of -- to anybody's insurance company or

payer of the claim. And so the information has already been given up, that is -- has to happen if you have an insurance company paying your claim.

Secondly, as I stated earlier, this information does not come to the State. It comes to the database that is administered through a contractual arrangement between the State and the database administration company. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Thank you, Mr. Speaker.

So because I've given up my personal information to an insurance company, there's no way that I can opt out to say my personal information should not be given to a third-party vendor that's working for the State? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I believe that -- that decision has already made when taking on medical expense that is covered by insurance and is covered in your insurance contract. Through you, Mr. Speaker.

lg/cd/ed
HOUSE OF REPRESENTATIVES

310
May 2, 2012

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Thank you, Mr. Speaker.

So it's the insurance contract that -- that -- that I'd have to take a look at to show that I automatically give up any -- any right to my personal information be given to a third party, or is that actually HIPAA? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

Mr. Speaker, we're wandering a little bit beyond the confines of this amendment and so, perhaps, my answers are not as precise as the Representative would desire.

The -- HIPAA prevents the disclosure of individually identified medical information and, of course, that's a federal law and applies completely to all of these circumstances, whether we use an all-payers claim database or not. And so that's not affected by this amendment. Information that is collected by an insurance company, as regards to your

lg/cd/ed
HOUSE OF REPRESENTATIVES

311
May 2, 2012

paid claim, is the information that would be collected
by this database. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Thank you, Mr. Speaker.

I'm trying to get to the point that if I give my
information on an insurance claim -- actually, my
physician gives the information for me on an insurance
claim, where is it in an insurance company's contract
with me that says they have the ability now to pass on
that information and make it public to any other user,
whether it be a database of the State, whether it be a
third-party vendor? The way I understand it, this
amendment is what gives the insurance company the --
the responsibility to pass on that information; is
that true? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

This amendment puts a requirement on the
insurance companies to report its paid claim
information, that is correct.

lg/cd/ed
HOUSE OF REPRESENTATIVES

312
May 2, 2012

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Thank you very much, Mr. Speaker.

Now, one of the other interesting things about this amendment, as I look at the amendment, which become the bill, is that it will require for physicians to give up their information on the claim form, as well. And I guess what we'll see is that fit -- that physician was reimbursed for a certain amount of money for the claim, and then we'll be able to track that information and somehow give that out to -- to users so they can see the cost of information or -- excuse me -- the cost of medical care.

My question, through you, Mr. Speaker, is during this process was -- did any testimony come through that talked about the result of contracting for physicians, or I should say the effect on contracting for physicians with insurance companies if -- if their information is widespread known what each insurance company is reimbursing? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, there is no discussion of that, and it is not required under this amendment.

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Thank you very much, Mr. Speaker.

My concern is this -- is if all of a sudden now we can and in widespread format, you know, give all the information out to all the insurance companies about what each insurance company is reimbursing for each procedure that takes away a significant amount of power for the physicians. Now, I would -- and I say from contracting with those insurance companies, and I'm sure they're going to be aware of that, which gives me a great opportunity to applaud the good Chair of the Public Health Committee and -- and the Governor's Office for including the Connecticut State Medical Society into this amendment as a member of the All-Claims Payer Advisory Group.

With that, Mr. Speaker, I'll take my seat, and I'll reserve my opportunity to talk on the bill.

Thank you.

DEPUTY SPEAKER RYAN:

Thank you, sir.

lg/cd/ed
HOUSE OF REPRESENTATIVES

314
May 2, 2012

Representative Thompson of the 13th, on the amendment, sir.

REP. THOMPSON (13th):

Good evening, Mr. Speaker.

I will speak to the amendment, but I would like to take us down a slightly different trail. This -- this amendment will open up the healthcare system, I think. It's a sharing of information. We have taken some legislation this year, for example, using information technology, we will be able to provide instant guidance to pharmacists administering various medications to cancer victims and that will be of the highest quality, and so on, but what does it do? It opens it up to some people who may be in a hospital receiving Medicaid or Medicare, and so on.

We know that there's a World Health Organization that evaluates the quality of care, how it's provided and they actually rank countries. And the last time I looked, the World Health Organization, I think, ranked the United States in the level of care they provide -- provided as a 18. There are 17 or 16 countries and health care systems in nations that are at a higher level than us.

However, the cost of healthcare in America is off the table, off the chart, much more expensive than those European countries that have universal healthcare systems. The quality of healthcare is at a much higher level, and we are driven by economic conditions rather than what is best for our nation in providing healthcare. And from where I sit, I think it's a disgrace that we have thousands of people in this state who do not have easy access to healthcare.

So we are looking at this legislation, proposed legislation, from that perspective: what's it going to cost, how we're going to do this, how we're going to do that, and so on.

I think it's time that all of the providers, we shouldn't just say, well, the Connecticut Medical Association, whatever, will be invited to be part of this, and so on and so forth. They should be right in on it from the very beginning. We have one of the greatest medical schools in the country, perhaps, in the world, down at Yale. We have a wonderful university medical school that's highly rated, but yet, we have a shortage of primary care providers in our state.

We stand back aghast at somewhat that we have a system in our state, which doesn't get very much attention, the federally qualified health centers, which we did something the other night, which I think, will promote that, and we have some money in the bonding package, which will help. But it's a nonprofit organization and their doctors are -- their primary care doctors are probably sacrificing. They make -- I'm sure they make a decent living but a primary -- they're sacrificing in comparison to doctors, young doctors, who come out and look to go into the specialties because that's, perhaps, where the money is or that's where the challenge is.

Well, I think the challenge is making sure that everybody has healthcare, and this may be a step in that direction to improve the quality of healthcare. And certainly, we should all support that. But somewhere along the line, we really have to face up to the fact that the rest of the world looks at us and says they can't imagine that the cost of healthcare in America is so high. Yet, there are millions of people who don't have access to it.

You go to France, everybody access to it, and the quality of care is at a much higher level than it is here.

So I think we ought to support this legislation and support other legislation that we've already acted upon and continue to support reaching out to build a base to reach out to all those people who are in need of healthcare, and we'll have a better healthcare system. This is a step in that direction, but the real step will come when we all wake up to the fact that somewhere there is a World Health Organization that's looking at our system and saying it's very expensive, and a lot more expensive than other systems around the world that are doing much better job in providing decent healthcare to its population, and they're the better for it.

So I'm sorry to take you down that path -- but no, I'm not sorry. I think we got to keep saying these things. We got to keep saying that let's not be led down the primrose path of this is too expensive, that's too expensive. We ought to bring in all the players and say, look, we can do better than we are doing at a better -- at a lesser cost and just look at what we did with Birth to Three. We've saved millions

of dollars in that system because we're doing the right thing. We're getting healthcare to kids who need it and because of that so many of those kids when they reach school age, they will not require special education, saving millions of dollars to our towns, cities and our state.

So, I think we ought to be much more positive in looking at this. Not to throw all the concerns out the door about privacy and confidentiality, and so on, but let's get together with the rest of the healthcare world and say, folks, we've got a serious problem. The World Health Organization has evaluated us, we're not doing very good, as far as the quality of care, unless we can afford it and that's not the way we should be going.

So let's move on with this bill. It's a step forward. It should be done. It will open some doors, but most important, I hope that everybody who hears me tonight will take a look at the World Health Organization, take a look at what's going around in other countries, even in other states in this -- in America that are making due and sacrificing a bit, but the main objective is to provide healthcare to

everyone, and that's what we should be thinking about.

This will be a step in that direction.

Thank you, Mr. Speaker for your patience and understanding.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

We certainly appreciate hearing from you.

Representative Shaban of the 135th, sir.

REP. SHABAN (135th):

Thank you, Mr. Speaker.

And through you, a few questions to the proponent, if I may?

DEPUTY SPEAKER RYAN:

Please proceed, sir.

REP. SHABAN (135th):

Thank you, sir.

Looking at the amendment and listening to the debate, I'm trying to get a better understanding of what kind of information we're going to be compiling - - or the insurers and everybody else will be compiling and sending off to the state. And I think I -- I got the notes right. I just want to confirm them if I may.

We're going to -- the patient data is going to be in the report, so to speak? Through you, I mean the name is what I'm asking.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, the information that will be in the report will be taken from paid claims. That information now, as we've already heard, is routinely collected and aggregated from -- by insuring entities and third-party administrators that aggregate information will be what is put all in one place in this database. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Thank you, Mr. Speaker.

Yes, and that's right. I understand that and I appreciate that, claims data, diagnosis treatment, cost, what's been reimbursed, essentially. Potentially, the patient -- person, I guess. The -- the -- my -- my question really goes to the payer or the insurer. Is the name or the identity of the payer

lg/cd/ed
HOUSE OF REPRESENTATIVES

321
May 2, 2012

going to be in the -- in the data that's being
aggregated? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

Mr. Speaker, I do have not the specific
regulations for this. And I can tell you that the
information that goes to the third-party database
administrator is specific to claims that are paid and
enables patients to be followed and outcomes to be
examined on an aggregate basis. And so the ability,
which I think the Representative is concerned about to
attach a specific identification or name or number or
individual to a specific medical condition or claim is
protected. That is protected under both federal and
state regulation.

And the extent or the protocol that is used to
scramble or protect those identifiers, while I can't
tell you specifically what that protocol is, I can
tell you that it is required to be, as I said,
scrambled or protected in a way that keeps an
individual patient from being identified by an
individual person.

lg/cd/ed
HOUSE OF REPRESENTATIVES

322
May 2, 2012

I hope that's helpful.

Thank you.

Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Thank you, Mr. Speaker.

And through you, yes, and I do appreciate that, I do understand that you're using the HIPAA laws. And I think we cite the -- the code of federal regulations and the HIPAA laws in this amendment where the amendment -- where the identity of the patient will arguably be protected or, at least, that's the goal.

My question really goes more toward the identity of the payer, the insurance company, so to speak. Will that information be contained in the aggregate report? And -- and the reason I ask is because if we're -- if we're trying to track outcomes and costs and a way to aggregate data and come to some kind of conclusion, my assumption is -- and that's what I'm trying to confirm, that the payer and what was paid is going to be in the data; is that correct? Through you.

DEPUTY SPEAKER RYAN:

lg/cd/ed
HOUSE OF REPRESENTATIVES

323
May 2, 2012

Representative Ritter.

REP. RITTER (38th):

I apologize to the Representative. The answer is yes.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Well -- and through you -- thank you.

And through you, we mentioned some, you know, privacy laws under state federal law, my -- my concern the thing that jumped out at me right away was antitrust laws, also a federal law, but also captured in our state law.

Under federal and state antitrust law, aggregate data between competitors in a -- in a, quote/unquote, in a competitive market, where you can compare information, such as business plans, pay-outs, pay-ins, costs, business models, anything that could lead to information from one competitor going to another competitor is under the antitrust laws, illegal. And I know this through my practice so.

So, through you, Mr. Speaker. My question is has that issue been examined when this amendment was being crafted? Through you.

lg/cd/ed
HOUSE OF REPRESENTATIVES

324
May 2, 2012

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I can tell you that in the eight states that currently have all-payers claim database that has not been an issue. And the reason is because the information is paid claims only. There is no information about, for example, a contractual arrangement that might have been negotiated between a provider and a payer or anything of that such. And so consequently, it is my understanding there have not been issues of the type the Representative is concerned about.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Thank you, Mr. Speaker.

And thank you for the response.

Well, I -- that's -- I guess that's kind of good news that if there are eight states that are doing something similar, there haven't been those issues. I'm going to do a little research on my own because I'm concerned that if you're compiling who's making the payment and what kind -- and how much payment they

made, pursuant to whatever policy, pursuant to a particular diagnosis or treatment, that somebody under section 2, line 51, it says we're going to make all the all-payer claims database available to any state agency, insurer, employer, healthcare -- I mean there's a whole list of folks who can get this information.

So my concern is and I raise it because I'm not sure it's captured here. We deal with HIPAA, but we don't deal with the antitrust sections of the federal and state laws. That a competitor, whether from outside the state or inside that state, can use this compiled data, mine it for information and get a competitive advantage that was not the intent of this bill, obviously.

So that's my concern, but let me move on, if I may. And I think one of the previous question or folks may have asked you this but if they did, I apologize.

As a patient, can I opt in or can I opt out, I guess, is the better question of having my information reported? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

lg/cd/ed
HOUSE OF REPRESENTATIVES

326
May 2, 2012

REP. RITTER (38th):

Through you, Mr. Speaker, my understanding is that you cannot. That decision has already been made when you acquired insurance.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Well, I guess that decision will be made acquiring insurance if I know I'm making that decision. Under this law, what notice, if any, do patients get that, hey, your claims information is going to get aggregated and sent up to wherever, New Britain, Hartford, wherever. Under this -- under this amendment, is there such notification required?

Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, it is my understanding there is no such notification required because such notification has already been given, either through the arrangements with your insurance companies or through your arrangements when seeking medical care.

A patient gives permission for their payment information to be conveyed to that third-party payer.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Thank you, Mr. Speaker.

Well, I -- I'm not sure -- I'm not sure I agree or understand because I'm insured today, today. And let's say this law passes tomorrow but my insurance policy, you know, goes -- goes on for another year or two. At some point, there's got to be some overlap where first, I was not subject to this law and, then, suddenly I am subject to this law. And suddenly, you know, at one part of the time line, my information was not being forwarded to a federal aggregator, but at some point of the time line my information is being forwarded to a federal aggregator. But if there's no notice to me, how am I making a decision with respect to my information? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I'm not sure I understand the question that the Representative has asked. If he could restate it for me please.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Thank you.

It was a long question, I apologize.

If no one tells me this is happening how am I giving my consent? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, the individual patient is not giving their consent. The information is coming from paid claims aggregated by their insurer that would be between the insurer and the patient.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Thank you, Mr. Speaker.

So my -- my information, I -- what I, hypothetically, obviously, actually not, if this law passes. My information of what I've treated for, what

I've been diagnosed with, what my doctor's been paid for, what my doctors diagnose. That information is going to get sent by my insurer to a central aggregator but I -- but I'm not given an opportunity to say yes or no? Is that the result here?

Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, as I understand the situation today that already occurs routinely with insurers, and it does not require an individual decision at a later date on the part of an individual insured person.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

All right. Well, thank you, Mr. Speaker.

Well, I'm a little concerned. I'm not -- frankly, I'm not sure if that's accurate or not, but I -- I appreciate the Chairman's thoughts on the topic.

Under the HIPAA laws, when a patient goes to a doctor, they get a form that says, you know, Healthcare Privacy Protection Act. And it says that

lg/cd/ed
HOUSE OF REPRESENTATIVES

330
May 2, 2012

we will send, you know, you have to sign here, give your consent, you, the patient, have to give your consent to send your medical information in order to get your -- your -- your claims paid by that insurer under HIPAA. That's the -- and it's actually called the HIPAA disclosure, by now, I'm sure everyone has seen one.

And that's -- and that's really the genesis of my question because if my healthcare provider is required to give me notice of disclosing information to my insurer, why -- I'm not and -- through you, does HIPAA not require a similar disclosure or -- or consent from the next step in that chain, i.e., my insurer then giving that same information to somebody else? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I am not aware of such a requirement in the HIPAA law.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

All right. Well, I appreciate the response. I'm -- I think we're running a ground here on -- if my doctor can't give out the information without my consent to my insurer but then suddenly my insurer can without my consent, that -- that's seems to be a break in the chain. So, perhaps, that's something that we can drill down on.

Moving on in the bill, section (h or lines 67 through 73, will do some discussion before, the \$1,000 a day, potential \$1,000 a day penalty.

Through you, Mr. Speaker, the civil penalty assessed at \$1,000 a day, if a doctor codes in something wrong -- which happens -- a nurse, a doctor somebody codes in something wrong, you know, a broken foot coded in as a high cholesterol, who knows. You entered the wrong number. What -- what I'm trying to figure out is -- is, you know, how -- where's the wiggle room there to prevent a -- a reporting -- a reporting entity from being exposed to civil penalties of a very large amount based on a third party. Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker. Once again, the information that goes into this all-payer claims database is paid claims information from the third party, the insurer. It is not at the point where the provider, say a physician, is fixing that broken foot and might code the bill incorrectly. It would be the payment information and if there's a correction that's made to that payment information, there's no reason not to believe that that correction would not also be aggregated in the same manner as any other paid claims information by the third-party insurer. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Thank you, Mr. Speaker.

Yes, fair enough. I guess that makes sense if they're going to adopt regulations under this, there will probably be some kind of amendment procedure, I suspect, which -- which probably -- which makes some sense but I raise the issue only because it jumped out at me.

The last couple of questions, moving on in the bill. New section, lines 82 through 107 -- and really

lg/cd/ed
HOUSE OF REPRESENTATIVES

333
May 2, 2012

I'm looking at the bottom of it, it's the new language added I guess by this amendment where we define reporting entity. And a reporting entity means -- and there's a whole list of names and titles and statutory references and whatnot but starting on line 103 through -- and ending on line 107, a reporting entity does not include an employee welfare benefit plan, as defined under ERISA, as amended from time to time -- which is ERISA -- that is also a trust established pursuant to a collective bargaining -- excuse me -- pursuant to collective bargaining subject to the federal Labor Management Relations Act.

Through you, Mr. Speaker, why does that carve-out exist and what does it do?

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Thank you.

Through you, Mr. Speaker. Mr. Speaker, that refers to plans that are more generally referred to as Taft-Hartley plans. And their employees are exempted because they're exempted already from state regulation and regulated by the feds under ERISA and can't come under the provisions of this amendment.

lg/cd/ed
HOUSE OF REPRESENTATIVES

334
May 2, 2012

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Well, that's -- here we go, we just opened a can worms. If -- is it -- is it the intention or at least the Representative's understanding that if your welfare benefit plan is subject to federal law, under ERISA, that then your information patient, your patient information or -- and/or the payer information, paid claims that that is not going to be subject to this state law? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, that particular provision refers to the plan only. Those plans generally rely on third administrators and those third-party administrators would be the responsible reporting entities under the prior lines in that particular section. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Well, thank you.

I'm not sure you -- I'm not sure, maybe I misunderstood. Why aren't these folks going to report the same way as any other folks would report? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker. If they reported, it is quite likely it would be a duplicative reporting that would occur because the third-party administrator -- third-party administrators are required to report in the earlier descriptions of reporting entities and that happens so that we will not have duplicative reporting. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

And thank you, Mr. Speaker.

All right. That may make -- I think I understand the -- the thrust. You're saying that there's an intermediary that's already reporting, so the plan itself doesn't have to report because it's the same information. I think I -- understand the -- the representation.

But if it's an ERISA plan that's subject to collective bargaining that does not have a third-party administrator, would they, then, be subject to this new provision under our law? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I believe that would be the case. We spent -- I'll be honest, Mr. Speaker, quite a bit of time on this particular section of the bill with the intent of capturing all of the potential reporting entities but capturing the information only once, for the reasons that I described earlier. Obviously duplicative reporting would destroy a lot of the -- the integrity of the database so that is the intent.

And in -- further on in the bill, I know it's very clear that there will be further examination through regulation, and if that has to be stated more clearly, I certainly hope it will. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Thank you, Mr. Speaker.

And I -- and I do appreciate that response because it -- it, frankly, answers the question that I have, and it sheds some light on it.

Last question, I -- I note on the next page, lines 119 through 121. That our office -- or potentially new Office of Healthcare Reform and Innovation is going to -- would be charged with recommending, advancing executive action and legislation to effectively and efficiently implement the Affordable Care Act and state healthcare reform initiatives.

The Affordable Care Act, I think -- I think it's defined earlier on. I'm assuming that's the federal health care act that got passed a year -- a couple of year -- a year or two ago? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker. That's current law language, Mr. Speaker, and is not changed by this amendment, but for the Representative's purposes, the answer would be yes.

DEPUTY SPEAKER RYAN:

lg/cd/ed
HOUSE OF REPRESENTATIVES

338
May 2, 2012

Representative Shaban.

REP. SHABAN (135th):

Through you, are we mandated -- and I don't know the answer to this. I'm asking you because I don't know. Under the Affordable Care Act, are we mandated to do this type of information aggregation, or is this something we're doing on our own? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I'm not aware of a -- of a mandate under the Affordable Care Act.

DEPUTY SPEAKER RYAN:

Representative Shaban.

REP. SHABAN (135th):

Thank you, Mr. Speaker.

And I thank the Chairwoman for her time.

I've got some concerns, but I want to keep listening. I appreciate it.

Thank you.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative Candelora of the 86th, you have the floor, sir.

lg/cd/ed
HOUSE OF REPRESENTATIVES

339
May 2, 2012

REP. CANDELORA (86th):

Good -- good evening, Mr. Speaker.

Thank you.

If I may, a couple of questions to the proponent
of the amendment?

DEPUTY SPEAKER RYAN:

Please proceed, sir.

REP. CANDELORA (86th):

Thank you, Mr. Speaker.

My questions really pertain to the sections 16
through 26 and how we have structured the funding of
this mechanism. I'm wondering why we have this type
of funding stream set up in this amendment? Through
you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, because there is no
other funding presently stated to manage this
initiative.

DEPUTY SPEAKER RYAN:

Representative Candelora.

REP. CANDELORA (86th):

Thank you, Mr. Speaker.

So I -- I guess as it's -- as it's written here, this special advisor would be seeking out federal grants or private monies in order to fund the program, and the budget is set by the Office of Policy and Management.

Is this something -- I guess, is this something that's unique that we're doing here today? I haven't seen this type of structure set up in any other agency, and I'm wondering why we have it set up in this manner where the secretary of OPM would approve this budget as oppose to the General Assembly? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I probably can't actually -- really comment if this is completely unique throughout all of our state government. However, it was set up in this way to finance this initiative from sources outside of state funds that would be federal and private funds.

The language in lines 20 and 21, asking the special advisor to submit to the secretary of OPM, would ensure that, as it states, beginning in line 24,

lg/cd/ed
HOUSE OF REPRESENTATIVES

341
May 2, 2012

that no cost or contract services have been incurred
for which funding has not been secured.

Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Candelora.

REP. CANDELORA (86th):

Thank you, Mr. Speaker.

And I -- I do appreciate that.

So clearly the program -- the spending of the
program needs to be offset by any revenues they bring
in.

My -- my next question would be, would this
expenditure fall under our spending cap? Through you,
Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

To be honest, Mr. Speaker, through you, that was
not discussed in setting this up, but I don't think I
see any reason why it would not be handled as any
other expenditure. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Candelora.

REP. CANDELORA (86th):

Thank you, Mr. Speaker.

And I appreciate the Chairwoman's answers to my questions.

That is just one of my concerns under this bill. As I know, the original fiscal note had -- in the underlying bill had cited the expenditure to being between 1 million and 2 -- 2 million dollars, potentially. And so setting up this type of framework, while we're avoiding that fiscal note to the State, I think it could be fairly contemplated that we would be spending possibly somewhere in that range.

Regardless of that, the expenditure portion really has no limit. While it's limited by the revenues that are brought in if this special advisor is able to bring in \$5 million, then, they could conceivably have a \$5 million budget approved by the secretary of OPM. And my concern is -- is if it does fall under this spending cap, I think it should be part of the General Assembly's process in part of the budget because as we just saw last year in our budgetary process, I -- I think we're about \$1 million under the spending cap.

So there are certainly times that we bump up very close to it, and so I'm just not sure how this would impact our process if, in fact, we have this special advisor who can now create a budget offline from what we're doing in the General Assembly process.

I don't know how that would end up frustrating our entire budget process that we would be working on the biennium. Especially, also, given that the budget would be submitted June 15th, annually, to the Office of Policy and Management that would probably always fall outside the window of the General Assembly and fall outside the window of when we are -- when we craft our budget.

So I'm -- I'm just a little bit concerned of how this implicates the spending cap and, also, just the general policy of potentially handing over the car keys of this -- of this fiscal matter to the secretary of OPM because I'm not familiar of any type of structure that we have in state government. I think, one of our major tasks here is to craft a budget and, certainly, in the short sessions, it's -- it's one of primary duties to look at budget adjustments.

So it's clearly under the purview of us to be the fiscal stewards of the State of Connecticut. And

we're potentially transferring that responsibility -- although it's a small portion -- but we are transferring that responsibility, that oversight to the Executive Branch.

In the past, we've had other agencies, like Judicial, where we've contemplated how to address those budget matters, but we always came back to the same conclusion that we needed to be the final arbiters of their budget. And so I think, appropriately, we've quite proudly have made sure that we have kept autonomy over all of our agencies, whether they be Executive, Judicial, or Legislative, and I think that's appropriate, but I am I'm just gravely concerned of this section.

I imagine it, it certainly helps the bill because it -- it eliminates a fiscal note that -- that lies in the underlying bill, but again, I think the public policy that were setting forth here is quite extreme.

I think that at the very least our Appropriations Committee should be having some sort of general oversight over this, or certainly, at the very least but most importantly, I think the General Assembly should be weighing in on this agency's budget. And so I just have strong concerns for this amendment.

lg/cd/ed
HOUSE OF REPRESENTATIVES

345
May 2, 2012

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Will you remark further on the bill -- on the amendment before us? Will you remark further on the amendment before us?

If not, I will try your minds.

All those in favor of the amendment signify by saying aye.

REPRESENTATIVES:

Aye.

DEPUTY SPEAKER RYAN:

All those opposed, nay.

REPRESENTATIVES:

Those voting Nay.

DEPUTY SPEAKER RYAN:

The ayes have it. The amendment passes.

Will you remark further on the --

The amendment is adopted -- excuse me.

Will you remark further on the bill as amended?

Representative Carter of the 2nd District.

REP. CARTER (2nd):

Thank you very much, Mr. Speaker.

You know, as we -- as we spoke about the bill, the amendment that became the bill earlier, one of the -- one of the largest problems I think we had with this -- well, first off, let me be positive. Let me be positive. This is actually a great concept. This bill can provide so much information and so much data for the public health youth in this state. It's a very, very good bill. You know, for instance, we can find out if we have more heart disease in Tolland than we do in Fairfield. We can find out if have we have more asthma in Greenwich than we do in New London. So it's a good bill, it's a good concept.

The problem that we've had with this, is the way we collect and what we do with personally identifiable information. Ladies and gentlemen of the chamber, often we hear about places across the United States where we see a newspaper article and you hear 9500 people are subject to a data breach, or you hear 10,000 people or 100,000 people, recently, I think out in Minnesota. The problem with this bill is we're taking all of our information, our vital health information, and we're putting it all in one place.

Now right now, the insurance companies all have that information spread out for each company, Aetna

has one, Cigna has one. And God forbid, one of those gets hacked, we lose you know, anywhere from, I don't know, 125,000 to 200,000 lives but imagine lives in -- in data -- not lives -- but imagine what happens if we lose millions of identities because a third-party system's security was hacked.

I put it to you, ladies and gentlemen, that -- that we should take some very simple -- very simple common sense steps to keep this from happening.

Ladies and gentlemen, there's going to be an argument on the floor that says we can't use this database unless we have personal identifiable information. I put it to you that we can. We can submit those insurance claims, we can take everything that people need for a study, they can take the insurance companies number, they can even take the last four, but they don't need a social security number and they don't need a person's name. In fact, if you look at this data, we've talked about using it as any other study. Right? We say this data can be used as a study and we -- we want a large amount of it so it's statically significant. Well, ladies and gentlemen, anybody who enrolls in a study has the ability not to get in the study. They have the

ability to opt out, they have the ability not to be a part of it if they'd like.

You know, in Connecticut, when we do this it's going to encompass everyone. There's no opportunity for anybody to get out of this thing.

Mr. Chairman -- or excuse me -- Mr. Speaker, the Clerk has an amendment. It's LCO Number 4420, would you please ask the Clerk to call, and I'd be allowed to summarize.

DEPUTY SPEAKER RYAN:

Will the Clerk please call LCO 4420, which will be designated House Amendment Schedule "B."

THE CLERK:

LCO 4420 House "B" offered by Representative Carter.

DEPUTY SPEAKER RYAN:

The speaker seeks leave of the chamber to summarize the amendment.

Is there objection to summarization, is there objection?

Hearing none, Representative Carter, you may summarize the amendment.

REP. CARTER (2nd):

Thank you, Mr. Speaker.

The amendment before the chamber, basically, allows for the -- I should -- the information that is given to the state or the third-party vendor will not include information that is patient identifiable. The -- the idea is that it will not have social security information or names or anything like that; that it can include everything else that we want to use for data but no patient identifiable information.

Mr. Speaker, I move adoption of the amendment, and I ask when the vote be taken, it be taken by roll.

DEPUTY SPEAKER RYAN:

The question before the chamber is adoption of House Amendment Schedule "B," and there's been a request for a roll call vote.

All those in favor signify by saying aye.

REPRESENTATIVES:

Aye.

DEPUTY SPEAKER RYAN:

I believe that when the roll call is taken, it be taken by roll.

Will you remark further on the amendment before us? Will you remark further on the amendment before us?

Representative Carter.

lg/cd/ed
HOUSE OF REPRESENTATIVES

350
May 2, 2012

REP. CARTER (2nd):

Thank you, Mr. Speaker.

As I said before, this is a very common sense way for us to remove patient identifiable information that was given to the third party so it's not in one -- one database. Insurance companies still have the ability to track from company to company as somebody moves so we can follow a patient over long term. The important part about that is we want to make sure the data that the third-party vendor has that we're going to use in this state is valid. And they're going to be opportunities that somebody along the way needs to check that data and then go back to the insurance companies and they can track it back to make sure it's the real patient. But you don't need a social security number, or you don't need patient identifiable information and the state administered database or the third-party administer database to do that.

Ladies and gentlemen, I hope you will please support the amendment.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

lg/cd/ed
HOUSE OF REPRESENTATIVES

351
May 2, 2012

Will you remark further on the amendment? Will
you remark further on the amendment?

Representative Perillo.

REP. PERILLO (113th):

Mr. Speaker, thank you very much.

If I may ask a question or two to the proponent
of the amendment?

DEPUTY SPEAKER RYAN:

You could if he was there.

Representative Carter, prepare yourself.

REP. CARTER (2nd):

Prepared.

REP. PERILLO (113th):

Mr. Speaker, thank you very much.

To Representative Carter, through you, I -- I
notice here that it -- it expressly includes the
language, "other patient identifiable information,"
and it would exclude that from the data set. If -- if
you could just describe for me and for the chamber,
what types of information you're referring to when you
talk about "other patient identifiable information"?

DEPUTY SPEAKER RYAN:

Representative Carter, if you could speak up so
Representative Perillo can hear you.

lg/cd/ed
HOUSE OF REPRESENTATIVES

352
May 2, 2012

REP. CARTER (2nd):

Thank you very much, Mr. Speaker.

What we're referring to -- listen, part of the problem is that we don't know what information is going to be sent in this database at this time. We do know that the data is going to include information that they can track the patient. Right now, it looks like it's going to be a social security number, probably a patient's name. We're told that it's going to be in three different locked boxes in the system to where it's going to be separate and great security, et cetera, et cetera. We don't really know that but a very common sense approach would be this amendment will just say anything that actually identifies the patient doesn't get put into the claim when it's transmitted to the third-party vendor's database. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Perillo.

REP. PERILLO (113th):

Mr. Speaker, thank you very much.

And I thank the proponent for his answer to the question.

I was actually hoping his answer would be a little bit more robust. There are a number of different ways in which you can identify an individual. One of them that comes to mind immediately is the individual's address. If you use a street address in a specific town, you know, there's one or two people or three or four, a family lives at that address.

And through you to the proponent of the bill, would individually identifiable information like that be covered by this amendment? Through you, sir.

DEPUTY SPEAKER RYAN:

You want the proponent of the amendment? You said the proponent of the bill?

REP. PERILLO (113th):

I -- I would like to ask the proponent of the amendment.

DEPUTY SPEAKER RYAN:

Okay.

Representative Carter.

REP. CARTER (2nd):

Thank you, Mr. Speaker.

It's my understanding that a street address or any kind of information that would identify the

lg/cd/ed
HOUSE OF REPRESENTATIVES

354
May 2, 2012

patient directly would be patient identifiable and
this amendment would keep that from being transmitted.

Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Perillo.

REP. PERILLO (113th):

Mr. Speaker, thank you very much.

And I think that's excellent news.

One of the issues we heard in committee, one of
the issues we heard during the hearing from those who
testified was their concern that individually
identifiable health information would allow
individuals -- would allow organizations, employers,
people in the general public to know what individuals
had, in terms of diagnosis, what treatment they had
received.

This amendment that the Representative has put
forth will control that risk. If we're truly
interested in preserving the well-being of our
patients, one of the things that we must be cognizant
of is part and parcel of that well-being is their
right to privacy and our need to secure it.

This amendment does that. It does it well, and I rise in support of it, and I would urge my colleagues to support it.

Thank you, sir.

DEPUTY SPEAKER RYAN:

Thank you, sir.

Will you remark further on the amendment?

Representative Sawyer of the 55th.

REP. SAWYER (55th):

Thank you, Mr. Speaker.

You know, oftentimes, in this chamber we have sat down and talked very seriously about -- or stood rather -- I should apologize -- talked very seriously about protecting people's identity. We have taken -- we have masked people's information, if they have been state police, if they have been judges. Certain other correctional officers, we have masked their information.

You know, I think if we're looking at people's personal health information, I think the will of the chamber should be to follow some of the federal law that is very cognizant of people's privacy. We've tried to follow the HIPAA laws in other pieces of

legislation, and this amendment is very serious about doing just that.

I don't want my personal information to be sold unless I know it it's going to be sold. I certainly don't want the family addresses and names of children to go off to we don't know where. So in this particular case, Mr. Speaker, I would highly applaud this very simple, one line amendment that protects a patient's privacy.

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, ma'am.

Representative LeGeyt of the 17th.

REP. LEGEYT (17th):

Thank you, Mr. Speaker.

I rise in strong objection to a vote against this amendment.

And the reason I do that is because it's such a simple fix. It doesn't encumber the industry. It's definitely does not encumber the patient base.

And if I may, Mr. Speaker, a couple questions to the proponent of the amendment?

DEPUTY SPEAKER RYAN:

Representative Carter, prepare yourself.

lg/cd/ed
HOUSE OF REPRESENTATIVES

357
May 2, 2012

Representative LeGeyt.

REP. LEGEYT (17th):

Thank you, Mr. Speaker.

Does this amendment, in any way, compromise what you described as a good bill and a good concept that would give our healthcare industry much needed data. Does this -- does this amendment, in any way, compromise that?

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

I think that's a very good question because, first off, I'll -- I'll say the short answer is no. And the reason why is we still have the ability to get all the data about those patients over a long period of time. It just requires whatever the third-party database administrator to do is to track the insurance numbers -- see when the healthcare claim goes, it could be an insurance card information. And whenever somebody changes their insurance, it goes to -- let's say, they go from United to Aetna. That information - - Aetna knows they're getting somebody from United. That information can be tracked, so they can create a profile where they track which insurance company this

person goes to without having their social security numbers.

Now, it'll take that data -- or that vendor to go back to the insurance company to figure out who that patient actually is but only if they need to. If there's a request somewhere along the way for a third-party agency or somebody to go in and validate that data, that's where they have the ability to do it.

So, no, it will not compromise the information that we want to use for public health in the state.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative LeGeyt.

REP. LEGEYT (17th):

Thank you, Mr. Speaker.

And would the impact of this amendment cause more work and more confusion in maintaining and preserving the data that this bill hopes to maintain and preserve. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Through you, Mr. Speaker. It's -- it's hard to say. I don't think I can comment on how much work or

confusion because I don't -- I don't administer a database, but it would stand to reason that somebody who is a large scale company administering large databases have ways to cross walk this information back and forth. I don't know how much additional that would cost, but if it did cost anything extra in the contract, if it did, I think it would certainly be worth, in my opinion, that it would be worth protecting our -- our citizen's identification. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative LeGeyt.

REP. LEGEYT (17th):

Thank you, Mr. Speaker.

This bill as Representative has suggested as amended is an excellent idea. It takes us a long way towards being able to use our health -- our collective healthcare data to make plans to determine trends, to realize concerns about methods of treatment and geographical changes in conditions. And this amendment takes this bill in an even more positive direction because it provides a method whereby that data can be acquired and used without compromising the names and identities of the people from which the data

is obtained. It's a simple idea. It would make this wonderful idea a very productive and protective one, and I urge my colleagues to support it.

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative Ritter of the 38th.

REP. RITTER (38th):

Thank you, Mr. Speaker.

Mr. Speaker, this has been a very interesting discussion about this amendment, and I certainly rise to oppose the amendment. I could not ask my colleagues more strongly, as a matter of fact, to oppose this amendment if indeed they are interested in the beneficial outcomes from this program.

The inability to, when necessary, specifically validate, I know is something that the proponent of the amendment is quite sure that with a little bit of additional expense and a little bit of additional legwork could be accomplished.

And I -- I do want to thank him for acknowledging that we need to be able to validate this data upon request. That is important. But more importantly is the anticipated impacts and use of the data.

The inability to fully and conclusively track across different, say, insurances, different statuses, as a patient goes -- goes or patients go through their lives and the system is -- is very important.

One of our biggest frustrations, Mr. Speaker, in trying to do this work without this kind of data, without the ability to have all of this data aggregated in one place. And data that effectively represents all of us in the State of Connecticut is just that point, we can't do it. Patients or citizens go in and out of on and off of, for example, our medical assistance programs, the Medicaid program under private insurance back out again.

One of our continuing concerns is our inability to judge those outcomes is to be able to track them effectively. All of the things that we anticipate being the benefits of this database, the power of the database. I understand that there -- it's very -- there's -- there's a -- all sorts of assurances that, well, we'd be really able to just do that, perhaps, on an individual basis if we had to with a little extra legwork. And I would submit to you, Mr. Speaker, that the ability to, then, to actually do that without extreme additional expense, as well as accurately do

that while maintaining the integrity and the completeness of the database just is not there.

I appreciate the concerns of a lot of people in this chamber for privacy. I would point out that as the bill very clearly states, the protections and the privacy under the federal government are fully and completely are respected by this amendment. And indeed we hope to have strengthened through our ability to use appropriately qualified expert outside vendors to manage this information and to keep these identities separate from us here in this state and, yet, allow us to use the data.

And for all of these reasons, Mr. Speaker, I encourage my colleagues, please to vote no on this amendment.

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Will you remark further on the amendment before us? Will you remark further on the amendment before us?

If not, will the staff and guests, please come to the well of the House. Will members please take your seats, and the machine will be opened.

THE CLERK:

The House, Representatives is voting by roll call. Members to the chamber. The House is taking a roll call vote. Members to the chamber please.

DEPUTY SPEAKER RYAN:

If all the members have voted, will the members please check the board to determine if your vote has been properly cast. If all members have voted, the machine will be locked, and the Clerk will take a tally.

Will the Clerk announce the tally.

THE CLERK:

House Bill 5038, House Amendment "B"

Total number voting	143
Necessary for adoption	72
Those voting Yea	49
Those voting Nay	94
Those absent and not voting	8

DEPUTY SPEAKER RYAN:

The amendment fails.

Will you remark further on the bill as amended?

Will you remark further on the bill as amended?

Representative Carter of the 2nd.

REP. CARTER (2nd):

lg/cd/ed
HOUSE OF REPRESENTATIVES

364
May 2, 2012

Mr. Speaker, I rise for the purpose of the amendment.

DEPUTY SPEAKER RYAN:

Please proceed, sir.

REP. CARTER (2nd):

Mr. Speaker, the Clerk has an amendment in his possession. It's LCO Number 4622. Would you please ask the Clerk to call it, and I'd be allowed to summarize.

DEPUTY SPEAKER RYAN:

Will the Clerk please call LCO 4622, which will be designated House Amendment Schedule "C."

THE CLERK:

LCO 4622 House "C" offered by Representatives Carter and Perillo.

DEPUTY SPEAKER RYAN:

The Representative seeks leave of the chamber to summarize the amendment.

Is there objection to summarization? Is there objection?

Hearing none, Representative Carter, you may summarize the amendment.

REP. CARTER (2nd):

Thank you, Mr. Speaker.

The amendment LCO Number 4622 gives the ability for a healthcare provider to notify a patient at the time of service that they can opt out of this ability to provide their information to the all-payers claim database.

Mr. Speaker, I move adoption of the amendment. When the vote be taken, I ask that it be taken by roll.

DEPUTY SPEAKER RYAN:

Question before the chamber is adoption of House Amendment Schedule "C," and there's also been a request that when the roll is taken, it be taken by roll.

All in favor of that signify by saying aye.

REPRESENTATIVES:

Aye.

DEPUTY SPEAKER RYAN:

I believe the 20 percent has been met. When the roll is taken -- when the vote is taken, it will taken by roll.

Will you remark further on the amendment?

Representative Carter.

REP. CARTER (2nd):

Thank you very much, Mr. Speaker.

You know, as we spoke about throughout the bill and throughout the last amendment that there's a concern that we're giving up private information and as -- and as the good Chair of Public Health had mentioned, there's additional concern, I guess, of how complicated this database can be.

Mr. Speaker, may I have it a little quieter in the chamber please?

DEPUTY SPEAKER RYAN:

As you've heard the proponent of the amendment would like to be able to be heard. So I'd ask you to be quiet and to take your conversations outside because I believe there's going to be a conversation, and I believe he's going to want to be able hear what is said.

Thank you.

Representative Carter.

REP. CARTER (2nd):

Thank you very much, Mr. Speaker.

Now, I don't feel like I have to yell.

You know, private information that we protect is -- is some of the most vital stuff, we don't want it to fall in the wrong hands. And obviously, we spend thousands of dollars trying to create the best

databases but a lot of them aren't fool proof. And as we've heard so far, there's a real concern that if we don't give patient identifiable information to the system, we won't be able to track the patient. So let's say that's true for a moment. Who gives us the right, as the state, to tell people that they're going to have to give up their information to a database without their choice.

Any study that is done, any study, patients have the ability to opt in or opt out. They have a choice. They have a choice if their information is going to be used for anything. We're not giving them a choice and it's not up to the insurance company to choose for us. Patients don't know that. The bottom line is if we want the ability to have patients know where their information is going, we got to give them a choice.

Ladies and gentlemen of the chamber, this amendment gives them a choice. They can opt in or they can opt out. It's pretty simple. We're not worried about how the data is going to be tracked. If you've opted into this thing, you've opted in. And you've given it your trust to the third-party administrator, who's going to manage this database. But if you opt out, then you have -- then you have the

lg/cd/ed
HOUSE OF REPRESENTATIVES

368
May 2, 2012

good sense to know that your data's not flowing out there. And by the way, with your data, it's going to include your health history. So that's -- that's a pretty scary thing for some people. So I'll tell you what, this is a common sense amendment. I really hope that folks give its due and please support the amendment.

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative Perillo of the 113th.

REP. PERILLO (113th):

Mr. Speaker, thank you very much.

I am very proud to stand with Representative Carter in offering this amendment that's before us.

How can we honestly look at the residents in the State of Connecticut and say we're looking out for you. We want to make sure you're healthy, we want to make you're safe, we want to make sure that it is cost-effective and in your best interest, but then not ask them if it's okay. We're going to take your data, but we're not going to tell you that we're taking it. And we're not going to ask your permission to take it. You're bamboozled. We got your data. There's nothing

you can do about it. You can't say yes; you can't say no.

This amendment changes that. This amendment gives people a choice. This amendment gives people control of their own personal health information. Individuals with mental health disorders, individuals with sexually transmitted diseases, individuals who have very extensive medical histories and, you know, what maybe you don't want anybody else to know about it. This amendment gives them the right to say no.

I don't want you to share that information, I don't want somebody else to know. I don't want my employer to know. I don't want anyone to know because this is private, this is mine. The bill without this amendment does not give patients that choice. It does not give your constituents, our constituents, to say I don't want it shared. In order to fix that, in order to restore choice, restore control to patients, to residents of the State of Connecticut, this amendment must be passed. Because without it, patients have no control over their own personal health information, and I don't think that's acceptable.

This is a very simple fix. Tell people that we're taking their information and give them the

lg/cd/ed
HOUSE OF REPRESENTATIVES

370
May 2, 2012

option to say no you can't have it. Without this amendment, we can't do that that is why this amendment is so important and that is why I proudly rise in support of it today, and I would urge everyone in this chamber to do the same.

Thank you, Mr. Speaker. .

DEPUTY SPEAKER RYAN:

Thank you, sir.

Representative Williams of the 68th.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

Good evening.

If I may, just a question to the proponent of the amendment.

DEPUTY SPEAKER RYAN:

Please proceed, sir.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker. ' .

Through you, to Representative Carter, the -- on the last amendment that was offered, the case was made by the proponent of the amendment that we need to be adequately able to track certain patient information in order to reach the goals that this bill is trying to reach.

My question to you is, would this still allow a particularly reasonable sample size to still accomplish the goals that this bill is trying to reach? Through you.

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Thank you very much, Mr. Speaker.

You know, that -- that number, through you, Mr. Speaker is all going to be driven by how many people opt in and opt out. But you got to know, I mean in a state with millions and millions and millions on the insurance rolls, it's -- it's -- there's no question in my mind, whatsoever, we're going to have a large sample size. I mean, if you look at some of the largest studies done that -- that medical science looks at, you're maybe talking about 48,000, 50,000 people, and that's a huge trial.

So it's -- it's certainly, my opinion, that the goal, which is a -- is a laudable goal of this bill. Remember this is a great bill because it does good things and we have good data. The only part is the rat in the bill, and it -- it crosses party lines. It's -- it's everybody issue because we all have data.

lg/cd/ed
HOUSE OF REPRESENTATIVES

372
May 2, 2012

This will allow the sample size that we need and protect individual data. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Williams.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

Through you, to Representative Carter, so all of the other information that we need, under your amendment, all the other information that we need in order to reasonably execute the goals of this bill, all that medical information would still be available? If I'm understanding you correctly, except for the name, and the address, et cetera, of the patient; is that correct? Through you.

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Through you, Mr. Speaker, what this amendment does is it opts out the entire individual. It does not opt out just their social security number or their patient identifiable information. It says, that individual is not going to be participating in this database.

Now, remember part of the problem in the -- what we were talking about earlier is the fact that we need to be able to track these people from insurance company to insurance company. Well, this eliminates any tracking, this eliminates any data problems, it basically just says the insurance are going to have some people marked that that data does not get transmitted, and it's up to the patient. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Williams.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

And I thank the gentleman for his answer.

I think I understand now the difference between the amendment that was offered before and the amendment that's being offered now.

Mr. Speaker, would it be appropriate for me to direct a question on the amendment to the proponent of the bill?

DEPUTY SPEAKER RYAN:

If that's what you're going to do, sure.

Representative Williams, you can now direct your question to Representative Ritter.

lg/cd/ed
HOUSE OF REPRESENTATIVES

374
May 2, 2012

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

And thank you to Representative Ritter for her willingness to answer this question.

Through you, to Representative Ritter, the amendment that's before us, if I'm understanding it correctly, would allow a patient to opt out of this reporting.

And my question is if this amendment were to be adopted, would this bill still be executable given that there will still be a sample size available for our understanding, again, as a way to execute the bill? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

And I thank the Representative for her question -
- for his question.

The power of and the potential of the database is the ability to acquire the information across all types of insurances, across all populations in our state. And the opt-out feature would, indeed, weaken that. The more that opted out, the closer it would

get to the present system now where we are continually frustrated -- and I know everyone in this chamber has expressed this frustration in these discussions about our ability to understand everything that we could about our healthcare system and about opportunities that we might have to make it stronger and more efficient.

So, yes, it would significantly weaken that and take away the power of the effort, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Williams.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

And I thank the gentlelady for her answer.

I -- I certainly can appreciate the desire to collect that data and to have a larger sample size. And I think that this, as Representative Carter and Representative LeGeyt have said, this is a laudable goal. This is a goal that I think so many of us here in this chamber and throughout the state of Connecticut share but not at the expense of people's privacy, not at the expense of people's privacy.

We have seen time and time and time again where mistakes happen in government. It's not that people

lg/cd/ed
HOUSE OF REPRESENTATIVES

376
May 2, 2012

are bad intentioned. It's not that people have sinister goals but mistakes happen. We've seen records get lost in -- in DRS cases. We've seen records get lost in other areas of state government. Computers that have been stolen, et cetera. Human error happens. And I would argue that the most precious privacy right that people have is their right to privacy in healthcare.

Now, I understand that we say, well, perhaps, this won't be a problem, we're going to try to protect people's privacy. We can't guarantee it, we can't guarantee it. We can't look all of our constituents in the eye and say, folks, we guarantee you that this information will not become public.

I respect the Chair of this committee. I respect the intent of this bill. I would urge members to support the amendment, so that we can all support the bill as it goes forward.

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, sir.

Representative Shaban of the 135th.

REP. SHABAN (135th):

Thank you, Mr. Speaker.

I, too rise in support of this amendment for many of the reasons that you've just heard, but, I think, let's drill down to really the core issue here. We have a bill before us that's trying to do laudable things, and I think most of the folks in this room support that idea, but what we're doing without passing this amendment is placing government over the people it serves.

The decision we're making on this amendment is who comes first? Who makes a decision about what people want to do with their lives, their information, their privacy, who's in charge? Is it the government, or a bureaucracy we're going to create or is the people?

Well, I submit that, at a minimum, as public servants, we, at least, owe the people the obligation to make a choice, just make a choice. I mean under HIPAA, as it is now, we -- we President Clinton signed a HIPAA law, you know, into law 15-some-odd years ago. Your information, your private information is protected because exactly that, it's a private matter, it's a private decision.

So if we, as the State of Connecticut, are going to say, hey, we'd like to use, citizens, your private

information, give them a choice, give them a choice. Because if we're not giving them that choice and we're not giving our -- our constituents the ability to opt in or opt out, we're saying, You know what, folks? We know better than you.

We got a bureaucracy we're about to create under the Lieutenant Governor's office, and we got -- we got studies and blue ribbon panels and -- and all kinds of data, and we know better than you, don't worry about we've got your back. Not good enough. That is not good enough, that is not who we are as a people or as a state.

So let's just -- this is a common sense amendment. This gets it done. This isn't us up here burning clock, like a lot -- like sometimes you hear us up here doing. This is actually something that makes this bill better, and I think everybody knows that. Are we going to choose people, or are we going to choose government? Please support the amendment.

DEPUTY SPEAKER RYAN:

Thank you, sir.

Representative Lavielle of the 143rd.

REP. LAVIELLE (143rd):

Something new, Mr. Speaker.

Good evening. How are you?

I rise in very strong support of this amendment, as well. I've -- I've been listening to this, and Representative Perillo made the point awhile back, and I think several others have, as well, that health related information is something that everyone considers private. It's one of our most basic pieces of information that, I think, everyone considers private and has been given to understand that they may keep private and, of course, this is true.

And I -- and I understand in listening to the discussion about this bill why there is a need for a base of information -- and understanding all of the different of accumulation of things that come up in the course of managing a healthcare system, but I'm sorry, I have not heard once in the discussion a single good reason why all of this information must be patient identifiable. I simply haven't.

And I would -- I would challenge anyone who is proposing to support the bill without this amendment to justify why people must divest themselves of the information that is the most private to them in our society where we have, as a basic principle, the ability to control our own destiny.

lg/cd/ed
HOUSE OF REPRESENTATIVES

380
May 2, 2012

So I -- I cannot see, frankly, any reason for not supporting this amendment.

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, ma'am.

Representative LeGeyt of the 17th.

REP. LEGEYT (17th):

Thank you, Mr. Speaker.

This amendment, even if it's not as good, in my opinion, as the prior amendment, which failed, this amendment is crucial to protecting our personal information in light of the stronger and more appropriate benefits that the -- that this bill provides.

We have an opportunity to collate, aggregate, and analyze healthcare data for many of our citizens in Connecticut, and this bill would authorize and allow that to happen. But there's no need to use our personal information. The benefit of knowing that my healthcare information is out there and that my name and address is attached to it doesn't improve the value of that information for use by anyone who's trying to draw some conclusions.

Not only that but as other representatives have shared tonight, we have an issue here, a balance to be struck between doing some public good by gathering this information so it can be analyzed and used to determine trends and make decisions that will improve the value of our healthcare and, at the same time, we are compromising our privacy unnecessarily.

There's no benefit to be had from using our names and addresses. We can have a healthcare number and our -- our healthcare information can be gathered and used that way. There are some things that we might give up and let our -- and give up our privacy in favor of, I can't imagine that this is one of them.

And I would ask everyone in the chamber, who has a chance to vote on this, to decide if they would like to be the one to offer their healthcare information up and tag their name and address to it or, more importantly, as you survey in your mind the names of your constituents that you know, do you think they would want that to happen to them?

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative Srinivasan of the 31st.

lg/cd/ed
HOUSE OF REPRESENTATIVES

382
May 2, 2012

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

I, too, rise in strong support of this amendment.

The goal with the underlying bill, which actually is an amendment in itself, is without a question, common good. We are trying to get that common good through the basic amendment, which we've been talking about for a good several hours now. But in this amendment that is right now on the floor of the House what we're trying to see is balance, that common good with the voice of our citizens of the citizens of our good State of Connecticut.

Do our citizens, do our constituents, want to give up that most important private information about themselves, about their family, without even being asked that question? We are not saying no. We are not saying that you cannot get this information. We are asking a basic question, Do you want -- Do you not want that information to be shared? Such a simple, logical question and every -- every constituent, every patient gets to decide to share that private information of theirs. They do or they do not.

That is all that this amendment is asking for. Giving them that option. Do they want to share their

most personal, their most private component of their lives without even being asked, Do you want to do that?

I strongly support this amendment, and I hope that with this amendment, the amendment that we're going to be talking about later would be a lot easier for all of us to pass because we know we are hearing the voices of our constituents.

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative Sawyer of the 55th District.

REP. SAWYER (55th):

Thank you, Mr. Speaker.

In other parts of state law, Mr. Speaker, Connecticut's citizens have freedom. They have the freedom to opt out.

Right now your DMV sells your information. They sell it and they make quite a bit of money, but you have the right to contact the DMV and opt out. If you do not, Mr. Speaker, want someone to solicit your home you have the right to opt out and call -- and get on the no-call list to opt out.

Mr. Speaker, I'm going to say that there is no data collection that is so important that I am willing to give away the personal freedom of choice, the personal freedom to opt out. I'm not going to give that away for my constituents.

Mr. Freedom -- Mr. Speaker, it's about freedom. It's about people's freedom to choose privacy. There is no data collection that is that important that I would mandate, as a government, that you have no say.

It's the worst thing that government can do to take away someone's right to choose. It's absolutely wrong. Mr. Speaker, I will be supporting this amendment. If this amendment fails, I will not be supporting the underlying bill.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative Williams of the 68th District.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

Briefly for the second time on the amendment, I was listening to some of the other debate.

And even if we accept the notion that the sample size, you know, needs to be as large as the proponent says that it is -- and I will accept that in order for

this bill to be successful. We can, at least, get the ball rolling on this very good concept by accepting this bill now, seeing what data we collect, what data we can track and then possibly, if this is successful, coming back next year.

I mean we all know that -- that, you know, many of our bills that become law are successful; many of those bills that become law are not successful. And so giving the ability of patients to opt out of this -- and by the way, we're not talking about opt in. We're making the concession that we're saying they can still opt out, would give the patient some relief that their privacy will be intact, and it will still get it us on the road to collecting and tracking that data.

I mean, folks, this is a House bill we can amend this bill to give patient's privacy, send it up to Senate almost as a pilot program, almost like a pilot program on steroids, put the pilot program in place, track that data and come back next year, and possibly modify if we have to. But there's so many of us who I know would like to support this concept here tonight if we just give that privacy to patients -- actually, let those patients maintain that privacy. Let the

lg/cd/ed
HOUSE OF REPRESENTATIVES

386
May 2, 2012

Senate vote on it with the amendment and come back
next year and deal with it.

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, Representative Williams.

Representative Betts of the 78th.

REP. BETTS (78th):

Thank you, Mr. Speaker.

I just want to echo and say I want to share -- I
do share the exact same sentiments as Representative
Sawyer. I won't repeat what she said or what the
other people have said but I, too, will also be
opposing the underlying bill if we do not honor and
respect the individual rights of people.

I think once they understand what the goal is and
why the data is needed, I don't think you'll see many
people opting out, but I don't believe it's in our
position to be sitting here not honoring those
individual rights, and that's the reason why I'll be
supporting this amendment.

Thank you very much.

DEPUTY SPEAKER RYAN:

Thank you, Representative Betts

Representative Larry Miller of the 122nd.

lg/cd/ed
HOUSE OF REPRESENTATIVES

387
May 2, 2012

REP. MILLER (122nd):

Thank you, Mr. Speaker.

I rise in support of the amendment.

Many hospitals down -- especially down South, are -- are having people to come in to have some work done, you know, not work done but coming in for some kind of medical attention, and all of a sudden they find out that they have a \$90,000 bill and they say, What are you talking about, you know, I haven't been here in three years. Somebody stole their ID number -- from a from a computer and -- and used it to get free medical care and that's one thing that's been happening more. It's identity theft but they're using medical numbers to have medical care rather than to steal somebody's money. In the sense, they're stealing money, but it's in the form of medical service.

My hospital down in Arkansas, they don't have any -- they give us an account number and that's it, our name and address. And there's a six or seven digit account number, and that's the only thing that is shown anywhere on -- on our records when we go down there. On the insurance bills, it's a little different, but they -- they're very concerned about

lg/cd/ed
HOUSE OF REPRESENTATIVES

388
May 2, 2012

identity theft down there and privacy issues are --
are key to those people down there.

And I think it should be key up here, as well.
Nobody wants to have their information exposed -- all
-- you know, in different areas by different people.
So I would advise the chamber to at least give this
thing a try and see what happens, but I -- I think
they should vote for this amendment and put it on the
bill.

Thank you.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Will you remark further on the amendment before
us?

Representative Ritter of the 38th.

REP. RITTER (38th):

Thank you very much, Mr. Speaker.

I've already had one opportunity to speak on this
amendment, and I believe I've made it very clear that
I would like to ask my colleagues, please, to reject
this amendment.

This amendment, Mr. Speaker, as we have had an
opportunity discuss and has been acknowledged around
the floor only serves to weaken this effort to and --

lg/cd/ed
HOUSE OF REPRESENTATIVES

389
May 2, 2012

and -- and take away the potential advantages that we can receive from this effort, from this work. And it really renders our data not only of far less value in Connecticut but, also, for any other measurement purposes and, consequently, it would accomplish no purpose. I urge rejection of the amendment.

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Will you remark further on the amendment? Will you remark further on the amendment?

If not, will staff and guests please come to the well of the House. Will members please take your seats. The machine will be opened.

THE CLERK:

The House of Representatives is voting by roll call. All members to the chamber. The House is voting on Amendment "C." All members to the chamber.

DEPUTY SPEAKER RYAN:

Have all members voted? Have all members voted?

If not, will the members please check the board to determine their vote is properly cast. If all members have voted, the machine will be locked, and the Clerk will take a tally.

lg/cd/ed
HOUSE OF REPRESENTATIVES

390
May 2, 2012

Will the Clerk please announce the tally.

THE CLERK:

House Bill 5038 House Amendment "C"

Total number of voting	139
Necessary for passage	70
Those voting Yea	52
Those voting Nay	87
Those absent and not voting	12

DEPUTY SPEAKER RYAN:

The amendment fails.

Will you remark further on the bill as amended?

Will you remark further on the bill as amended?

Representative LeGeyt of the 17th.

REP. LEGEYT (17th):

Thank you, Mr. Speaker.

I'm glad to have the opportunity to rise and speak on this bill. And I have just one brief scenario to share that I think impacts our decision on this bill, and I'm please to share it.

I used to work in a hospital. I worked in the operating room, and we performed therapeutic abortions. And clearly, the opportunity for someone to choose to have a therapeutic abortion was a choice based on their privacy, a decision to exercise their

privacy. This is what undergirds the opportunity for that procedure to occur.

And the fact that a procedure like that, which is based on their right to privacy, would then be subjected to sharing name, address and they would not be allowed to exercise their right to privacy in the -- in the publication of the information about that procedure for which they did allow -- they were allowed to use their right to privacy, sets up a paradox, in my mind, that I can't abide. And based on that, I would urge my colleagues to vote against this bill.

Thank you, Mr. Speaker.

Deputy Speaker Aresimowicz in the Chair.

DEPUTY SPEAKER ARESIMOWICZ:

Representative Davis of the 57th, you have the floor, sir.

REP. DAVIS (57th):

Thank you, Mr. Speaker.

And I have a few brief questions for the proponent of the bill as amended.

DEPUTY SPEAKER ARESIMOWICZ:

lg/cd/ed
HOUSE OF REPRESENTATIVES

392
May 2, 2012

Representative Ritter, please prepare yourself.

REP. DAVIS (57th):

Thank you, Mr. Speaker.

Through you, Mr. Speaker, is there any recourse if the privacy is ultimately breached in this system seeing how we have -- we just did not passed those two amendments that would protect that private information? Through you, Mr. Speaker.

DEPUTY SPEAKER ARESIMOWICZ:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, oh --

Through you, Mr. Speaker, we discussed that earlier this evening, Mr. Speaker. This amendment does not have any additional provisions because they are already provided for under both federal and state law. Through you, Mr. Speaker.

DEPUTY SPEAKER ARESIMOWICZ:

Representative Davis.

REP. DAVIS (57th):

Thank you, Mr. Speaker.

And she doesn't have to go into great detail and I -- I did miss that and I apologize. What are some of those recourses that people can take under federal

lg/cd/ed
HOUSE OF REPRESENTATIVES

393
May 2, 2012

and state law, briefly if I could? Through you, Mr.

Speaker.

DEPUTY SPEAKER ARESIMOWICZ:

Representative Ritter.

REP. RITTER (38th):

Mr. Speaker, I must apologize to the representative and ask him to please restate his question.

DEPUTY SPEAKER ARESIMOWICZ:

No problem, madam.

Representative Davis, would you please repeat the question, sir.

REP. DAVIS (57th):

Certainly, Mr. Speaker, and through you, and I apologize if it was gone into detail a little bit earlier but could -- could the kind lady, please, briefly explain what the recourse under state and federal law will be for someone if their privacy is breached through this system? Through you, Mr. Speaker.

DEPUTY SPEAKER ARESIMOWICZ:

Representative Ritter.

REP. RITTER (38th):

lg/cd/ed
HOUSE OF REPRESENTATIVES

394
May 2, 2012

Through you, Mr. Speaker, under federal law, the HIPAA law disclosures must be kept confidential and not in -- individual patient information must not be disclosed. Through you, Mr. Speaker.

DEPUTY SPEAKER ARESIMOWICZ:

Representative Davis.

REP. DAVIS (57th):

Thank you, Mr. Speaker.

So this -- if the information is breached, it could potentially open the state up to liability?

Through you, Mr. Speaker.

DEPUTY SPEAKER ARESIMOWICZ:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, there is nothing in this amendment that changes the liability of the state in any way that I am aware of.

DEPUTY SPEAKER ARESIMOWICZ:

Representative Davis.

REP. DAVIS (57th):

Thank you, Mr. Speaker.

And I thank the -- the kind Chairwoman of the Public Health Committee for her answers this evening.

Mr. Speaker, I understand the concept. As many people have said earlier, I understand why, perhaps, gaining this information would be important for public health issues, not only here in Connecticut but also in the country and, perhaps, across the world. But my concern lies with the fact that the privacy can be breached. That information can be given out. I mean, we hear time and time again of information being breached, people's social security numbers, people's names, their addresses. Some other types of personal financial information. But this, right here, under this bill, we could be talking about your personal health information, even more private for many people than their financial information. And under this, you potentially could have financial information linked to it, as well, because it goes through your medical history.

So, Mr. Speaker, because we weren't able to amend the bill this evening and put in those protections against privacy and make it so that people's personal information could be protected, if they so choose, as we saw in the last amendment. I cannot support the bill, as amended, here tonight for those simple reasons that we must protect individuals' private

health information, as the State of Connecticut, and this bill opens that up for the potential of that information being lost and us being unable to protect them the way that we should.

So, through you, Mr. Speaker, I cannot support the bill as amended.

Thank you.

Deputy Speaker Ryan in the Chair.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative Srinivasan of the 31st.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

The amendment, if it were to become the bill, creates a carve-out, who is and who is not in the program and that is the concern. We talked about earlier that when we tried to get the amendments in, the database would not be adequate, the database would not be complete and that is why these -- some of the previous amendments were voted out but what we have here if we already creating a carve-out.

Through you, Mr. Speaker, a few questions to the proponent of the bill.

DEPUTY SPEAKER RYAN:

Representative Ritter, you are ready to hear some questions?

Please proceed, sir.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

Through you, Mr. Speaker, a patient who is a self-pay, a self-pay patient, taking care of his -- inaudible -- own bills, will that person's information be in the system? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, the answer is no.

DEPUTY SPEAKER RYAN:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

And that is the point, that here we're creating a carve-out in the system where we are not encompassing the entire patient base -- database at all.

We already have and, as we know, in this day and age, more and more physicians are not participating in insurance companies. Patients are paying out of pocket and dealing with their own medical bills, so we already excluded that group of people. So this information that we are trying to get, at the cost of privacy, at the cost of security, is already flawed because you have a group of people that will not be participating, people who are self-pay.

Through you, Mr. Speaker, another question to the proponent of the bill?

DEPUTY SPEAKER RYAN:

Please proceed, sir.

REP. SRINIVASAN (31st):

Through you, Mr. Speaker, when a patient has met the maximum deductible for that particular year, they still go back to the doctor to get the services but at this time there is no insurance involved because they've already met the maximum for that particular year. And for some patients, unfortunately, it can happen as early as May or June. For a good six months of the year, five months of the year, these patient's have no insurance at all. So when they go to the physician to be seen, they're -- they're paying --

lg/cd/ed
HOUSE OF REPRESENTATIVES

399
May 2, 2012

their bills -- if at all they do, out of their own pocket.

Through you, Mr. Speaker, will these patients be a part of this payer database? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, all patients that are covered under the reporting entities will be a part of this database, Mr. Speaker. So if that claim is reported to the insurance company it will be -- whether it is actually paid by the insurance company or not, it will be included, that is my understanding, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Through you, Mr. Speaker, I just want to make sure I'm clear and the Chamber is clear. I thought it was only paid claims that were part of the system and not all claims that went into the system? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

lg/cd/ed
HOUSE OF REPRESENTATIVES

400
May 2, 2012

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

And that is a good distinction, the Representative is attempting to make, but it is my understanding from the definition of reporting entities that claims are reported to those entities would be the claims paid.

That is my understanding, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

I think we need to be very clear on that because there's a big difference between -- between the two entities. And I'm hoping that before we are asked to press our red or green buttons, we will have clarification as to who is going to be included in this. Is it only when the claims are paid or even if a claim is made and that claim is not paid? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Ritter.

lg/cd/ed
HOUSE OF REPRESENTATIVES

401
May 2, 2012

REP. RITTER (38th):

Mr. Speaker, I believe I answered that question,
Mr. Speaker.

DEPUTY SPEAKER RYAN:

All right.

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

And I want to thank the Chairwoman for her kind
answers.

And my concern with this amendment is, once
again, the carve-outs. The privacy of an individual
is or could be threatened here and we are not even
giving the opportunity for that patient to say I do or
I do not want to be included in this system.

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative Williams of the 68th District.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

I have a few questions on the underlying bill to
the proponent of the bill. And I was out of the
chamber of legislative business for a while earlier

lg/cd/ed
HOUSE OF REPRESENTATIVES

402
May 2, 2012

and I wanted to make sure that I -- I'm not asking a question for the second time as Representative Ritter just pointed out so please feel free to -- to let me know.

So if I may, a few questions to the proponent of the bill.

DEPUTY SPEAKER RYAN:

Please proceed, sir.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

Through you to Representative Ritter, in line 17, the section where line 17 resides speaks to the issue of the special advisor to the Governor seeking funding from the federal government to plan and implement this all-payers claim database program.

My question is what -- what types of federal funding are available and will -- is it anticipated that the bulk of this funding would come from the federal government or from the State or from -- where would most of this funding come from? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter, do you wish to answer this again?

REP. RITTER (38th):

For the fifth or sixth time, Mr. Speaker, I believe the language is fairly clear, in lines 17, that the funding would come through the federal government and other private sources to cover the costs of this plan. There is no defined partitioning or allocation or distinction of where the bulk of the funding would be coming from, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Williams.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

And -- and my other question is line 171 through 73. There's a penalty being assessed a civil penalty of not more than \$1,000 and my -- my question is where would that \$1,000 go? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I can tell you that it will go where civil penalties go. The bill does not stipulate any different location. I assume that that is paid to the Treasurer of the State of Connecticut.

DEPUTY SPEAKER RYAN:

Representative Williams.

lg/cd/ed
HOUSE OF REPRESENTATIVES

404
May 2, 2012

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

I'm -- I'm not personally familiar with where civil penalties go myself, which is why I'm asking. I didn't know if there -- so what you're suggesting, through you, Mr. Speaker to Representative Ritter, is that this will go into some dedicated fund having to do with healthcare specifically; is that correct?

Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, there is no stipulation in this language that it would go to a dedicated fund or any -- any other healthcare-related fund.

DEPUTY SPEAKER RYAN:

Representative Williams.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

I -- if it's appropriate, I'd -- for my understanding of how this bill works or -- or how our existing statutes work, I'd like to pose a question to someone who may know the answer to the question in the absence of defined deposit where a civil penalty may

lg/cd/ed
HOUSE OF REPRESENTATIVES

405
May 2, 2012

have been assessed. I'm trying to figure out where typically that would go in the absence of it being in our proposed bill form.

Through you to anyone who may know the answer to that question.

DEPUTY SPEAKER RYAN:

I think you have to be a little more specific to if you want to get an answer to that question.

REP. WILLIAMS (68th):

Perhaps the Chair of the Judiciary Committee, if -- if that might be appropriate. And I'd be happy to restate my question if the Chair of the Judiciary Committee would like?

Representative Fox.

Representative Williams would like to know where these funds would go, if you know.

REP. FOX (146th):

Thank you, Mr. Speaker.

Through you, Mr. Speaker, it might help if he rephrases the question.

REP. WILLIAMS (68th):

Understood.

Through you to Representative Fox, in line 71 of this bill -- and I'll just read this to you if you don't happen to have it open.

It reads, a civil penalty assessed under this subsection, shall not -- shall not be allowed as a cost -- I'm sorry, it's not line 71.

In line 70 -- line 70 reads that a civil penalty be assessed in an amount not to exceed \$1,000 per day.

There appears to be no other specificity in this section as to where that would be deposited. Is it typically deposited into a -- to the General Fund; is a check written to the Office of the State Treasurer? When civil penalties are assessed and there's no specificity, where do they go? Through you.

DEPUTY SPEAKER RYAN:

Representative Fox.

REP. FOX (146th):

Through you, Mr. Speaker, I believe it would go to the General Fund, but I'm not completely certain but that -- that -- that's where I would expect it to go.

DEPUTY SPEAKER RYAN:

Representative Williams.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

And this is not your bill, I'm certainly not trying to put you on the spot.

Do you know in other circumstances in our statutes if it is common for that not to be specified or if we assess a civil penalty on a another situation would that be specified to be deposited into a specific state account? Through you.

DEPUTY SPEAKER RYAN:

Representative Fox.

REP. FOX (146th):

Thank you, Mr. Speaker.

And through you, it would be my expectation that unless it is otherwise specified, it would go to the General Fund. They're certainly are civil penalties that are imposed for certain acts that are not specified, and it would be my understanding that that would go to the civil -- to the General Fund, unless otherwise specified.

DEPUTY SPEAKER RYAN:

Representative Williams.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

And I thank the gentleman for his answer.

And through you to Representative Ritter, this \$1,000 penalty for failure to comply with the reporting requirements is -- is that enough of a deterrent, or was it determined throughout the negotiation process -- was it determined that's enough of a deterrent to stop noncompliance in this section? Through you.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, in the discussions that we had around the setting of the penalty, there was some concurrence that this would provide a deterrent.

Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Williams.

REP. WILLIAMS (68th):

Thank you, Mr. Speaker.

And I thank the gentlelady for his answer.

DEPUTY SPEAKER RYAN:

Representative Sayers of the 60th District.

REP. SAYERS (60th):

Thank you, Mr. Speaker.

I rise in strong support of this legislation.

You know, I served ten years on the Public Health Committee, and every time we attempted to do legislation, the one thing that made it much more difficult was the -- the lack of adequate data on the actual health of our state and where the needs were for future healthcare.

For instance, when we look at our nursing homes, we're told that we're over bedded and under bedded in some areas of the state. And yet, we have no accurate data to know whether we do need more beds or less beds. And as we move to home care we have no idea of knowing how many people going home from the hospital requiring that.

We -- we look at the problems when UConn first -- the John Dempsey Hospital first spoke about expansion. We did not have accurate information to really know whether or not we would require more hospital beds, less hospital beds, whether this would have a major future impact on our hospitals here in Hartford. And as many of our hospitals throughout the state begin their mergers, we have no way of having that kind of data that we really need to know what future healthcare needs of residents of this state. And

without this data, we have no way of future planning.

We don't know where we need doctors.

A few years ago, we had a shortage of nurses. Currently right now, we no longer have that shortage and we have shortages in other areas, such as in physicians. And without understanding and fully having good knowledge and data of where the future healthcare needs are in this state, we will never be able to make that kind of planning. And we end up with problems where we're trying to address things after the fact without having that information.

We have been really trying for years to get this data, and I really am so thankful for the Chair of the Public Health Committee, the fact that they're moving forward on doing this -- this -- this year. And I will tell you between HIPAA patient's rights, which also protects the confidentiality of patient's information, we do not have to worry about that information. That information is out there. It is used for so many things already. If people think that that data is going to be suddenly front-page news or something, they're sadly mistaken. This information will be utilized to insure that in the future we can provide our citizens with much better healthcare.

lg/cd/ed
HOUSE OF REPRESENTATIVES

411
May 2, 2012

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative Perillo of the 113th, who is --
oh, there he is. Okay.

REP. PERILLO (113th):

Mr. Speaker, thank you very, very much.

I -- I would just like, if I could to clarify
some sections of the bill, so I can understand exactly
what -- what areas of the healthcare world this does
involve. I'm specifically referring to lines 82
through 107. This has to do with definitions.

As I understand the definition of an "all-payers
claims database," it -- it does seem to relate to
medical insurance claims, dental insurance claims,
pharmacy claims, and other insurance claims
information including enrollment and ineligibility
files.

Just to clarify if I may, ask one question to the
proponent.

All that insurance information would generally
come from insurance companies, that is the goal of
this. Correct?

DEPUTY SPEAKER RYAN:

lg/cd/ed
HOUSE OF REPRESENTATIVES

412
May 2, 2012

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, yes.

DEPUTY SPEAKER RYAN:

Representative Perillo.

REP. PERILLO (113th):

Thank you.

And I appreciate the answer.

Just to follow up on that as we move through the definitions. We get to "reporting entity," which is mentioned on line 87. And I read it, it says, a reporting entity would be an insurer or healthcare center that provides coverage, a third-party administrator, a pharmacy benefits manager, fraternal -- fraternal benefits society as described in section blah, blah, blah, that transacts health insurance business in the state.

So just to clarify, those are all insurance companies; is that correct?

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

Mr. Speaker, I'm not completely sure it is correct to typify all of those as insurance companies. Some of them are benefits managers or what we might more commonly refer to as third-party administrators of claims.

And the intent of the bill and the intent of the definitions under "reporting entity," as I have said before, is to capture all of those -- of those claims across all payers. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative Perillo.

REP. PERILLO (113th):

Mr. Speaker, thank you very much.

I would agree that some of these are benefit administration agencies but, indeed, some of them are insurance companies. They all seem -- most of them seem to bare risk in some way shape or form. So I guess my question to the proponent of the bill is do some or all of these fall under the oversight of the insurance commissioner? Through you, sir.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I believe some of them do. I believe the answer is yes.

DEPUTY SPEAKER RYAN:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker.

I appreciate that answer.

In that case, I would move that this bill be referred to the Insurance Committee.

(Pause.)

DEPUTY SPEAKER RYAN:

The Chamber will stand at ease.

(Chamber at ease.)

DEPUTY SPEAKER RYAN:

The Chamber will come back to order.

The motion before the Chamber is to refer this bill to the Insurance Committee.

Anybody wish to speak to the motion?

Representative Sharkey.

REP. SHARKEY (88th):

lg/cd/ed
HOUSE OF REPRESENTATIVES

415
May 2, 2012

Thank you, Mr. Speaker.

I urge rejection of this motion.

Referrals to the Insurance Committee are not a mandatory referral under our rules; and therefore, I would ask my colleagues to vote down, vote no on this motion.

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Any further comments on this motion?

If not, I will try your minds.

All those in favor of the motion, signify by saying aye.

REPRESENTATIVES:

Aye.

DEPUTY SPEAKER RYAN:

All those opposed say nay.

REPRESENTATIVES:

Those voting Nay.

DEPUTY SPEAKER RYAN:

I feel pretty sure that the motion failed, and we're back to the bill as amended before us.

Representative Perillo, I believe you still have the floor.

REP. PERILLO (113th):

Thank you very much, Mr. Speaker. I appreciate it.

Having been involved in the movement of this bill through the process, having heard the public hearing testimony, having worked in good faith with the Governor's office, with the Chairs, Vice Chairs, my Co-Ranking Member on the Public Health Committee, I've been very optimistic that this bill was something that could move forward. Something that I could support. And in fact, earlier today, I continued to be optimistic that it was something that I could support.

But today's discussion troubled me quite a bit. Today's discussion indicated very, very clearly to me that there is an unwillingness in this body and in this legislation to inform Connecticut residents that we are taking their personal health information and using it without their knowledge. There's clearly an unwillingness to give people the choice to present their health information to the State of Connecticut for research and for study. There's an unwillingness to do that. When we're unwilling to recognize people's right to privacy and when we're unwilling to give them the right to choose, whether their personal and private health information will be held somewhere

else or passed along that signals to me a fundamental problem with the bill itself.

This is a bill that has moved along in good faith. This is a bill that many people believe in. And I, myself would admit and agree that this data that would be gathered from this bill can be beneficial as we deliver healthcare benefits here in the State of Connecticut. But all of that benefit, all of that potential for growth, for improvement in our healthcare administration does not and should not trump Connecticut residents' right to privacy, right to know where their health information is going and right to choose whether or it should or should not go.

A "yes" vote on this bill, as amended, says to Connecticut residents, we want your info and we don't care what you think about that. We want your info and we don't want to tell you we're going to take it. We want your info and we don't even care if you have the right to choose or whether you give it to us or not, we're going to take it. And that's a problem. We need to respect people's rights, we need to respect people's privacy, and we need to respect the dignity of Connecticut residents by preserving for them their inherent rights.

And with that, I -- I would love to support this amendment in this bill, as I have in the past. I would love to be able to do that because I think the potential benefit is there but because of this Chamber's unwillingness to offer those rights to individuals here in the State of Connecticut, I cannot support this bill as amended.

Thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, sir.

Representative Carter of the 2nd.

REP. CARTER (2nd):

Thank you very much, Mr. Speaker.

You know, as we spoke on this -- as I spoke on this many times this evening, you know, the constant message has been there's an issue out there with data theft and healthcare. In fact, last year, it rose by about 30 percent at a cost of \$6.5 billion to the healthcare industry. And unfortunately, one of the -- one of the things about medical information that is so important is that it usually has your social security number and your date of birth attached to it, very similar to healthcare claim information.

We haven't given anybody the right to opt out of this bill -- or excuse me -- out of this database and with that and the -- and the large numbers of patients that are going to be exposed to the state, what'd we say? Millions. I mean we got 3.5 million people in the state. Let's say 2 million people are in this program, 2 million people now are at risk of having their data stolen, and by the way, a lot of those -- those breaches happen with third-party vendors. It's about 46 percent of them.

Mr. Chairman -- excuse me -- Mr. Speaker, I'd like to make a motion that because of the -- the large scale data breach that could happen that we refer this to Judiciary.

DEPUTY SPEAKER RYAN:

The motion before us is to refer this to Judiciary.

If the Chamber would stand at ease for a second.

(Chamber at ease.)

REP. CARTER (2nd):

Mr. Speaker?

DEPUTY SPEAKER RYAN:

Representative Carter.

REP. CARTER (2nd):

Thank you, Mr. Speaker.

I would like to withdraw the motion.

DEPUTY SPEAKER RYAN:

Thank you, sir.

The motion is withdrawn.

Is there any objection? Is there objection?

Hearing none, the motion's withdrawn.

Representative Ritter of the 38th.

REP. RITTER (38th):

Thank you, Mr. Speaker.

I feel like I've been speaking on this bill for quite a bit tonight, and I would like to offer a few more points in support of the bill.

This legislation gives us the ability to provide an enormous benefit for the citizens of the State of Connecticut. As many of my colleagues have expressed, not just tonight but continuously over at least all eight years that I have been here in this chamber, we are continually thwarted by our inabilities, not just the thwarted, frustrated and prevented from realizing any decent progress on providing reliable and dependable data for which we can do analysis on how to

best provide healthcare benefits for people in the State of Connecticut.

For some, that's not a very big deal because perhaps they have employer-sponsored insurance. The businesses are paying for it. Or perhaps the insurance companies are dealing with it while they're managing claim denials and trying to process claims in the fairest possible way, and the insurance companies are dealing with it. For many other people, who are in medical assistance programs of the State of Connecticut, quite honestly, the taxpayers are paying for it.

In their efforts and their trusts that we are doing the best that we can to provide decent, adequate and possibly efficient or effective protection for our citizens, but we do that in the absence of data, Mr. Speaker, and you've heard that tonight from people across this room.

We're not all, perhaps, data analysts but I bet every person in this room knows the benefit of decent data to use and only decent decision -- and decent decisions can never follow anything other than decent data. We all know that, we all acknowledge that.

We've been told over and over again that this destroys or injures the privacy that people, the citizens of Connecticut, have; that it takes away their ability to protect themselves; and that is simply not true, Mr. Speaker.

Mr. Speaker, there's federal law that protects this privacy. State laws and regulations that will follow. This information is not going to be kept in someone's personal laptop by a state employee, Mr. Speaker, and we've been very clear about that throughout the night.

The data breaches, the -- and -- and regrettable incidences that you hear about where, perhaps, a laptop is taken or an old legacy system is some -- is breached by a hacker in Bangladesh or -- or something similar is not going to be happening here. Those situations do not happen to data that is properly secured, that's encrypted and that's used where the most modern technology is used to protect and keep it. And that's what will be happening here, Mr. Speaker.

And I cannot encourage my colleagues more strongly to, please, support this bill.

Thank you.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Representative O'Neill of the 69th District.

REP. O'NEILL (69th):

Yes, thank you, Mr. Speaker.

I guess during the course of this debate, I -- I -- and I haven't listened to absolutely every word of it as you have. So I may have missed this, but it's always been my understanding that when you're conducting research, which is what this is, it's a gathering data for giant research project, that the research subjects are supposed to give informed consent before they agree to participate in this kind of a project. And I have not heard or had any inclinations or -- or intimation that any kind of informed consent is going to be granted or sought during the course of this data gathering, data mining, kind of, operation that seems to be going on here.

So -- and at the risk of repeating a question that may have been asked before, is there going to be informed consent on the part of the subjects of this research project? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

I assume you're directing that to the Chair --

REP. O'NEILL (69th):

Yes.

DEPUTY SPEAKER RYAN:

Okay.

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker.

Mr. Speaker, this bill does not require any additional consent, other than that it currently exists between any particular individual and their insurance company.

DEPUTY SPEAKER RYAN:

Representative O'Neill.

REP. O'NEILL (69th):

Well, I guess then I would ask what is the basis for that conclusion? Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

I believe it's to you again, Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker.

The basis for my conclusion is of reading of the legislation that is before us. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative O'Neill.

REP. O'NEILL (69th):

Well, the legislation may not require informed consent, but the ethical constructs of people who do research, scientific research, gathering information about medical conditions and -- and this sort of thing that we're talking about, studies that involve human subjects, which is what we're talking about here. It's my understanding that under federal law, you're required to obtain informed consent of the subjects of the research.

And we can pass all the laws we want, I mean, I know we've been doing that with some regularity lately that ignore federal law or contradict federal law, but it is there some provision -- apparently, there isn't -- but I'll ask to make clear. Is there any provision in here that somehow obviates the need for informed consent? Through you, Mr. Speaker to the Chair of the committee.

DEPUTY SPEAKER RYAN:

Representative Ritter.

REP. RITTER (38th):

Mr. Speaker, the information that we're talking about being available is aggregated information. It

lg/cd/ed
HOUSE OF REPRESENTATIVES

426
May 2, 2012

is not information of the individual nature that I believe, Representative O'Neill is speaking of and that is governed by the particular laws and requirements that he is talking about.

I would like -- I would like to point out to a couple of other things. First of all, that -- one moment -- that the provisions -- the federal provisions over the privacy of that information, as we have stated many times tonight, are protected and, specifically, addressed by this amendment. There's no weakening of those.

The bill provides for a databank of aggregate information. The bill does not do any research that would require the types of permissions that Representative O'Neill is speaking of. Through you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Representative O'Neill.

REP. O'NEILL (69th):

Thank you, Mr. Speaker.

Well, I understand the bill doesn't do any research, but the bill does do is create a databank, which is going to be accessed by people who are going to conduct the research. Once your information is in

the databank, there's never going to be an opportunity to raise an objection to the research that's going to be done with that data. I mean, it's -- it's sort of -- it's sort of a blank check that people are not actually even being asked to sign. It's being written in their name by the legislature today. And, I guess, I don't understand how that comports with the concept of informed consent, which is the very core of ethical research.

So I mean, it sounds to me like it's very clear that there is no informed consent provision here. There's no methodology to even with withdraw the consent if it were to be object to being part of one of these -- this massive research project. And -- but if -- if you were normally going to have a research project, you would normally have informed consent. This sort of leaps all over that as if there is some sort of magic that we can just ignore these basics rules that both the scientific community and, I think, the federal government require if you're going to conduct any kind of research involving human beings.

I thank you, Mr. Speaker.

DEPUTY SPEAKER RYAN:

Thank you, Representative.

Will you remark further on the bill as amended?

Will you remark further on the bill as amended?

If not, will staff and guests please come to the well of the House. Will members please take your seats. The machine will be opened.

THE CLERK:

The House of Representatives is voting by roll call. Members to the Chamber. The House is taking a roll call vote. Members to the Chamber please.

DEPUTY SPEAKER RYAN:

Have all members voted? Have all members voted?

If all members have -- will members please check the board to determine if their vote is properly cast.

If all members have voted, the machine will be locked, and the Clerk will take a tally.

Will the Clerk please announce the tally.

THE CLERK:

House Bill 5038 as amended by House "A."

Total number voting	139
Necessary for passage	70
Those voting Yea	93
Those voting Nay	46
Those absent and not voting	12

DEPUTY SPEAKER RYAN:

The bill, as amended, passes.

Are there any announcements or introductions?

Representative Widlitz of the 98th.

REP. WIDLITZ (98th):

Thank you, Mr. Speaker, for the purposes of an announcement.

DEPUTY SPEAKER RYAN:

Please proceed, ma'am.

REP. WIDLITZ (98th):

Thank you.

The Finance, Revenue and Bonding Committee will meet tomorrow morning at 10:30 in Room 2E, so we hope to everyone there.

Thank you.

DEPUTY SPEAKER RYAN:

You're welcome, ma'am.

Representative Gentile.

REP. GENTILE (104th):

Thank you, Mr. Speaker, for the purposes of an announcement.

DEPUTY SPEAKER RYAN:

Please proceed, ma'am.

REP. GENTILE (104th):

**JOINT
STANDING
COMMITTEE
HEARINGS**

**PUBLIC
HEALTH
PART 1
1 – 352**

**2012
INDEX**

SENATOR GERRATANA: Thank you so much, Marie. Thank you for bringing this to the attention of our General Assembly. And thank you also for educating us. I know I learned quite a bit when we did meet. And, you know, very often we wonder why very young people who are engaged in athletics, you know, contests and competitions and sports, unfortunately, you know, may become ill or even collapse and die on -- on the field, and that is extremely upsetting.

And this is just a simple and effective way to prevent that from happening. So we're happy you are here and Matthew is here. And also, Senator McLachlan, thank you so much for your bringing this bill to our attention also.

Are there any questions, comments? If not, thank you both for coming today. Thank all three of you. Bye-bye, Matthew. I want to hold that baby.

A VOICE: (Inaudible.)

Go bye-bye now. Next on our list, a hard act to follow, Commissioner Bremby, but we welcome you here. Commissioner Bremby from the Department of Social Services. Good morning.

COMMISSIONER RODERICK BREMBY: Good morning. Matthew, would you like to come up. Well, we're out of money. Good morning, Senator Gerratana, Representative Ritter, and distinguished members of the Public Health Committee. My name is Rod Bremby. I'm the Commissioner of the Department of Social Services. I'm here before you this morning to speak very briefly in relationship to three bills before you.

The first is Senate Bill 55, it's AN ACT EXPANDING THE MEMBERSHIP OF THE PHARMACEUTICAL AND THERAPEUTICS COMMITTEE. This committee

HB 5243
HB 5038

adverse health impact to the mercury amalgam in dental fillings, we are opposed to this proposal.

Lastly, House Bill 5038, and this is AN ACT IMPLEMENTING THE GOVERNOR'S BUDGET RECOMMENDATION CONCERNING AN ALL-PAYER CLAIMS DATABASE, or an APCD. An APCD is a warehouse which tracks health care utilization and cost information across a broad list of payers. Having timely access and accurate information will be important tools in our efforts to improve quality, reduce costs and promote transparency. Based on the experience of other states, we believe that the APCD will be a valuable resource in gaining a better understanding of the state's various health care delivery systems as well as the growing needs of Connecticut residents.

The proposed bill appropriately places the highest importance on the protection of personal privacy and security of these data in the database design and policies and procedures that will govern data use. We at DSS are excited about this opportunity, and we look forward to working with the Office of Health Care Reform to address these protected health information issues so that they are consistent with state and federal confidentiality laws.

In a past professional life, I had the opportunity to be responsible for an APCD, and we know that there's tremendous value in the use of this resource. So with that I'll stand for questions.

SENATOR GERRATANA: Thank you, Commissioner. I'm sorry I don't have your written testimony here in front of me or I couldn't find it online, but perhaps at some point it could be submitted to the committee and that's fine. I don't have any questions. I fully understood your comments.

COMMISSIONER RODERICK BREMBY: My apologies. We'll ensure that we get those to you.

SENATOR GERRATANA: Sure. That's -- that's fine. Are there any questions or -- yes, Representative Hetherington.

REP. HETHERINGTON: Thank you. Commissioner, welcome. I -- would you describe a little bit about how individual confidentiality is protected in the construction of the database.

COMMISSIONER RODERICK BREMBY: There are a number of ways and steps that one could take in designing the security and protection of personal information within the -- these APCDs. Typically the information is either disaggregated from the user identification or the data is encrypted in a way that you can't reaggregate the data to expose an individual or their course of treatment.

There are also privacy laws that are available in terms of disclosure or sharing of that information from someone or anyone other than the original source of that data. In Kansas, what we used was de-identified data. So the data that was submitted for us was stripped of identification from the payer. So what we had was a claim that had the event, that had the ICD codes or the cost codes so that we could get a sense of the trends or utilization.

Other states have full disclosure of information including the client's name, those databases require additional safeguards. And I must say that since we were one of the first states to have one, we didn't have the technology that was available to later state adoptees like Connecticut where we can provide technological tools to provide for safety and safeguarding of that information within the database.

REP. HETHERINGTON: I see. I've read the bill and I'm just trying to get an overall understanding of it. The data is assembled from insurers and others who pay claims on behalf of patients, is that correct?

COMMISSIONER RODERICK BREMBY: That is correct.

REP. HETHERINGTON: So that a regular, well, pardon me, a -- a health care provider, your primary care physician for example, would not be directly contributing to the database, is that correct?

COMMISSIONER RODERICK BREMBY: Only in so much as that information is provided back to a payer to pay for that service or that claim. This is an attempt to pull information from the claims side of the record and perhaps match that with some other sources for overall utilization of information.

REP. HETHERINGTON: Is the confidentiality treatment, the encryption if you will, does that take place before it goes into the database? In other words, when the information is in the database, is -- is it encrypted?

COMMISSIONER RODERICK BREMBY: It depends on your database design. As currently configured, we have not reached that decision here in Connecticut about the design and specifications. But we would see encryption as a means of ensuring that data is protected in the transmission of that data to some other location. I don't know to what extent we would look at that or require that as it sits or as it rests within the database, but that's certainly something that would be under consideration.

REP. HETHERINGTON: Thank you, Commissioner.

COMMISSIONER RODERICK BREMBY: You're welcome.

REP. SRINIVASAN: Okay. Thank you.

COMMISSIONER RODERICK BREMBY: (Inaudible) other states.

REP. SRINIVASAN: Thank you, Commissioner. Thank you, Madame Chair.

SENATOR GERRATANA: You're welcome. Any other questions?

Yes, Representative Carter. Thank you. Sorry.

REP. CARTER: Thank you, Madame Chairman, I appreciate it. Commissioner, thank you for your testimony. Quick question or actually a couple quick questions, right now with trying to collect data on health claims, is something being collected now? I mean how does the state know what's going on currently?

HB 5038

COMMISSIONER RODERICK BREMBY: In terms of the state's program and in terms of our Medicaid clients, we do collect that data in order to make payments and it sits in a -- what we call an MMIS database. What we're trying to do with this APCD is identify those claims from all other payers so that that collection of information is either centralized or available so that we can perform analysis across all payers, not just Medicaid, but all -- everyone.

REP. CARTER: So when you say it will -- it will be on the claim side, I had a little confusion with respect to the reporting agency. Are the reporting agencies giving you claims data that they're (inaudible) insurance company or the insurance company themselves -- excuse me -- is this a little bit better? All right. I guess my question is with respect to the claims data, are you taking data from the person making the claim or the insurance company receiving the claim?

COMMISSIONER RODERICK BREMBY: We're looking to receive that information from the insurance companies, the payers, those payers.

REP. CARTER: And then if those payers don't report, then they're the ones who are assessed the fee of not to exceed \$1,000?

COMMISSIONER RODERICK BREMBY: I believe that is correct.

REP. CARTER: Okay. Thank you very much.

SENATOR GERRATANA: Thank you, Representative Carter. Any other questions? If not, thank you Commissioner Bremby for being here today.

COMMISSIONER RODERICK BREMBY: Well, thank you very much.

SENATOR GERRATANA: You're welcome.

COMMISSIONER RODERICK BREMBY: Thank you, Matthew.

SENATOR GERRATANA: Next we have Senator Scott Frantz

SENATOR FRANTZ: Good morning.

SENATOR GERRATANA: Welcome, Senator.

SENATOR FRANTZ: Good morning. Thank you. Great to be here. And I have to say that in all my three years here in the General Assembly, Matthew is the toughest act to follow, and he didn't say anything. We can all learn from that maybe. I was told that the soul of gravity and impact is - is conciseness and shortness.

Good morning, Representative Ritter and Perillo, Senators Gerratana and Welch. Thank you so much for allowing me some time and all other members

SB 260

Thank you, Madame Chair.

SENATOR GERRATANA: Thank you. Any other questions?
If not, thank you for coming today. Take care.

ERICA VENEZIA: Thank you very much.

SENATOR GERRATANA: Next is Vicki Veltri.

VICTORIA VELTRI: Good afternoon, Senator Gerratana, Representative Ritter, all the members of the Public Health Committee. I'm going to make this very quick for you because I know you have a very long day ahead of you, and I actually another thing ahead of me. So I just want to inform the committee, you have my testimony, that the Office of the Healthcare Advocate supports Governor's Bill 5038 which would establish an all-payer claims database in the state of Connecticut, a long overdue tool that I think we need in the state and is actually the one thing that most people on all sides of health care issues, for the most part, I think can agree on as a way to improve health care going forward in the state.

We really need to get control of health care costs, but we also need to get control of our quality, improve quality, and improve our health benefits designs, establish public health initiatives where necessary, and this is the one kind of tool that will get us there the fastest and have the critical mass necessary to make those adjustments going forward. So we really support it. Like I said, you have my testimony before you and I know you have a long day, so I don't want to keep you hear having to listen to me deliver a long piece of testimony. So if there's any questions, I'm here happy to answer them.

SENATOR GERRATANA: Thank you. It's always good to hear from the Office of the Healthcare Advocate,

particularly on this matter.

Representative Hetherington.

REP. HETHERINGTON: Thank you very much. Thank you for being with us today. I had a question or two on the bill and that is the extent to which the data will be made available, I'm looking at lines 164, 165, it says the database (inaudible) any state agency, insurer, employer, health care provider, consumer of health care services. Why would an employer need this data?

VICTORIA VELTRI: Well, like a lot of small businesses and businesses out there, I think employers are very sensitive to health care costs and what kind of experience they know they're having with the health care costs versus the system as a whole. So they might want to see that kind of data. And I should say, that would be de-identified data, so they would not be seeing any particular consumer.

But they would be able to compare their own experience with the experience of the state as a whole and the quality that we're seeing, and costs. So maybe they can use that information to drive negotiations going forward on their own -- their own health plan costs or do design wellness programs, for instance. But that -- that would be a reason that an employer would want to see the data, I would think.

REP. HETHERINGTON: I see, and it says consumer of health care services, well, that's all of us isn't it?

VICTORIA VELTRI: That is correct. But I do think -- I think what you're going to see is there's been a movement nationally, and I think it's a good one, to improve the transparency of health care costs and quality going forward. And there is a

real need for consumers when they're evaluating whether or not they want to choose -- whether it's choosing a provider, a hospital, a health care plan, whether it's a business deciding whether their health plan is a good one or not, or whether they want to design another program, they'd like to see the data that the state is -- the state's experience with respect to all health care plans to see, you know, does -- do our hospital expenses appear in this region to be higher than in this region and why is that so?

And would that effect the decision, from a consumer perspective, to go to hospital A versus hospital B? That's just a very generic example, but there are dozens and dozens of ways to use the data. You may want to know, you know, how many people have asthma in Connecticut? Is the prevalence worse, you know, over time? Is it geographically worse in one area of the state or another? So all sorts of reasons --

REP. HETHERINGTON: Would the -- would the data be specific though as to hospitals, I mean, you mentioned so you could choose a hospital? So you could go on the database -- I could go on the database and find out how Norwalk's figures are as compared to Stamford Hospital?

VICTORIA VELTRI: Actually -- actually I do not know the answer to that question. But I do know, I mean it will be a robust -- it's all claims. It's all claims from all providers. I don't -- I don't know that the detail will be broken down by carrier. But I suspect based on the analysis that's been done in other states in the uses of the all claims payer claims database is that you can make distinctions among different kinds of providers groups and entities.

Jeannette DeJesus, who's the Governor's Special Health Care Advisor -- Advisor on Health Care

Reform, excuse me, is going to be up here in a few minutes to explain the full details of the design, because the bill is actually being run out of her office and she's been actually the person who's been doing the most in terms of the design with the other states and the carriers. But that is, I mean that is the purpose. It's really a comparison tool and it's an evaluative tool for us to use going forward to initiative real reform efforts in the state. And it's a missing piece right now.

REP. HETHERINGTON: Would I be -- just one last question, would I be able to tell, for example, what -- what the data is for my town?

VICTORIA VELTRI: I -- I suppose you could decide -- you could design -- design it in such a way, yes, to be zip-code oriented so that you could determine what's going on in your town versus another town, yes, that can be done. That can be done. And you should -- the committee should know, we have this kind of information. On a smaller scale the state has been doing this for years in the Medicaid program.

And I think you're going to hear from I think Sharon Langer from Connecticut Voices of -- For Children is going to talk about the robust things that you can do when you have this kind of claims data available to you in improving, for instance, Medicaid policy or the state employee plan. The Comptroller has been doing this too for years. So taking this information, putting it all together, with 3.5 million lives that we have in the state, will really improve the direction of health care in Connecticut, I believe.

REP. HETHERINGTON: Okay. Thank you.

VICTORIA VELTRI: You're welcome.

REP. CARTER: Thank you, Madame Chair.

SENATOR GERRATANA: You're welcome. Thank you. I think that's it. Thank you so very much --

SANDRA CARBONARI: Thank you.

SENATOR GERRATANA: -- for your testimony, and we look forward to it in writing also, that would be helpful. Thank you.

Next is Jeannette DeJesus. Welcome. And I believe you have two others of your staff or experts on your bill.

JEANNETTE DEJESUS: Yes, thank you.

SENATOR GERRATANA: Thank you.

JEANNETTE DEJESUS: I had hoped that we could deliver this testimony because of its somewhat technical nature with you having full stomachs, right after breakfast, so I'm glad to see some of you having lunch.

HB 5038

I'm Jeannette DeJesus, and I work as the Governor's Advisor on Health Reform. And I'd like to, because of the nature of my testimony on an all-payer claims database, it -- it being somewhat technical, I'd like to introduce our General Counsel in the Office of Health Reform Innovation and our Senior Policy -- Health Policy Analyst, Laurie Graham and Bobbi Schmidt. And they are here because they are somewhat expert in the area of all-claims database -- databases, and will be available to answer your questions.

So let me apologize in advance. I generally don't stick closely to testimony, but because of the technical nature of this, I will. And we do have additional copies if the committee would like them.

SENATOR GERRATANA: Yes, yes, we would. I don't have anything in writing. So we'll have our clerk help there. Okay.

JEANNETTE DEJESUS: So while she distributes that, I would like to just veer for a second from my testimony and -- and tell you just a little bit about the process that we have followed in order to -- that -- that has brought us to this place of testimony as part of the Governor's package. We convened -- the Office of Health Reform and Information, convened a multi-payer group almost a year ago.

And the members of that group included leaders from state agencies, including DSS, DPH, the Department of Insurance, the Office of Health Care Access, Medicaid, the Comptroller's Office, and the Office of the Healthcare Advocate. In addition, it included the quasi-public Health Insurance Exchange leadership. The plans were all represented in our group, that is Aetna, Anthem, Cigna, ConnectiCare, United, and the hospital association and academic researchers all were part of this group that met, somewhat regularly, and that contributed to the decisions that are represented in the piece of Legislation that is before you. So, Senator Gerratana and Representative Ritter, I appreciate the opportunity to offer testimony in support of House Bill Number 5038, ESTABLISHMENT OF AN ALL-PAYER CLAIMS DATABASE PROGRAM.

An all-payer claims database, I'll begin with an overview of what it is. I'll then go on to talk briefly about -- define it, what it is, what other states are doing, discuss some basic and fundamental principles that guide our work, and then talk about its effects on health reform.

So an all-payer claims database is a resource

that is critical to the state's ability to transform its health care system and to improve the health outcomes of our citizens. Our health reform strategy here in the state seeks to improve quality of health care, to reduce health care spending, it continues to increase at rates that are unsustainable over the near and distant future, to make care more accessible, safe, and patient-centered, and to significantly reduce health disparities.

For these reasons and for many more, we must have comprehensive information on disease incidence, treatment costs, and health outcomes. The absence of this information hinders our ability to inform and evaluate state health policies and to provide the transparency needed to ensure people have the information that they need to make health care decisions.

We want our state to join other states in the establishment of an all-payer claims database. While there have been various efforts to aggregate health care data in the past, data aggregation of the magnitude and scale of this all-payer claims database are unprecedented here in the state of Connecticut. For the first time we have the inter-agency and community support, health reform leadership, and technical readiness to accomplish an initiative of this size and significance. The establishment of an all-payer claims database is a critical component of the state's health reform strategy and necessary to achieve its goals.

So what is an all-payer claims database, or an APCD? Every visit as you know -- every visit to a health care provider generates a claim for payment. Both public and private insurance plans routinely aggregate these claims into their own database. APCDs combine data from all payers in the state. This gives policymakers such as

yourselves statewide information on cost, quality, utilization patterns, and other health care measures. In the simplest of terms, an APCD will allow us to know how care is delivered, where care is delivered, and how much that care costs.

Publicly available data will give consumers and purchasers the tools they need to compare prices and quality as they make health care decisions, an ability that, you know, you and I have in almost every other area of our lives. These databases include administrative data from medical insurance, dental and pharmacy claims, and information about enrollment and eligibility. These data are collected from public and private payers, ideally from insured -- self-insured plans as well as Medicaid and Medicare.

This information typically includes patient demographics, diagnostic and procedure codes, and cost. The information can be used by policymakers, state agencies, researchers, and consumers to improve decision making and health care delivery.

I'll try now to give you a sense of what other states are doing in this area. Other states have made considerable progress -- progress toward establishing APCDs. And the Office of Health Reform & Innovation, which I direct, is working directly with APCD leaders in other states to benefit from their experience in developing robust APCDs that will serve the needs of Connecticut's citizens. And I -- I'd like to point out that the All-Payer Claims Database Council, the national organization has submitted testimony. In its testimony it states clearly that it has reviewed our work and our Legislation and approves and supports our approach to establishing an APCD in the state of Connecticut. You'll find that on page three and four of their

testimony.

With regard to other states, there are currently more than a dozen active efforts underway to establish APCDs with mandated reporting. There are four New England states that have existing APCDs. That includes New Hampshire, Vermont, Maine, Massachusetts, and, in addition, New York and Rhode Island are currently implementing an APCD. This is certainly a company that would be good for Connecticut to keep.

Already we have benefited greatly from the experience of these states in identifying best practices to streamline data submission. Efforts are being made to standardize common data elements that would improve the comparability of data from state to state. Standardization makes reporting easier for insurers and it is critical if we are to join in multi-state collaborations in the future.

Some fundamental principles that have guided our work and that will continue to guide our work, the protection of personal privacy and security of these data will be paramount as we design database architecture and the policies and procedures under which it will operate. We believe strongly that our need for information, no matter how great, must never compromise individual privacy. We will strictly adhere to federal and state confidentiality laws.

It is critical that the APCD serve a broad range of functions including, but not limited to, health plan and provider performance report cards, public health surveillance, state utilization patterns, and increased transparency to the consumer on cost and quality. It must be flexible, flexible enough to support changing needs and respond to technological opportunities that emerge over time. In addition to being

secure, the system will be interoperable, flexible and scalable to fit with other HIT initiatives.

Finally we want very much to incorporate analytics that result in actionable information and improves the delivery and affordability of health care in Connecticut. While states differ in their approach to managing protected health information, the highest level of privacy and security can be achieved in a variety of ways. Several states have recommended that we include Social Security numbers because they promote greater accuracy and access. Important decisions about the management of protected health information will be considered and made in consultation with the working group that has been meeting over the last year, and subject to public rulemaking such as with this committee.

Through that process, we will determine the best way to make the database as powerful as possible while ensuring the personal data is strictly protected. The Health Insurance Exchange that we are currently developing in this state will need the type of information that this APCD will allow us to have. And the Exchange we hope will be the first user of that -- of this information when it opens its doors in 2014 -- January of 2014.

The target date for the first release of data from the APCD is set to coincide with the startup of the exchange. It is, therefore, critical that the Legislation be enacted this session if we are to meet the needs of the Exchange and to successfully achieve other aspects of Connecticut's comprehensive reform strategy. Health reform provides you -- us with an unprecedented opportunity to make lasting and effective policy decisions.

An all-payer claims database will give us the

comparable, transparent information that has historically been unavailable in making policy and market decisions. We can change that. We can change that by passing this legislation and moving quickly to implement an APCD in Connecticut. Thank you.

SENATOR GERRATANA: Thank you so much, Jeannette. I do have a couple of questions regarding how this will work. I also was reading the Legislation, and you can correct me if I'm wrong, the -- the first thing is that this is a system, and I assume it's software, you know, basically, that this would be a system that could be utilized by the insurance exchange to offer information to consumers, am I correct in that?

JEANNETTE DEJESUS: Yes, but it has broader applicabilities --

SENATOR GERRATANA: Oh, yeah.

JEANNETTE DEJESUS: -- so I'll ask my colleague to answer.

ROBERTA SCHMIDT: Hi. Yes, that is one of the ways that the APCD can be used. Data can be produced to the exchange which it can then use in doing health plan reporting.

SENATOR GERRATANA: Right. Please, for -- for all of us, if you would identify yourself.

ROBERTA SCHMIDT: Oh, yeah. I'm sorry. Bobbi Schmidt, General Counsel.

SENATOR GERRATANA: Hi, Bobbi, Thank you so much.

ROBERTA SCHMIDT: Sure.

SENATOR GERRATANA: Yeah, it's very interesting. So this information will be collected and it looks

like, you know, under the Legislation that it can be broadly shared with a number of entities. I still don't have the big picture, and I guess I'm still formulating questions on it, but it is aggregating data in one spot, if you will, that has -- and this affects all payers. So this would be from medical offices, hospitals, insurance companies, perhaps?

ROBERTA SCHMIDT: It's claim data. It's claim data.

SENATOR GERRATANA: All claim data. Okay. Of course.

ROBERTA SCHMIDT: So it's data that we will get from the insurance companies. And just to go back to one of your -- your question about would be available to everyone. I -- I think it's important for us to clarify that we are not attempting to create something that is so transparent that anyone on any given day could just go up to a computer and access information, you know, willy-nilly. There are very strict rules and regulations around what is available, what is provided, and how it's provided. And it's -- and it's de-identified data and so it would be pretty difficult, possible, but pretty difficult to trace it back to any particular person or group.

SENATOR GERRATANA: Well, I always like to say, you know, when I'm looking at a piece of Legislation, you know, how is this applicable in the real world? So it was in the Legislation in the bill that, I'm sorry, I don't have it by line, but there -- it says the Special Advisor to the Governor on Health Care Reform or the claims database administrator shall utilize data in all-payer claims database to provide health care consumers in the state with information concerning the cost and quality of health care services that will allow such consumers to make economically-sound and medically-appropriate

health care decisions.

And I find that interesting. And I understand that we're not going to identify who these people are and they'll probably be given a particular nomenclature or the data will, in any event. But I'm trying to get my brain around how am I going to use it as a consumer.

JEANNETTE DEJESUS: You know, I'm not a data person and so I'll ask Bobbi to give you the correct, you know --

SENATOR GERRATANA: Sure.

JEANNETTE DEJESUS: -- technical answer to that.

ROBERTA SCHMIDT: There -- there are actually some great -- if -- if you care to go to them, some great resources for you. For example, in New Hampshire and in some other states, they have, and you can get to them through the websites which we can give you, but there's some fantastic self-service consumer portals where people can sign-on, and they put in information about themselves, where they -- where they live, in some cases what health plan they're covered under, and then, for example, if they're going to be going into the hospital for a particular procedure, they put in that information about themselves, and -- and they're able to get an estimate of what the cost of that procedure would be depending on where they chose to get the care. So it's -- it's a wonderful thing.

SENATOR GERRATANA: Yeah.

ROBERTA SCHMIDT: And it's something that some of the
--

SENATOR GERRATANA: Transparency.

ROBERTA SCHMIDT: Yeah, some of the insurance companies individually haven't, you know, begun to engage in these efforts, but this is really a way to do it across the state. So and again if you're interested, we can forward you some of those websites so that you can --

SENATOR GERRATANA: Sure, I would appreciate that.

ROBERTA SCHMIDT: -- look at them yourself.

SENATOR GERRATANA: That's fascinating. That's wonderful.

JEANNETTE DEJESUS: I would add to that that let's assume this committee has, let's say, \$100 for some -- for something, whatever, and, you know, and somebody comes and says, you know, you should use it for creating an asthma program in Bloomfield, Connecticut. And someone else comes and says, no, you should do this asthma program in New Haven. Five people from New Haven show up and say, yes, New Haven. Well, you could look at the database, and the database would indicate where the highest incidence, prevalence of asthma is. And you could, as Legislators, make a decision that really, it's -- it's downtown Hartford in the south end that could really use an infusion of programming around asthma treatment. And so as policymakers, it would offer that type of information.

SENATOR GERRATANA: Thank you. That is -- that is extremely useful. Thank you very much for that. I don't have any further questions or comments.

Representative Carter.

REP. CARTER: Thank you, Madame Chairman. You go to a great -- a great way in describing that we're going to be careful of privacy concerns. When the data comes to the state from the insurance

company, can it be de-aggregated -- did I say it the right way -- before it gets to the state to take away the patient identity?

ROBERTA SCHMIDT: There -- there have been -- Commissioner Bremby -- this is Bobbi Schmidt again, mentioned that there have been various techniques that have been used to protect privacy. And we've actually been, and -- and some of them as he mentioned in the database that he was involved with in Kansas, they -- they really split the personal identifiers out. And then he mentioned that today there, with the evolution of technology, to protect the information in transit and in storage, there -- there has been an evolution and more and more states are collecting personal identifiers together as -- as part of the data that's sent in, but doing so in a way that protects the data in transit and then when it's in the database. There are a variety of ways that that can be done.

We've actually been spending a good deal of time in the last several months talking with representatives from other states, and we -- we plan to continue to do that because the -- the technology is evolving at -- at such a pace that what we want to do is to really find the best possible solution that will both allow us to have as powerful a database as possible that can do as much as possible for the people of the state, but which will be as absolutely secure as possible.

REP. CARTER: Thank you. And -- and I -- like I said, I understand you're going a long way to make sure that our side of the fence is protected and that we're making sure that patients' information is not provided. But I guess what I'm saying, has any effort been looked at to say to the insurance industry or the reporters to say give us this information in standardized format, not related

to any kind of patient, so they -- they go a long way industry in protecting their -- their people. The question is, can we just get the data and use it without have any patient identifying information given to the state?

ROBERTA SCHMIDT: As -- as I mentioned, there -- there -- there are different -- different ways that one can do that. What I can tell you is, you know, based on the discussions that we've had so far, we have been very much encouraged or -- or it's been recommended from the states that we've spoken to that we do collect from the payers the patient identifiers. Because those states that have not have that have been restricted in what they can do with their databases.

But what we want to do is -- is really make sure that we -- if -- if we go that route, that we make sure that we have ways to protect that data as it's coming in and as it's residing in the data. Again I don't want to get into too much -- many specifics, but there -- there are ways to do that. And what we want to do is to find the best possible approach for the state, because it is a very important issue.

JEANNETTE DEJESUS: I'd like to add to that, please. I'd like to add to that that, you know, we already have a lot of data in this state. And we have, you know, data that identifies. And so we -- we have and so there isn't really -- we have it, it's available and we're -- the technology is evolving so quickly that we feel even more confident that we are able to protect privacy and provide security at a level that, you know, would really minimize, you know, breaches.

Although, I mean I don't think that we can really be overly concerned about -- about security and privacy. I would say, however, and I would caution us to not allow our concerns, our

legitimate concerns about privacy, to prevent us from pushing forward on these innovative and important initiatives that are so consequential for the people of Connecticut.

And I -- I would say we shouldn't do that anymore than we would, you know, eliminate the airline industry because there are some accidents sometimes. Certainly we don't want that to happen, but we don't want to be -- in Connecticut we don't want to be behind. We'd like to actually get ahead and in front of addressing some of these significant health issues that we have in the state like reducing costs and improving quality and eliminating health disparities and those sorts of things.

REP. CARTER: And I totally appreciate where you stand. I mean, obviously we need to find a way to do this. It's a good idea and it's a common sense idea to aggregate some of this data together. But, of course, you know, one of the major concerns of any American today is -- is their privacy. And I think we see time and time again where well-intentioned people let something slip or something happens.

And -- and there's a fundamental thought in many people's mind about their freedom as connected to their health care privacy. So I just want to make sure that we're doing due diligence in everything we do to make sure that's protected. Now the last thing I kind of wanted to ask also was with respect to the -- the fees, there's going to be some fee schedule for people to access this information including consumers is the way I would read the bill?

JEANNETTE DEJESUS: That's right.

REP. CARTER: Has anybody talked and given in how that would work or the amount of money?

LAURIE GRAHAM: That's a great question. This discussion about reasonable fees for data access is going on within our office and (inaudible) workgroup. We haven't come upon a final decision on how that would be orchestrated, but we are looking at other states as to how they've created reasonable fees for -- for the suite of -- of folks who could benefit from this data including consumers. Because clearly researchers will have a different data need for them, potentially need a much greater data set for their research questions than the consumer looking for cost by -- by a procedure. So basically what I would say is that we're considering that.

JEANNETTE DEJESUS: I would also add that, you know, across -- one of the things that I think is -- could offer us comfort in this process is that there are 12 states -- a dozen states that are already doing it. Our payers are -- some of them are already engaged and participating in these APCDs in other states. And we are benefiting greatly from the standardization, the rules and regs that they have already put in place and they have tested.

We have a multi-payer group which includes the payers, the hospitals, the decision making group that will look at those things, you know, over the next 6, 8, 12 months and -- and we, I'm sure, will be back here about a lot of these things. And then the other thing that I wanted to mention just going back is that, you know, the Legislation, if it were to pass, would have the Office of Health Reform and Innovation developing it and implementing it.

But there then has to be decision by the Governor that -- where this will sit and there is no, you know, I think that that's open and that could sit either in government or in a quasi- or in another

-- there are other possibilities. And we see health reform moving so quickly that there might be something that we don't even know about now. So that might offer you some comfort knowing that there's a possibility that the government will not be engaged ultimately.

REP. CARTER: Or -- or not knowing could scare the heck out of me knowing they probably will. The very last question, with respect to a fee system, is -- is the goal of the administration here to make this sustaining as possible with respect to the money raised through the fees to administer it?

ROBERTA SCHMIDT: I think our goal through the fees would be certainly to help with the sustainability of database. Right now we -- we don't know enough yet about the revenues that are being collected by other states to know how much of our, based on the conversations that we've had, we think it will -- will help, may not, you know, be sufficient to maintain the database from year to year so we would need to -- we will need to deal with that issue going forward.

JEANNETTE DEJESUS: But all indications now from the conversations that we've had are that it is more than likely that it will be self-sustaining. And some have even indicated that (inaudible) not something that we would, you know, be interested in, but certainly the issue of sustainability is something that we care about.

REP. CARTER: Thank you very much for your testimony. Thank you, Madame Chair.

REP. RITTER: Thank you.

Representative Srinivasan.

REP. SRINIVASAN: Thank you, Madame Chair. Thank you

for your testimony. A couple of questions that I have for you, I do agree that this is going to give us data on the costs, utilization patterns, and health care measures. I definitely agree with all of that. One of the things you talked about and also gave us this testimony is quality. And could you just enlarge how this data collection is going to have an impact as far of quality of services. I'm assuming that's what you mean by quality as to what, you know, how that will be accomplished, because obviously that is -- that is extremely important when you collect this and how are we going to use it in a meaningful way so that we have the best or better outcomes.

LAURIE GRAHAM: I did not announce myself earlier. I'm Laurie Graham from the Office of Health Reform. I'd like to address that question because I've -- I've used health care claims before for research questions, and I do know that answering quality questions with claims data has its limits. Utilization and expenditure data extracted from claims are really our bread and butter. Quality questions take much more of a nuanced approach, and I think invest -- researchers are really investigating those areas.

I think that the tool the APCD will -- will be is -- is being a tool for creating health plan report cards and provider performance report cards even -- if we have that level of data. There -- they provide sort of an overview of utilization and expenditures that allow policy makers and even providers or employer groups to decide what next steps to take maybe in their course of care for that type of patient, or -- or maybe in designing on what health plan benefits their employees the most.

Part of the APCD benefit to other states has been using the data to investigate ACOs and evaluate

their performance and some other care models that are patient-centered or otherwise. And like I said in the beginning, it's kind of a nuanced approach to the claims. We certainly aren't judging clearly with the claim data what kind of quality was delivered in the encounter, but you can begin to dig down into that information on the aggregate level to see how patients with a specific diagnosis are being treated across the state.

And that's one area that, of course, we can't do right now. Right now in -- in the Department of Public Health, you can collect information on how many children have been immunized, but you -- you can't really track that across all -- all payers necessarily in the way that we want to with the children who have been diagnosed with other illnesses. So, anyway, it's a more complicated question and I appreciate it.

Coming from a provider, I know that you are familiar with what it means to have an encounter with a patient and -- and to improve your own quality of care. And so I'm hopeful that the aggregation of this type will sort of allow us to start moving in steps towards creating almost a standard of care that we can closer adhere to.

REP. SRINIVASAN: Thank you very much for that very honest answer, because you definitely did make it clear that quality is going to be a very difficult component of this to accomplish, and -- and critique and -- and, you know, make plans, and I appreciate that very much.

JEANNETTE DEJESUS: If I might add, however, we will -- it -- it has -- it shows tremendous amount of promise for payment reform mechanisms and measurement and knowing -- enable us to know, you know, the volume, you know -- it will enable us to reimburse for value instead of volume. And so

within that area, we -- we believe that, you know, quality, you know, can be recognized, rewarded, and hopefully increase.

LAURIE GRAHAM: Representative, let me follow up on what I was saying. So the HEDIS quality measures were, you know, originally claims-based and PQRI and some of the other pay-for-performance models began out of a claims-based critique.

REP. SRINIVASAN: Thank you. Thank you. The other question I have is, you know, the data collection is extremely important, you know, that's the first step, very first step. And once we have -- but we all end up with all this collected data and then -- and then the analysis and the implementation is the second and the third step, very important because otherwise data collection just sits there that many reports which are there in volumes and volumes but no action taken.

What has been your experience with the other states that, for us it is, you know, we are in the infancy of this, but for other states that have already have this, what has been their experience in terms of using this information in a very effective way? Can you -- can give us some idea on that?

ROBERTA SCHMIDT: There -- there have been some states that have had APCDs for a while. New Hampshire, where the APCD Council is based, is one of the APCDs that's been around the longest, and they've done a lot of work. Again, we could provide you with their website and you could see the -- the kinds of studies that they've done and -- and have been published showing trends on -- on different health care issues statewide.

And -- and I think your point is -- is a really, really important one, which is we don't want this to become a -- an effort to collect data. We

want to make sure that part of this program and it's, you know, provided for in the law, it's -- it's up to us collectively to make sure that it occurs, that this really becomes not a collection vehicle, but a database program that will give us helpful and actionable information.

There's also, and -- and we can send this to you, we had Patrick Miller, the -- one of the chairs of the APCD Council came down and gave a wonderful presentation to the Health Care Cabinet here in Connecticut in December. And he prepared and presented a wonderful (inaudible) to us that included information on how states have used, including New Hampshire, APCDs. And again we'd -- we'd be happy to make that available to you as well.

JEANNETTE DEJESUS: May I add, please, that, you know, in the -- we -- we have never been in this situation in the context of how it's really quite different now with the passage of the Patient Protection and Affordable Care Act in 2010. States across the country are, you know, under a lot of pressure to adhere to federal requirements and regulations and --and the laws. We -- we see, for example, in the development of our Exchange, in order for it to be, you know, successful in this state, it will -- it will need information on which to base decisions.

And so we have other things in place and other pressures in the state that require the type of information that we don't have available now. And so I think that that reality, which is very different from where we've been in the past, will, you know, will -- will ensure that this is actionable data. And certainly our office is not interested in an initiative that compiles information that is not going to be very useful to policy makers and to delivery system providers.

REP. SRINIVASAN: Thank you very much. Now one more question, the -- the most important factor here, of course, is the fiscal note that's going to be attached to this. And I know you did say that this is going to be self-sustained and that and the other and I couldn't get that, who would be, you know, to run this program, to collect this information, analyze this and all of that, obviously comes with a cost. And who, I know you did allude to this earlier, but I just want clarification for myself as to who is going to be the person who's going to be funding this and what is going to be the revenue stream?

JEANNETTE DEJESUS: Money, money, money, money. This has -- has been a long process and it continues to be a process. And so let me tell you a little bit about what we're doing about money and how we're thinking about it now. First, we've already engaged in almost a year-long process of -- you know, and has costs related to getting us to this point. We are in this next phase going to be hiring a couple of folks that will help us to determine what this will cost in the next year -- next two years.

That report, that budget, will be made available to the Exchange. The Exchange will include that in our application to the federal government for extension of, I believe, Level One funding. There is precedent for this. New York State, I believe, has just done this. So we anticipate that the start up and initial implementation of the Exchange, excuse me, of the -- of the APCD, will be funded hopefully through monies from the Level One grant from the federal government.

Other states have indicated that the cost that they've attached to their data does generated income, and we believe that that's a model that we will, you know, explore and develop and -- and

hope to use. Certainly hospital association has provided testimony in support of this. They are one of the more experienced entities that collects data and, you know, has a fee attached to it, and my understanding is that that works pretty well.

And so we anticipate that it will need help initially in getting started. And then there are multiple mechanisms that can be used that are not, you know, state funding that -- that will be explored. And that is the type of planning that we'll engage in in the next year. The Legislation before you allows us to establish an APCD in the state and to engage in the conversation, development, and implementation of the initial phases of it. But there are lots of decisions that need to be made, and -- and that is one of them. And I'll ask my colleagues if they have anything to add to that?

ROBERTA SCHMIDT: Just to add briefly as to what Jeannette mentioned, the start-up expenses for the Exchange we believe we will be able to get through the grant, the subsequent grants that are submitted for the Exchange because this is such an important need of the Exchange.

And then as Jeannette mentioned, we're going to be looking more carefully at what we can expect in terms of revenues from fees along with -- other states have funded these in part through other grants and part through -- some of them have established different kinds of more broad-based assessment. So we're -- we're going to be looking at -- at those issues with -- with the help of a consultant who's been involved in the start up of quite a few of these.

REP. RITTER: Are there any other questions?

Yes, Senator Welch.

SENATOR WELCH: Thank you, Madame Chair. I do have a few questions, and I guess, first, let's look at this from the individual's perspective. I think that there are a number of people who embrace aggregating their medical information for whatever reason, portability, whatnot. And then there's some that -- that this just strikes great fear.

And -- and if I've heard your testimony correctly, it sounds like that -- that at some in time should this go forward, there will be a database that will have my Social Security number and everything that's ever been done to my body at one of these providers or being paid for by a provider, will be within that database, medically speaking? Is that -- is that correct just so I -

JEANNETTE DEJESUS: I don't know that anything that's ever been done to your body will be there, but for argument sake, yes, let's say there will be a record of that. That's what we hope.

SENATOR WELCH: Will an individual then have the option to opt out of having his or her information transmitted via a provider to this database?

JEANNETTE DEJESUS: My -- my understanding is that there is not a opt out/opt in option here. I'll yield to my colleagues to answer -- to confirm that or not. But I -- I want to emphasize to you that by the time I get -- I get the -- your information, I won't know that it's you.

SENATOR WELCH: So it's -- will one be able to opt out?

ROBERTA SCHMIDT: We're not aware of any states that have had an opt-out option. I do want to mention

one thing just to mention more specifically what -- what this -- what this is. There are also, you may be aware, there's something called, in Connecticut HITE-CT, which is a health information exchange. And what -- what goes into HITE-CT are actual medical records with, you know, extensive detail about your care, those come directly from the providers.

And this again just to make sure that -- that everybody understands, this is a database with claim data which does have information related to your -- your health care, so it has diagnosis codes, but it doesn't have the kind of extensive clinical information that's in a -- a health information exchange. As I mentioned, we're -- we're not aware in any state that there have been given the opt-out opportunities, but -- but also again we've -- we've been talking to states.

And as we -- as we've mentioned, there are very, very good ways to protect the data that comes into these databases. And to our knowledge, there haven't been any breaches, but -- but again, it's -- it's a very important concern of ours to make sure that we address that very carefully.

JEANNETTE DEJESUS: Just to clarify (inaudible) I think that's a very good point. So we might know that you had surgery to your hand because a claim was paid for that, was made for that. But we wouldn't know what is in your medical record about what your stay in the hospital was and those sorts of things. That would be in a separate record, and that's HITE.

SENATOR WELCH: Well, and -- and I do understand that. But I also understand that those codes can get pretty specific as to the types of procedures and the types of things that were used in the procedure. And it's, you know, maybe not for a

layman like myself, but for other people, it's probably pretty easy to reverse engineer and figure out what was going on.

JEANNETTE DEJESUS: I think that's probably the case. And just to add that for substance abuse, mental health, and HIV, that there are additional laws and regulations governing that type of data. And so that type of data might, you know, that would -- we would take that under separate consideration about how we get it, how we would handle it, that sort of thing, and follow, obviously, all the state and federal rules about the special handling of that kind of data.

SENATOR WELCH: And so if I may continue then and kind of I guess shift to the provider's perspective, it sounds like they -- they will be providing information as to actual costs, they will be providing information as to whatever negotiated costs they might have with another provider like a health care insurer, hospital. And you're going to grab all of that it sounds like?

ROBERTA SCHMIDT: Just to clarify, we're -- we're actually going to be not collecting information from the providers. All of the information that we get will be on the claim. What is on the claim is when it -- when it comes in, is there is information about the charge and what was paid. And we -- we appreciate that there is a concern about -- and it's been addressed in somewhat different ways in different states about actually disclosing the level of discounts that providers have -- have done.

And states -- states have -- have been concerned about that issue as well and -- and have -- have addressed it. For example, in New Hampshire, they don't -- they only disclose on their consumer portal what was actually paid for a service and not what was charged so that you

can't look at the level of discount.

SENATOR WELCH: And so then what's our intent with respect to that?

ROBERTA SCHMIDT: You know, we -- we are -- that's one of the issues that we're going to be considering. We have not had a chance to look at that in -- in depth as yet.

SENATOR WELCH: So if -- if this bill moves forward, that's an unanswered question that will be left up to this body to decide one way or the other how they're going to great that information?

ROBERTA SCHMIDT: There are many unanswered questions, you know, if this goes through. And we -- we intend it to -- to be that way. We have a multi-payer group that is comprised of -- of agency leadership, of the payers in the state, of leadership from the hospital association. And we've been in a process with them for the last year, which has resulted in -- in this piece of legislation. And if this were to go through, we would continue that process and take on the next set of significant questions and -- and seek, you know, to probably be back here again for those -- for those issues.

SENATOR WELCH: So I -- I guess I was a little confused at the outset. The -- your information is only going to come from the payers, from the insurance companies?

ROBERTA SCHMIDT: That's correct.

SENATOR WELCH: Okay. And then so what if I am self-insured as an individual?

ROBERTA SCHMIDT: Excuse me, it will come from -- the Legislation would authorize us to get information from the insurers and so from TPAs, the self-

funded plans. So it would allow us to get self-funded data as well.

SENATOR WELCH: And what if I am neither? I mean, what if I am uninsured as it were?

ROBERTA SCHMIDT: If -- if you are uninsured, we -- uninsured is a more difficult issue to address. And in at least one state, there's been a large hospital system that has worked with the APCD to set up a -- it's kind of a -- sort of a dummy claim system so it allows the -- the collection of information on the uninsured population so that that -- that can be considered as well. It's something that we talked about doing, and I think that we really should focus on as we go forward. Again it's not -- it's not an easy thing to do.

SENATOR WELCH: Just a few more, so I -- I think I heard you say that the first institutional organization that you expect to utilize the information is the Exchange itself. Can you tell me how you envision the Exchange using this information?

ROBERTA SCHMIDT: Yeah, they -- they, at the Exchange, we believe will use it in a variety of ways. One is for rate review purposes. They are required to do health plan reports. We expect that they'll use it in connection with that. Going forward under the ACA, there's going to -- states are going to have to establish a risk adjustment mechanism in the state to really try to balance the burden on health plans that are -- have people with more intensive medical problems and those that -- that don't.

That takes a lot of work to do that in a -- in a fair and meaningful way. And we would expect that the data in the APCD would be used to inform the creation of that process and actually the

administration of that process. So we -- we expect it will be used in a variety of ways by the Exchange.

SENATOR WELCH: And -- and I guess just if I could chase one thread that you left in your testimony. You said that we -- this information will help you reimburse for value instead of volume, and I'm not quite sure what you meant by we and reimburse and value, if you could just help me understand that.

JEANNETTE DEJESUS: I'll ask my colleague, Laurie, to help me in responding. I -- I used payment reform as an example of how this all-payer claims database might be useful with regard to rewarding for health outcomes within medical home situations instead of, you know, fee-for-service and volume. And Laurie can tell us more specifically about how this model was developed out of some of those considerations.

LAURIE GRAHAM: So I think if I could (inaudible) simply saying that value-driven health care is what consumers are looking for right now, and that's part of what health reform is aiming -- aspiring to deliver to the uninsured specifically so that they can be insured. And that there's an equal playing field for reaching quality -- quality care in their state, in their region, and even in their hospitals, using their insurance carrier, whoever it may be.

And like what I was saying earlier is that these claims data can be really used to evaluate value-driven programs that benefit plans have been designed around. Some of the accountable care organization models are looking at ways to create global payment reimbursement schedules to provide more value to patients as they are continued through a course of care with their -- their provider instead of just on a fee-for-service

basis every time they see their doctor or maybe a different specialist.

But it's -- it's kind of a complicated process, and I don't want to make it more complicated than it is. But essentially ACOs provide a performance model, are aimed at providing value in that delivery of care. And this isn't going to necessarily delivery of care itself, because this data, but the reports that are generated from this data can certainly inform how that hospital system sort of reimburses their providers or how a payer may decide to go forward with a different type of benefit plan.

ROBERTA SCHMIDT: Maybe if I could just follow up with a very specific example related to -- actually an initiative that we are -- embarked on and hopefully will be the recipient of a -- of a positive response in the near future. In the middle of January, the state along with the five large payers in Connecticut applied for a federal program called the Comprehensive Primary Care Initiative. And it's really focused on improving the level of primary care practice.

And what's it's doing is CMS wants to join with payers in selected markets to both infuse additional money into primary care practices to allow them to improve their IT infrastructure, to allow them to hire care coordinators, to really allow primary care providers to provide better coordinated care. But it's very clear that it's not just about -- it -- so -- and it's recognized that primary care providers can't, with the -- under the compensation decrease that they've been experiencing in recent years, that they -- that they can't do what they want to do.

But an important component of that initiative is that the primary care providers that participate in this are going to be held accountable for

improving their performance on certain quality metrics. And so the expectation is that the providers will be provided with data that they can use to evaluate their own performance and -- and improve it. And then the payers will use that in acting on certain incentives that will be given to their providers to improve their care.

So, for example, they said that their patients who have heart disease of a certain type, there were less admissions in a year. That might be a quality measure that they would be judged on. And it's really data that's used to evaluate that performance. And you could, if you didn't have an all-payer database, you could have each payer interacting separately with the providers that are in their network. If you have an all-payer database, you could use that as a vehicle to provide data to the providers across payers.

And, in fact, in its solicitation to us, CMS was asking whether we had multi-payer databases like all-payer databases that we could use to support this and actually said that if we did, that they might choose to actually join with us to provide the provider's data in an aggregated way. So that's just an example of how an APCD could be used to support a particular kind of payment improvement opportunity.

SENATOR WELCH: I appreciate that --

ROBERTA SCHMIDT: Sure.

SENATOR WELCH: -- one more question, Madame Chair.

Just to get this one out on the table, is this -- is this envisioned to be a vehicle through which other insurance companies or, for instance, a public option on the Exchange will have information to actually reduce or argue for lower reimbursement rates for certain procedures down the road? I mean is that -- do you understand

the question?

JEANNETTE DEJESUS: No, sorry.

SENATOR WELCH: Okay. So we're gathering all this information and we're going to have different rates for different procedures at different hospitals or whatever it might be, and it's going to be in the hands of -- of the Exchange or essentially it sounds like other people can access this information with certain qualifications.

I mean is this then information that's envisioned to be used to argue for lower reimbursement rates for certain procedures down the road? In other words, I see that health care company ABC paid XYZ at this hospital and I represent this insurance company over here, will I now be able to have access to that information to make the case that I should be paying less as well?

JEANNETTE DEJESUS: Well, insurance companies already have this information, and they use this information to make decisions all the time. I've always found it to be strange and unusual that I as a consumer can do comparisons about the vehicles that I purchase or the cereal that I purchase, but I have no idea what was paid out for the, you know, last time that I went to the dentist or the -- to the doctor or, you know, for -- and so this gives us the type of transparency that we need to make decisions, which is available in the market in almost every other way.

And I assume that some people might want to use the information to go to the least expensive doctor or hospital or whatever. But that's -- that's not something that I think we, you know, can control or even want to control. We want the transparency; we want the availability of data

support so we can make informed decisions. And, you know, that's the primary purpose of it.

SENATOR WELCH: Thank you. Thank you, Madame Chair.

REP. RITTER: Thank you, Senator Welch. Other questions?

Representative Perillo.

REP. PERILLO: Madame Chair, thank you. Just a few questions if I may. First of all, there is a provision in here as we've discussed for the state to give or sell this data to other -- I believe it's actually, the term is persons or -- or whatnot, is there any vision that there would be any sort of vetting process as to who could access this information? Not everybody is a good actor. So what's -- what's in store for that?

ROBERTA SCHMIDT: Typically what we've heard from other states is that they -- they -- they have data available in different ways. So again a state like New Hampshire will have an actual consumer portal where people can go in and get estimates as to their -- the cost of care at different hospitals. Then there are, as we understand it, in New Hampshire certain really basic data sets that are available to anyone, basic information. And I -- I don't know that they would -- would charge for something like that.

Then for researchers or others who really want to do more extensive research, there typically is an IRB kind of a process set up to really look at those research requests, make sure that they are sensible, reasonable, that people are requesting and getting only the data that they really need to do the research that they want to do.

And I believe that it's in connection with those

larger data requests that, generally speaking, that fees would be assessed. Again we're going to be looking into this more in detail, but that's -- that's the general way that it works from the conversations that we've had thus far.

REP. PERILLO: The reason why I ask, is I can almost, sort of, envision an entire industry popping up of clearinghouses who can back into data to actually identify us and allow potential employers, you name it, to access that information. So I'm just wondering whether or not we're going to make sure that it is indeed utilized for health care operations as HIPAA would refer to it.

ROBERTA SCHMIDT. Okay. Right. And as I mentioned, there -- there -- what -- what we're hearing is that there is an IRB kind of a process for more detailed research requests to again make sure that the data that's given is necessary and that it's protected and that -- that it's reasonable, and really a fair request.

REP. PERILLO: Second question, I understand there will be some sort of effort to de-identify information and Social Security numbers were thrown out, that immediately gets my back up because Social Security numbers are hardly de-identified and very easy to trace back, but I don't want to get into that detail. I would imagine, though, there's an effort to be able to link individual health data to some sort of common individual number -- call it what you want -- in order to follow the continuum of care. Is that correct? And you have mentioned standards of care. Is the thought process that we're then going to be moving towards clinical pathways and dictating to providers how they will provide care in sort of quote, unquote, cookbook medicine? Is -- is the goal of this to -- to generate that? There seems to be a capacity to do that and I

don't know what the end-game is.

ROBERTA SCHMIDT: You know, you use the term cookbook medicine, I don't think that that's -- that certainly isn't -- isn't our goal. I think our goal is to be able to provide information that's scientifically based that can be helpful to providers in -- in improving the care that they provide, you know, in the system as a whole. But -- but again we're -- we're not talking about cookbook medicine. But again, you know, I think that many providers really are pushing for and will welcome the kind of feedback that they can get from a database like this to help inform them and -- and take steps to improve the care that they're providing.

REP. PERILLO: I mean again the reason why I ask is because last year in one of the iterations of the health care -- many bills we had about the Exchange, there were quite a few as you recall, one item that was originally included in one of those bills, it was at the end of the day excluded, was the idea that standards of care would be generated and that there would actually be -- that would be linked to malpractice and a provider who worked within the standard of care regardless of the outcome, would actually be basically held harmless from potential malpractice suits. So it -- it's not crazy that I'd be thinking about this since it's something that actually has come forth as recently as last year.

JEANNETTE DEJESUS: I want to -- I want to assure you that my comments about standards, Representative Perillo, have to do with standards in patient confidentiality, security, and privacy. And that this database would take absolutely every precaution to ensure that we have the highest level of -- of those protections. And that we -- standards for those things are being developed

and tested across the country in these APCDs that are already established. And we benefit greatly from that.

And so my comments about standards were really about the protection of individual privacy and security of the data. With regard to your previous question about Social Security numbers which makes everyone nervous, myself included, so much so that when I purchased cable recently and I was asked for my Social Security number, I said I could live without cable. And then a week later, I said, okay, I'll give you my Social Security number and got it anyway.

So, you know, a right way of communicating that really all of this information and data that we're so concerned about is really out there. And I think that this provides us with a very controlled way where we can impose the type of protections and security that we believe are appropriate for individuals, always taken in balance with what we need in order to be responsible about how the decisions that we make with regard to policy and health, you know, delivery.

And so there are lots of advancements around de-identifying data, encrypting Social Security numbers. I'm not an expert in -- in data, but in working on this with my colleagues, you know, I've learned that if we were to have Social Security numbers, they would be encrypted, they would be kept in what I think of as a locked box which is separate from the identifier and only under, you know, highly prescribed extreme situation, you know, could we connect these identifiers with that.

We wouldn't really even need to do that, but we want to be very careful that the data that we collect is -- is reliable, and that it is

accurate, and that, you know, when people move or have name changes, that we don't lose information and therefore -- thereby, you know, 'we're using a database that is really no better than, you know, the information that we have now. And so I think we have to be very careful to balance our -- our legitimate need for protecting the -- protection and security of individual rights and also helping us to move forward in a way that allows us to take advantage of innovations and -- within the health care field.

REP. PERILLO: And I -- I surely understand the importance of being able to follow the continuum of care. One of the challenges in health care, as Dr. Srinivasan would say is we really don't ever get that data so you -- you know what you did and you don't necessarily link the outcome to the -- the care. But I am -- I am concerned that we have referred over and over again to using the data to determine the best way to treat patients, the most effective, efficient, whatever, and we can all support that.

What I'm concerned about is -- and I mean no disrespect to -- to those in the room, you ladies here, but I don't necessarily trust the State of Connecticut to -- to tell a doctor how to provide care. Crazy me, but I -- I would much rather a doctor be relying on clinical research rather than just numbers that have been extracted from health insurance company databases.

JEANNETTE DEJESUS: I just -- before my colleague actually gives you probably a much more enlightened response than I, I -- I want us to be careful about identifying this as, you know, the government having our information. The government already has our information, and there -- many companies have our information.

And I -- I believe actually that this is one of

the ways that we can actually ensure that data information is being used appropriate because of the level of transparency, because of the level of -- of protection that you can ensure this APCD has that we are interested in this APCD. So I -- I think that this is actually one of the ways that we can ensure that that happens.

LAURIE GRAHAM: Just to follow up on your question, I think you're probably referring to the quality benchmarking and performance benchmarking that I was referring to earlier. I certainly wasn't going as far as to say that us as a state office would be conducting those reports, although that could be possible too. There are number of uses for the data and I'd love to share with you that part of the efforts of this office in preparation for the APCD and its development, its design, its implementation, is to reach out to a number of stakeholders, the researchers I was mentioned who use the data to design their ACO or a payer who uses this information to design a new health plan or payment system to their providers.

We're reaching out to those stakeholders, we're reaching out to researchers, providers, payers, to generate use cases for the APCD and really understand how they will be using this data. And part of it is creating this sort of value-oriented approach. But it's certainly not the limit to what we are interested or it's -- it's not actually confined to -- to that purpose.

You know, at the very start or at the very ground level for the APCD, other states are using the APCD for the state employee report cards for the state employee health plan. They're using it for DPH activities that I was sort of alluding to earlier regarding immunizations and surveillance that they're currently doing.

But then on top of that, some of the reports that

they're seeking on specific types patients that perhaps have a prevalence of disease in this state. And then finally DSS would be looking at this information, as Commissioner Bremby said earlier, to really investigate the Medicaid program and compare it to some commercial programs if they can, or to really dig down deeper into the Medicaid program and how they are operating it and how they can improve it. But really it's a range of uses which aren't yet (inaudible) but they're definitely in our discussions for our process.

I accept your -- your input right now, because I think it's really valuable to -- to raise awareness on -- on that concern. Or that consumers, especially maybe -- or providers would especially be concerned that this would change the standard or care or -- or influence the standard of care. But certainly establishing the database is the first step to creating protocols to how it will -- how the data will be accurately used.

REP. PERILLO: Thanks. I -- I appreciate that. I don't know that it necessarily quells my concerns. I know that it will be used in a number of different ways. I know it's not linked or -- or intended to use -- use for one, I'm just saying that I'm not necessarily comfortable with all of the possibilities, but I appreciate the answers. Thank you.

REP. RITTER: Any more questions from the committee? I think that obviously judging from the interest in the committee, we definitely are seeking a lot more information about this. So I would encourage you to provide it around the privacy issues and the intended use, I think, clarity would be very helpful for the committee. And I understand that this is a short session and time is an issue. I fully understand that, but I

think we will be very willing to help you provide that to every committee meeting. And it might be that some of common themes that you heard here would be most appropriately addressed specifically in that. So I would ask for that.

JEANNETTE DEJESUS: Thank you. We would be very happy to -- to provide that. And I would like to offer this committee obviously access to my colleagues. Please feel free to call them. They will come to you, they will work around your schedule, and you should feel free to have conversations with them or with me with regard to your concerns and your interest in this. And we will make that a priority in our office. Thank you.

REP. RITTER: Thank you. And I suspect we may take you up on that.

Next we will be hearing from Olwen Gurry and to be followed by Debbie Prescott.

OLWEN GURRY: Good afternoon. My name is Olwen Gurry. I am a practicing registered nurse at Danbury Hospital. And I am the mother of two wonderful children and patient advocate. Can you hear me now?

REP. RITTER: If you could speak up just a bit, it would be helpful.

OLWEN GURRY: Okay. My name is Olwen. And I'm a registered nurse at Danbury Hospital. I'm the mother of two wonderful children, two healthy children, and I'm also a patient advocate. I was fortunate to become involved with Marie Hatcher and her wonderful son, Matthew, who's living testimony of the positive outcome to early intervention. I came today to urge you to support Senate Bill Number 56.

As mentioned earlier, congenital heart defects is

MATTHEW KATZ: I -- I can. If you want I can --

SENATOR GERRATANA: A little administrative problem. Hold on.

MATTHEW KATZ: That's okay.

SENATOR GERRATANA: You may -- you may testify. Thank you.

MATTHEW KATZ: Senator Gerratana, Representative Ritter, and members of the Public Health Committee, my name is Matthew Katz. I'm the executive vice-president and CEO of the Connecticut State Medical Society, and on behalf of our more than 8500 members and the Connecticut Chapters of the American College of Physicians and American College of Surgeons, thank you for the opportunity to testify.

I think 12 hours ago we heard testimony from Commission Bremby, as well as Advisor Jeannette DeJesus about the benefits of an all-payer claims database. We do not question those benefits. In fact, we support the development of a database or databases for educational and informational purposes for physicians, insurers, employers, policymakers, state government, as long as the data is valid, reliable, relevant, and transparent.

Unfortunately as currently written, however, the physicians of Connecticut must oppose House Bill 5038. This bill -- many things outlined in this bill are beneficial. However, there are very few safeguards. It fails to meet the accuracy, transparency, due process, external validation and oversight requirements to create -- to prevent unreasonable risk, patient confusion, deception, unjust and -- and disruptive patient-physician relationships. It also potentially provides unfair disparagement of qualified physician reputations as currently written.

H.B. 5038 should require to -- that physicians have full access to the underlying claims data, including an opportunity and process to correct any errors and submit additional information. Not a single physician to my

knowledge was part of the work groups and development process in this, but most of the data coming forward would be coming from physicians, and based upon the patient information based on that.

The other thing I want to identify is there was some inaccurate information about the data that would actually go in. Even though there are still CMS 1500 forms, the data that would be transmitted to this would be coming through the X12 Standard Data Transaction Sites, the 835s, the 837s, the 270, 271s. Information needs to be identified as to what claims -- what claim information is actually being submitted. Physicians and other providers need to be able to have accurate, important information. They need to be able to evaluate it. They need -- need to know what the methodologies in the underlying is. They need to make sure that there is full transparency in disclosure, not only the physicians, but the general public. There needs to be clear standards of statistical significance using confidence levels and sample size requirements.

Physicians need to have the right to review and correct any errors. Participation should be initially voluntary. If the data is used for purposes of quality and improvement, why are we asking patients and physicians to be -- to charge or having to actually have to pay for it? It's really an opportunity -- and I'll -- I'll finish -- for educational endeavor and approaching, looking at utilization. Why should we charge patients? Why should we charge consumers or physicians that are supposed to be making informed decisions?

So with that you have my written testimony. We do believe in and support the concept of an all-payer claims database, though we believe that there are problems associated with how this one is presently constructed.

SENATOR GERRATANA: Thank you, Matthew. I guess we don't have your testimony. Perhaps it could be submitted.

MATTHEW KATZ: I know a written -- it was -- the written testimony was submitted. I will make sure that you have it, but we have --

SENATOR GERRATANA: Thank you.

MATTHEW KATZ: -- eight points of corrective action that we think are necessary in order for physicians to --

SENATOR GERRATANA: Good, good.

MATTHEW KATZ: -- and we do want to work with the administration, with you, with Jeannette and with the Commissioner. However, we think that the way it's constructed is very problematic and troubling. We would suggest using the Wisconsin model as opposed to the Kansas model. No one -- no physician and patients are accessed in the Kansas model.

SENATOR GERRATANA: Right, right.

MATTHEW KATZ: But the Wisconsin model was fully implementable and usable, and has demonstrated some benefit.

SENATOR GERRATANA: Thank you, Matthew for that. We'll certainly look forward to seeing your written testimony, and also this, of course, comes from the Governor through (inaudible), so perhaps you should have a discussion with them, also.

MATTHEW KATZ: And we will, and I -- again, I -- I think that we are very much in support and there is a need for an all-payer claims database.

SENATOR GERRATANA: Okay.

MATTHEW KATZ: -- and repository warehousing system. I've had the fortune of developing one and advising on another national database. I can tell you that they're valuable for researchers as well as for the public on physicians, insurers, everyone, but they have to be constructed well. There have been a number of national law suits over

databases that were constructed poorly. We want to make sure that we start out on the right foot.

SENATOR GERRATANA: Absolutely. Thank you. Points well taken. Any questions? No. All right. Thank you very much. Let's see. We're going back to House Bill 5334.

Margaret Miner is here. She will testify.

MARGARET MINER: 8:00 is the witching hour. Might be time for one of those B12 shots that we were hearing about earlier. Is this on? Yes.

I'm Margaret Miner, executive director, Rivers Alliance of Connecticut. Good evening, chairmen.

I brought in and submitted written testimony on 5334. While I was sitting here, I also wrote by email and I hope I can just send it to the Committee, testimony on 275, the chemicals of special concern.

SENATOR GERRATANA: Sure.

MARGARET MINER: The -- the thrust of that bill aligns very well with advocacy we're doing on the pending general permit for pesticides to be applied in waters, aquatic pesticides and transparency.

Getting information out to the public is -- is essential to having good decisions and an educated public, so I'll email that off my little device here.

SENATOR GERRATANA: Thank you.

MARGARET MINER: On 5334, you have the testimony. It's the abandonment of a water supply source which needs to be done from time to time. It has implications for the conserved lands associated with that source. It also has implications for how you calculate stream flow, because it will -- there will be less total water available in the system, and that will affect the calculations of what stream flow releases should be in many cases.

SENATOR GERRATANA: Thank you.

MARGARET MINER: Okay.

SENATOR GERRATANA: Are there any other questions, or -- ? No.
Thank you for coming.

MARGARET MINER: Thank you very much.

SENATOR GERRATANA: Thank you for being so patient.

MARGARET MINER: It was very educational.

SENATOR GERRATANA: (Inaudible). Let's see. I don't see Sharon Langer here. Is there anyone left to testify? Okay. Who's that? Susan?

SUSAN ISRAEL: Hi. I'm Susan Israel. I'm a physician and I appreciate this opportunity to express my views on 5038.

I wish that it would not be enacted until regulations and technologies are in place that would assure patient privacy and control over their records. Unfortunately the public thinks that HIPAA protects them when, in fact, it basically says that hundreds of people can see their records without their consent as long as they sign privacy agreements.

Going back to 5038, it calls for information from enrollment and eligibility files besides insurance claims. So I don't know offhand how much that delves into peoples' private information, but it's a question that I would have.

Dr. Deborah Peel is the founder of the national organization, Patient Privacy Rights, that's trying to get patients control back of their data. And she has detailed the technologies that do exist that allow patients to control their data, and to even track it online. And I have that in detail in my submitted testimony.

Another problem, for example, is in HIE, too -- too, the Health Information Exchange that's now being established, is that they -- it defines the unauthorized release of data as a breach only if it is decided by the processors to be significant enough to even notify the patient. And I was wondering how 5038 defines a breach, and what recourse patients will have?

5038 uses, I believe, the federal regulations to finding what constitutes the de-identification of patient data, but they are just not adequate enough to stop the re-identification of the data. I guess people -- technology people are working on this issue, but currently -- and I think 5038 is following the current federal rules -- really are not comforting.

This same thing applies to the proposed UPIs which is the Unique Patient Identifiers, and really there's nothing to stop someone from finding the identity of a patient by cross-referencing all the databases that are available.

Dr. Peel continues to say that UPIs would become a defacto universal identification system, far more harmful than Social Security numbers, enabling millions of government and corporate workers to snoop into anyone's medical records. Claims that UPIs would be kept separate from personal and financial IDs are wishful thinking. All health records have financial records attached, making it easily to re-identify the data.

Thank you very much.

SENATOR GERRATANA: Thank you. Thank you very much for your testimony. Are there any questions? No. Thank you. We also have it online.

SUSAN ISRAEL: Good. Thanks.

SENATOR GERRATANA: Is there anyone left to testify? I guess not. Then in that case I will say that this Hearing is closed.

**JOINT
STANDING
COMMITTEE
HEARINGS**

**PUBLIC
HEALTH
PART 2
353 – 705**

2012



TESTIMONY
BEFORE THE
PUBLIC HEALTH COMMITTEE
LEGISLATIVE OFFICE BUILDING
MARCH 7, 2012

My name is Eric George and I am Associate Counsel for the Connecticut Business & Industry Association (CBIA). CBIA represents approximately 10,000 businesses throughout Connecticut and the vast majority of these are small companies employing less than 50 people.

While the federal government has passed health care reform and Connecticut has begun the process of establishing its federally-required health insurance exchange, more still needs to be done to lower costs and more needs to be done to improve the health of our citizens. Employers find health care costs rising faster than other input costs. Some providers are unable to generate sufficient patient revenue to cover costs. Some patients cannot get timely access to optimal care. And too many individuals remain without health insurance, engage in unhealthy behaviors and live in unhealthy environments.

For the business community, the issues of health care quality, cost and access are critical. After numerous years of double-digit and near-double-digit increases, health insurance has quickly become a product that many people and companies find they can no longer afford. In addition, the cost of health care directly affects businesses' ability to create new jobs.

Therefore, CBIA asks this committee to support **HB 5038, AN ACT IMPLEMENTING THE GOVERNOR'S BUDGET RECOMMENDATIONS CONCERNING AN ALL-PAYER CLAIMS DATABASE PROGRAM**. Healthcare-related data transparency is critical for consumers and physicians to make the best informed health-related decisions. It provides them with the tools they need to compare quality outcomes and cost implications.

HB 5038 advances the openness of healthcare data transparency, and we would be happy to work with the Committee on this initiative throughout the rest of the legislative process.

Again, please support **HB 5038** and thank you for the opportunity to offer CBIA's comments on this legislation. I look forward to working with you on this and other issues related to the reforming Connecticut's healthcare system.

The Connecticut Coalition of Taft-Hartley Health Funds, Inc

Making Quality Health Care Affordable

Testimony in Support of
H.B. 5038: An Act Implementing the Governor's Budget
Recommendations Concerning

An All Payer Claims Database Program

Public Health Committee

March 7, 2012

Senator Gerratana, Representative Ritter and Members of the Committee:

I am the Executive Director of the CT Coalition of Taft-Hartley Health Funds. We are a not for profit, voluntary organization of self-funded, labor and management jointly administered health plans providing benefits for approximately 50,000 Connecticut union members and their families

We are pleased to submit testimony in support of House Bill 5038 to create and implement an All Payer Claims Database Program (APCD) in Connecticut. This proposed legislation is long overdue and will allow health plan sponsors, such as our Coalition members, as well as state agencies, consumers, public health and policy researchers and all our citizens to better understand and evaluate how and where our precious health care dollars are spent. This information will provide policy makers, plan sponsors, payers, providers and consumers with the ability to understand best practices, make better health care decisions and to design and implement the most cost effective arrangements that enhance the quality of healthcare

All payer claims database programs are well established and functioning in a number of other states including our New England neighbors Massachusetts, Vermont, New Hampshire and Maine; and many other states are in various stages of exploration or development of their own programs. In fact, there is a national organization of government, private, non-profit and academic organizations focused on the development and deployment of state-based all payer claims databases called the All Payer Claims Database Council. Their website is www.apcdcouncil.org.

Page 1 of 2

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Member Health Funds

Bricklayers Local 1 CT

Connecticut Carpenters

Connecticut Pipe Trades

Electrical Workers Local 90

Heat & Frost Insulators &
 Allied Workers Local 33 CT

Iron Workers Local 15 & 424

NE Health Care Employees
 District 1199, SEIU

Operating Engineers
 Local 478

Painters & Allied Trades
 District Council 11

Plumbers & Steamfitters
 Local 131

Roofers Local 9

Roofers Local 12

Sheet Metal Workers
 Local 40



The Connecticut Coalition of Taft-Hartley Health Funds, Inc

Making Quality Health Care Affordable

We recognize that this initiative represents a major change for both payers and providers in Connecticut. But it is a change that is necessary and inevitable and where APCDs have been established, the added transparency has proven to be a significant benefit for employers and consumers alike— and does not pose a threat to the payer/provider relationship.

Two final but critical notes. First, I'm sure all Committee members are concerned about the security and confidentiality of health care data, protected health information. We share that concern, as do our members and most people in this era of near daily reports of unintended disclosures of confidential banking, credit card and protected health information. We believe that the necessary technology and security protocols do exist and that they should always be considered of the utmost priority. For that reason, we do not believe that the inclusion of social security numbers is necessary or critical to the success of an APCD and we urge that they not be included in the required data at this time

Second, since the potential for significant civil penalties exists for the failure to report required data, we believe there should be a specific exemption for reporting entities where their claims data is submitted by other reporting entities

Thank you for the opportunity to provide testimony and, again, we strongly support passage of H B. 5038

Respectfully Submitted,

Robert Tessier

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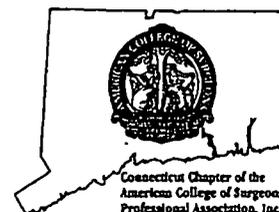
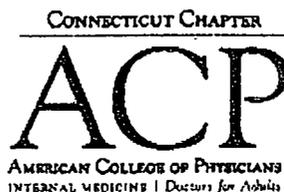
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 Local 131

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Roofers Local 12

Sheet Metal Workers
 Local 40





**Connecticut State Medical Society
Connecticut Chapter of the American College of Physicians
Connecticut Chapter of the American College of Surgeons
Testimony on House Bill 5038 an Act Implementing the Governor's Budget
Recommendations Concerning an All-Payer Claims Database Program.**

**Public Health Committee
March 7, 2012**

Senator Gerratana, Representative Ritter and members of the Public Health Committee on behalf of the more than 8,500 physicians and physicians in training of the Connecticut State Medical Society (CSMS) and the Connecticut Chapters of the American College of Surgeons and the American College of Physicians, thank you for the opportunity to present this testimony to you today on House Bill 5038 An Act Implementing the Governor's Budget Recommendations Concerning An All-Payer Claims Database Program.

In an effort to increase transparency in the health care system, lower the cost of health care, and study health care trends and population health, states such as Connecticut are mandating the creation of all payer claims databases (APCDs) APCDs typically include data derived from medical, pharmacy, and dental claims from private and public payers. Currently 14 states either have or are implementing an APCD APCDs are potentially valuable sources of data for policy-makers, physicians, patients, payers, and purchasers of health care if the claims data is accurate and reported in a usable format. CSMS strongly supports the development of APCDs as an educational and informational tool and resource for physicians, insurers, policy-makers and patients, if constructed in a way that provides valid, reliable and relevant data in a transparent manner. But as it is currently written, CSMS must oppose HB 5038, [BILL TITLE]

Aggregated, accurate health care claims data has the potential to provide useful information concerning health care service resource utilization That is because claims data contains information concerning: the specific services that patients receive; patient diagnoses, the payer who paid for the services, the health care professional who provided those services, the particular procedures performed, the treatments obtained, and the service setting, including the specific facility where the services were provided This data also has the potential to enable state policy-makers to help foster key improvements in the state's health care delivery and financing system by identifying where health care resource utilization varies in key populations, identifying trends in population health, identifying potential targets for public health interventions and by supporting the efforts of physicians and other health care providers to improve the health care services they provide by giving them access to this data

Aggregated, accurate health care claims data also allows researchers to identify health care claim trends and variations that warrant further analysis and investigation However there are limits to what this data can show State and national clinical registries provide valuable clinical and outcomes data Researchers should supplement health care claims data with this additional information as it becomes available, and in no event should claims data alone be used to reach conclusions which require consideration of outcomes and other clinical

information, such as determining the efficiency of specific treatments or the specific public health interventions to be undertaken

Accurate, comparative health care claims data support physicians' efforts to design targeted quality improvement initiatives and to compare their own performance with that of their peers

However, inaccurate health care claims data used for these purposes can be harmful, and an APCD that fails to meet the accuracy, transparency, due process and external validation and oversight requirements creates an unreasonable risk of patient confusion and deception, unjustified and injurious disruption of patient-physician relationships, and unfair disparagement of qualified physicians' reputations. HB 5038 should require APCDs to provide physicians with full access to the underlying claims data, including an opportunity and process to correct errors and to submit additional information for consideration

In addition, CSMS believes that it is imperative that the proposed All Payer Claims Database (APCD) in this state ensures all the following:

- (1) that physicians, physician organizations, providers, health care purchasers, and state policy-makers receive reliable, valid, meaningful, and accurate information when making important health care decisions,
- (2) that any programs that evaluate the performance of physicians use accurate, meaningful, and statistically valid measures, methodologies and data, and that those measures, methodologies, and data and any limitations associated with those measures, methodologies, and data are completely transparent and fully disclosed to physicians and the general public, and
- (3) that clear standards of statistical significance using confidence levels and sample size requirements be developed before any data is reported on by insurer, provider or provider group and that the sample size and confidence level reporting be at the quality measure level,
- (4) that physicians have the right to review, and correct any errors in, performance evaluations or the data upon which those evaluations are based,
- (5) that participation is voluntary and parties "may" deposit their data, as opposed to requiring it through the use of "shall"
- (6) that if the data is to be used for the purposes of quality improvement and consumer decision-making, that providers and consumers not be charged a fee to access information,
- (7) that a separate non-profit entity be formed to establish the APCD and that entity have no financial or other ties to existing for-profit health insurers,
- (8) that patient information is protected and safeguarded and that patients, employers, and health-care providers be protected by all necessary means, including deletion of patient identifiers

APCDs and Physician Profiling

Nearly every major health insurer sponsors a physician profiling program to drive pay-for-performance, tiered network, narrow network and/or public reporting systems. If these profiling programs are to be of any value in helping physicians improve their performance, each physician and physician group which has been profiled must also receive the detailed data upon which the profile score has been based, as well as appropriate benchmarking data against which the profile score can be compared. The reports health insurers currently provide to

physicians are often not helpful to physicians due to several limitations in the way insurers report the profiling data. Unfortunately, HB 5038 does not make significant progress in improving the utility and transparency of physician-profiling activities because it does not require health insurers that access the claims data to follow consistent standards for reporting physician data. CSMS believes that there should be mandated physician reporting standards, including guidelines for quality reporting, resource use reporting, transparency, and reconsideration requests. These would increase the uniformity and depth of data of insurers' and others reports and boost the value and utility of the data to physicians.

Measuring physicians' performance based on quality and cost efficiency is a relatively new, complex and rapidly evolving area. To ensure that consumers receive reliable, valid, meaningful and accurate information when making important health care decisions, it is critical that physician-profiling programs use accurate, meaningful, and statistically valid measures, methodologies and data.

Because those using physician-profiling programs may have a financial interest in steering patients away from high-quality physicians and toward physicians with lower costs of care or reducing the size of the physician network to limit access to care, the profit motive may affect rankings in such programs. This is a potential conflict of interest requiring disclosure, scrutiny and oversight. The independence, integrity and verifiable nature of the profiling process are paramount.

Physicians who practice as an organized group ("medical group") regularly employ inter-specialty cooperation and team-based care to coordinate medical services for patients. Therefore it is administratively infeasible to segregate individual physician performance from that of the group as a whole. It would be misleading to the public to provide such individual physician data. No physician-profiling program should publicly disclose, or otherwise use for any network or reimbursement purpose, the ranking of individual physician members of a medical group that is subjected to a physician-profiling system. All physicians in a group practice should receive the same ranking as that of the group as a whole, to be identified as such.

Profiling systems which fail to meet the accuracy, transparency, due process and external validation and oversight requirements established by this legislation create an unreasonable risk of patient confusion and deception, unjustified and injurious disruption of the patient-physician relationship, and unfair disparagement of qualified physicians' reputations.

Though CSMS strongly supports the concept of the development of a well-constructed and well-maintained APCD in Connecticut. We would urge the committee to look closely at APCD legislation in Wisconsin, which we believe has built in most of the necessary safeguards that would make Connecticut's proposed legislation stronger. However, presently CSMS cannot support HB 5038 as presented because it fails to provide the necessary patient and physician protections and certainties of uniformity of data collection, tabulation, storage, analysis and reporting that would be necessary for such data to be used to make informed decisions about the health and safety of patient medical care in Connecticut.



Quality is Our Bottom Line

Public Health Committee

Public Hearing

Wednesday, March 7, 2012

Connecticut Association of Health Plans

Testimony regarding

HB 5038 An Act Implementing the Governor's Budget Recommendations Concerning an All-Payer Claims Database Program

The Connecticut Association of Health Plans (CTAHP) appreciates the opportunity to offer testimony regarding HB 5038 An Act Implementing the Governor's Budget Recommendations Concerning an All-Payer Claims Database Program.

We would like to thank the Governor and the Office of Health Reform and Innovation for taking the initiative to establish an APCD in the state. As an industry we look forward to working with policymakers to create an APCD that enhances the opportunity for the State to improve its understanding of the health of the population and to identify opportunities to share health care data that improve the system as a whole

As an industry we recognize that the data generated to pay claims can be a rich source of information about what is working and, what is not working, within our health care system and we have appreciated the opportunity to work with the State thus far in developing a solid framework for APCD policy. Establishing a clear understanding of the APCD's goals at the outset is critical to its success and we share the State's desire to ensure that the data collected is meaningful and achievable. The Office of Health Reform and Innovation has been very open to our comments and we will continue to work with them as the legislation continues to be refined. We also, as always, are available to members of this Committee if you have questions.

Thank you for your consideration.



STATE OF CONNECTICUT

DEPARTMENT OF PUBLIC HEALTH

TESTIMONY PRESENTED BEFORE THE COMMITTEE ON PUBLIC HEALTH
March 7, 2012

Dr Jewel Mullen, M.D., M.P.H., M.P.A., Commissioner, Department of Public Health, 860-418-7029

House Bill 5038 - An Act Implementing the Governor's Budget Recommendations Concerning an All-Payer Claims Database Program

The Department of Public Health supports House Bill 5038.

The Department thanks the committee for choosing to take up the Governor's proposal to implement an All-Payer Claims Database (APCD) Program. An APCD is a large-scale database that systematically collects health care claims data from a variety of payer sources on claims from most health care providers. Data sources currently available to the Department, such as hospital, vital statistics, survey and public health data, are insufficient to inform and affect change in our health care delivery system. The area of greatest information deficiency is health care provided in settings outside of hospitals, particularly outpatient services. This has resulted in inadequate availability of information on provider populations, or sites such as physician offices; patients such as those with one or multiple chronic conditions, disease prevalence and incidence for patients treated in outpatient settings only; availability and distribution of outpatient services, and cost and payments for those services.

Below are a few examples of how availability of and access to an all-payer claims database would enhance the work we do at the Department of Public Health to improve the health status of Connecticut residents.

Access to the database will enable the **Office of Health Care Access (OHCA)** to carry out its statutory responsibilities, including

- To develop a complete picture of health care utilization patterns, availability of and access to health care services, and costs to aid decision-making and to assess the impact of health care policies on access, cost and quality
- To study outpatient services utilization patterns, to gauge the core health care needs of CT residents, to develop an inventory and evaluate the distribution of services in the state in order to identify unmet need for and/or gaps in services as a component of the Statewide Health Care Facilities and Services Plan
- To more effectively evaluate availability of and access to services in Certificate of Need applications to expand, terminate or implement new services, especially in outpatient settings, such as imaging centers, ambulatory surgery centers and mental health facilities
- To estimate the cost of care in all health care settings or an episode of care for specific conditions, e.g. diabetes, asthma, pregnancies etc
- To carry out cost benefit analyses for forgoing or delaying care for both the uninsured and the insured in Connecticut
- To identify areas of overutilization which do not improve the health status of CT residents

In addition to activities described above, the **Public Health Initiatives Branch (PHI)** would also utilize claims data

- To examine disparity in outpatient services utilization for specific conditions
- To determine if the recommended levels of routine care are being met by patients with specific conditions

The **Environmental & Occupational Health Assessment (EOHA) Program** would use the data

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- To assist in determining reporting completeness for reportable conditions such as carbon monoxide poisoning and occupational disease
- To develop a more complete picture of the true impact of environmentally-related conditions on the health of CT residents. For example, staff in the **Environmental Public Health Tracking (EPHT)** project, the core component of which is ongoing data collection and integration, would match health data (i.e., hospitalization, ED, outpatient and health care claims data) with environmental data (e.g., air quality and water contaminants) to track hazardous events, the extent of human exposure and the effects on the health of CT residents to propose effective and timely interventions and estimate associated costs
- To provide more complete data and improve development of educational messages on environmentally-related diseases

The **Crash Outcome Data Evaluation System (CODES) Project** links motor vehicle crash data with mortality, inpatient hospitalization and ED data to generate linked motor vehicle crash and injury outcome data to accurately determine the full impact of the effectiveness of highway safety and injury control initiatives directed at specific crash, vehicle, and person characteristics. Claims data would offset some of the limitations of the individual data sets to help generate population-based outcome information to better characterize crashes and associated costs. Linked crash and injury data will guide motor vehicle and pedestrian safety initiatives conducted by the Department of Public Health and its partners.

The **Injury Prevention Program (IPP)** uses patient data to support activities under the CDC Integrated Core Injury Prevention and Control Grant. Claims data provides data on patients in all health care settings which will facilitate fulfilling the goals of the grant: (1) to develop an injury surveillance system integrated with injury prevention and control, (2) to establish and maintain a State Injury Community Planning Group (ICPG) with representatives of injury related collaborations, organizations, and other partners to identify and prioritize state injury problems, and (3) to develop, implement and evaluate a state injury prevention and control plan that addresses unintentional injuries, traumatic brain injury, suicide and violence, describes the burden of injury in CT and includes strategies to reduce morbidity and mortality.

The **Connecticut Tumor Registry (CTR)** conducts follow-up on all cancer patients for vital status. The CTR uses data sources such as driver's license renewal date or hospital discharge date and discharge vital status to ascertain that a patient was alive at a certain date. An all-payer claims database extending to outpatient care and prescriptions would improve the completeness of follow-up by permitting the CTR to verify that a cancer patient was alive on the most recent date of medical care. The data will also aid in ascertaining that all cases are part of the Registry for completeness and quality assurance.

The **Birth Defects Registry** will compare diagnostic information in health insurance claims data and in-patient hospitalization discharge records to the CT Birth Defects Registry database to identify children with a birth defect diagnosis that are not part of the Birth Defects Registry. The information for these children will be added to the Birth Defects Registry to enhance case ascertainment and data quality assurance activities to improve the information in the Birth Defects Registry.

The **State Vital Records Office** will match claims data and in-patient hospitalization discharge records with death records to identify missing death records in the Vital Records Mortality database to improve the completeness of hospital reporting, mortality data and data quality assurance.

The **Office of Health Information Systems and Reporting** seeks to assess and improve the quality of Vital Records data, e.g., births for which Medicaid is the expected payer. Researchers in Arkansas linked 74% of their state's Medicaid claims for services related to pregnancy to birth records. The rest were not matched, either because the fetus died before delivery (16%), or because the Medicaid delivery could not be linked to a birth record (10%). Connecticut has been trying to quantify these two pools of potentially non-matched cases. An all-payer claims database would assist HCQSAR's quality improvement work related to births and other vital records.

The **Office of Emergency Medical Services (OEMS)** is mandated under P.A. 00-151 to report on emergency medical services (EMS) care that CT residents receive. OEMS utilizes hospital inpatient, ED and EMS patient care reports (EMS PCR) to obtain definitive diagnosis, principal problem and ultimate discharge status of the

patient in order to improve the EMS care received by Connecticut residents. Access to claims data will enhance the information OEMS utilizes to evaluate services.

The **Infectious Disease Program** (IPD) tracks reportable diseases such as varicella, hemolytic uremic syndrome, HIV/AIDS and TB by hospitals. IPD would use claims data to ensure completeness in reporting and/or identify unreported cases utilizing the relevant diagnoses codes.

Thank you for your consideration of the Department's views on this bill.

TESTIMONY PRESENTED TO THE PUBLIC HEALTH COMMITTEE

March 7, 2012

Jeannette B. DeJesús

Special Advisor to the Governor on Health Reform
Director, Office of Health Reform & InnovationTestimony Supporting House Bill No. 5038AN ACT IMPLEMENTING THE GOVERNOR'S BUDGET RECOMMENDATIONS
CONCERNING AN ALL-PAYER CLAIMS DATABASE PROGRAM

Senator Gerratana, Representative Rutter and distinguished members of the Public Health Committee, thank you for the opportunity to offer testimony on House Bill No. 5038, An Act Implementing the Governor's Budget Recommendations Concerning An All-Payer Claims Database Program.

I appreciate the opportunity to testify in support of the development of an All-payer Claims Database (APCD), a resource that is critical to the state's ability to transform its health care system and to improve the health outcomes of our citizens. Our health reform strategy seeks to improve the quality of healthcare; to reduce healthcare spending that continues to increase at rates that are unsustainable over the near and distant future; to make care more accessible, safe and patient-centered; and to significantly reduce health disparities. For these reasons and many more, we must have comprehensive information on disease incidence, treatment costs, and health outcomes. The absence of this information hinders our ability to inform and evaluate state health policies and to provide the transparency needed to ensure people have the information they need to make healthcare decisions. We want our state to join other states in the establishment of an All-payer Claims Database. While there have been various efforts to aggregate health care data in the past, data aggregation in the magnitude and scale of an APCD are unprecedented in Connecticut. For the first time, we have the inter-agency and community support, health reform leadership, and technical readiness to accomplish an initiative of this size and significance. The establishment of an APCD is a critical component of the state's health reform strategy and necessary to achieve its goals.

What is an APCD?

Every visit to a healthcare provider generates a claim for payment. Both public and private insurance plans routinely aggregate these claims into their own databases. APCDs combine data from all payers in a state. This gives policymakers statewide information on costs, quality, utilization patterns, and other healthcare measures. In the simplest of terms, an APCD will allow us to know—how care is delivered, where it is delivered, and how much it costs. Publically available data will give consumers and purchasers the tools they need to compare prices and quality as they make healthcare decisions. These databases include administrative data from medical insurance, dental and pharmacy claims, and information about enrollment and eligibility. These data are collected from public and private payers, ideally from insured and self-insured plans, as well as Medicare and Medicaid. The information typically includes patient demographics, diagnostic and procedure codes, and costs. This

information can be used by policy makers, state agencies, researchers and consumers to improve decision-making and healthcare delivery

Other States

Other states have made considerable progress toward establishing APCDs. The Office of Health Reform & Innovation is working directly with APCD leaders in other states to benefit from their experience in developing robust APCDs that will serve the needs of Connecticut citizens now and in the future. There are currently more than a dozen active efforts underway to establish APCDs with mandated reporting. Four New England states have existing APCDs, including New Hampshire, Vermont, Maine, and Massachusetts. In addition, New York and Rhode Island are currently implementing APCDs.

Already we have benefited greatly from the experience of these states in identifying best practices to streamline data submission. Efforts are being made to standardize common data elements that will improve the comparability of data from state to state. Standardization makes reporting easier for insurers and is critical if we are to join in multi-state collaborations in the future.

Fundamental Principles

The protection of personal privacy and the security of these data will be paramount as we design database architecture and the policies and procedures under which it will operate. Our need for information, no matter how great, must never compromise individual privacy. We will strictly adhere to federal and state confidentiality laws. It is critical that the APCD serve a broad range of functions including but not limited to health plan and provider performance report cards, public health surveillance, state utilization patterns and increased transparency to the consumer on cost and quality. It must be flexible enough to support changing needs and respond to technological opportunities that emerge over time. In addition to being secure, the system will be interoperable, flexible and scalable to fit with other HIT initiatives. Finally, we will incorporate analytics that result in actionable information that improves the delivery and affordability of healthcare in Connecticut.

While states differ in their approach to managing protected health information, the highest level of privacy and security can be achieved in a variety of ways. Several states have recommended that we include social security numbers because they promote greater accuracy and access. Important decisions about the management of protected health information will be considered and made in consultation with the workgroup and subject to public rule making. Through that process, we will determine the best way to make the database as powerful as possible while ensuring that personal data is strictly protected.

Health Insurance Exchange

The APCD will provide needed information to the new Health Insurance Exchange that will begin operations in January 2014. The target date for the first release of data from the APCD is set to coincide with the start-up of the Exchange. It is critical that the legislation be enacted this session if

we are to meet the needs of the Exchange and to successfully achieve other aspects of Connecticut's comprehensive health reform strategy.

Health reform provides an unprecedented opportunity to make lasting and effective policy decisions. An All-payer Claims Database will give us comparable, transparent information that has historically been unavailable in making policy and market decisions. We can change that by passing this legislation and moving quickly to implement an APCD in Connecticut.

I thank you and I respectfully urge the Committee to pass this bill.



Testimony before the Public Health Committee

Commissioner Roderick L. Bremby

March 7, 2012

Good morning, Senator Gerratana, Representative Ritter and distinguished members of the Public Health Committee. My name is Roderick Bremby and I am Commissioner of the Department of Social Services (DSS).

**H.B. No. 5038 AN ACT IMPLEMENTING THE GOVERNOR'S BUDGET
RECOMMENDATIONS CONCERNING AN ALL-PAYER CLAIMS DATABASE
PROGRAM**

The All Payer Claims Databases (APCD) is a data warehouse that tracks health care utilization and cost information. It combines claims information across insurance carriers and other payers so that more complete health care utilization and cost information is available. Having access to timely and accurate data across payers will be an important tool in our efforts to improve quality, reduce costs, and promote transparency. Based on the experience of other states, we believe the APCD will be a valuable resource in gaining a better understanding of the state's various health care delivery systems as well as the growing needs of Connecticut residents. The proposed bill appropriately places the highest importance on the protection of personal privacy and the security of these data in the database design and the policies and procedures that will govern data usage.

We are excited about this opportunity and look forward to continued participation in the development of this concept. We will also work with the Office of Health Care Reform and Innovation to assure that the disclosure of protected health information is consistent with state and federal confidentiality laws.

Thank you for the opportunity to testify. I would be happy to answer questions you have.

CONNECTICUT
VOICES
 FOR CHILDREN

Independent research and advocacy to explore the lives of Connecticut's children

Testimony Supporting

H.B. 5038: An Act Implementing the Governor's Budget Recommendations concerning an All-Payer Claims Database Program

Sharon D. Langer

Public Health Committee

March 7, 2012

Senator Senator Gerratana, Representative Ritter and Members of the Committee

I am a Senior Policy Fellow with Connecticut Voices for Children, a research-based public education and advocacy organization that works statewide to promote the well-being of Connecticut's children, youth, and families

On behalf of Connecticut Voices, I am here to testify in support of House Bill 5038 which would implement an All-Payer Claims Database Program (APCDP). This proposal offers an important opportunity for the state to collect from all payers of health care in Connecticut data that will allow stakeholders, including state agencies, the Health Insurance Exchange, insurers and consumers to understand the financing of insurance coverage and where those public and private dollars are being spent in the entire health care system. Armed with this data, the state will be in a better position to improve access and quality of care, as well as create incentives to drive down costs and improve overall health of the entire population of the state.

Connecticut Voices for Children brings a unique perspective in support of this endeavor. Since 1995, the Connecticut General Assembly has appropriated funds for independent performance monitoring in the HUSKY Program as a means of ensuring that tax dollars are spent wisely. Through this monitoring, Connecticut can track enrollment trends and the health care that children and families actually receive, including well-child care, dental care, emergency care, prenatal care, and other services.¹ The State contracts with the Hartford Foundation for Public Giving and in turn the Foundation funds the project via a grant to Connecticut Voices for Children. For the past 16 years, Mary Alice Lee, Ph.D., has directed the monitoring project, first at the Children's Health Council, and now at Connecticut Voices. In order for Dr. Lee to conduct the monitoring, Connecticut Voices for Children has had access to enrollment and claims data for the HUSKY program (Medicaid and more recently the Children's Health Insurance Program)

Connecticut Voices has been able to accomplish the analysis and monitoring of this dataset of individual health-related encounter and enrollment information in full compliance with all state and federal privacy laws and regulations and any restrictions related to the use of Medicaid data. At the same time, we have been able to produce reports that shine a light on, for example, whether and to what extent children are receiving preventive care, regular check-ups and any needed treatment. We have been able to monitor access to and utilization of oral health care services, the extent to which pregnant women are using tobacco, and the systemic challenges of providing coverage to different age groups, such as babies and older youth. Moreover, our reports provide data broken out by age, gender, race and ethnicity, and geographical area, so that special factors that may be related to these demographic characteristics can be understood and addressed.

Furthermore, Dr. Lee has been able to link birth data (housed at the state Department of Public Health) with Medicaid data (under the purview of the Department of Social Services) in order to

report on births to mothers in Medicaid and HUSKY. This linked dataset provides the only reliable method of determining which mothers and newborns received care funded by the State of Connecticut. It is the only source of information on maternal health and births to mothers with publicly funded coverage by age, race or ethnicity, and other factors that can affect or contribute to birth outcomes.² This kind of linkage and analysis of discrete datasets on a larger scale would be made possible by the creation of an all-payer claims data base. It would yield critically important statewide and population-wide information that is now unavailable for the state's non-Medicaid health care system.

In sum, we at Connecticut Voices wholeheartedly endorse the creation of an all-payer claims data base in compliance with relevant state and federal privacy protections. We fully support the goals of the APCDP Workgroup to use the data collected to improve health outcomes of all Connecticut residents, improve the understanding of health care expenditures in the private and public sectors, and increase efficiency in the delivery of health care in the state. We believe that a system can be designed that protects the privacy of patients and allows the public and policymakers to understand where our health care dollars are being spent, on what services those health care dollars are spent, and how to improve access to and the quality of health care for all our residents.

Thank you for this opportunity to testify in support of HB 5038. Please do not hesitate to contact me if you need further information.

¹ See for example, Lee, Mary Alice, Connecticut Voices for Children *Children's Dental Services in the HUSKY Program: Program Improvements Led to Increased Utilization in 2009 and 2010* (Dec. 2011); *Births to Mothers with HUSKY Program and Medicaid Coverage, 2009* (Dec. 2011), *Trends in New Enrollment in the HUSKY Program* (Dec. 2011) available at www.ctkidslink.org/pub_issue_12.html

² See, for example, Lee, Mary Alice, Connecticut Voices for Children *Births to Mothers with HUSKY Program and Medicaid Coverage, 2009* (Dec. 2011), *Births to Mothers with HUSKY Program and Medicaid Coverage, 2008* (Dec. 2011), available at www.ctkidslink.org/pub_issue_12.html.



**TESTIMONY OF
CONNECTICUT HOSPITAL ASSOCIATION
SUBMITTED TO THE
PUBLIC HEALTH COMMITTEE
Wednesday, March 7, 2012**

**HB 5038, An Act Implementing The Governor's Budget Recommendations
Concerning An All-Payer Claims Database Program**

The Connecticut Hospital Association (CHA) appreciates the opportunity to submit testimony concerning **HB 5038, An Act Implementing The Governor's Budget Recommendations Concerning An All-Payer Claims Database Program**. CHA supports the bill.

HB 5038 would establish a program to incorporate an all-payer claims database (APCD) as part of routine health data collection and reporting in Connecticut. CHA applauds this effort as a needed step in modernizing how healthcare resources are deployed in Connecticut.

Affordable healthcare and access to all levels of the care continuum, including for our most vulnerable populations, rests on our collective ability to bend the cost curve. The options left if we are not able to make adjustments are unacceptable. An APCD, if used effectively, can hold the key to bending the cost curve.

The concept is simple: gather all of the payment data available relating to healthcare in Connecticut to find out if healthcare resources are being effectively and fairly deployed. Developing this program is unquestionably a huge step forward in Connecticut's ability to address cost effectiveness in the healthcare delivery system. Unfortunately, implementation of a program of this scale is not simple. Other states, including Massachusetts, have struggled with the enormous and often overwhelming costs associated with hiring consultants and employees with the necessary expertise to analyze APCD information. Connecticut must learn from the experiences of other states, and create a more workable and useful APCD program that can provide valuable feedback to adjust healthcare resources without relying solely on state agency efforts and resources.

To accomplish this, analysis of the data needs to occur as soon as reasonably possible, and must allow for immediate public and private expertise to be brought to bear, while simultaneously ensuring that the data involved are protected through privacy and security measures.

The bill as drafted allows various stakeholders access to collected claims data, which will be necessary to achieve success. But much work will still need to be done to ensure that those stakeholders are able to use all available resources at their command to ensure that the APCD program improves care and cuts costs. CHA and its member hospitals possess considerable expertise in many key areas of healthcare data analysis that would be helpful to the program. We stand ready to help ensure that the program is successful.

CHA looks forward to working with the Office of Health Reform and Innovation, the special advisor to the Governor on healthcare reform, and the claims database administrator, once he or she is appointed, on this critical initiative.

Thank you for your support of HB 5038.

For additional information, contact CHA Government Relations at (203) 294-7310.

Bonhomme, Penny

From: Susan Israel [susie96@optonline net]
Sent: Wednesday, March 07, 2012 7 50 AM
To: PHC Testimony
Subject: Governor's Bill 5038

Public Testimony to the Committee on Public Health on Governor's Bill No. 5038, March 7, 2012

I appreciate this opportunity to express my views on 5038 I would wish that it not be enacted until regulations and technologies are put in place that would assure patient privacy and control over their medical records.

This may sound extreme, but as I see it, Bill 5038 and others like it, providing for large data bases, are functioning as global search warrants, seizing our medical records without our consent with the assumption that privacy will be maintained. Unfortunately, the public thinks that HIPAA protects them, when in fact, it basically says that hundreds of people can see their records without their consent, as long as they sign privacy agreements. Current governments have the best of intentions for patient care, but we need to make sure that 5038 does not provide a mechanism that would enable future governments and private companies to misuse the data against us, without us even knowing about it.

Dr. Deborah Peel, the founder of the national organization Patient Privacy Rights, said recently (1/ 23/12) in the *Wall Street Journal*, that we need to "implement existing technologies to allow patients to set default rules to govern data exchanges electronically... Consent rules can be changed instantly online, and sensitive information can be selectively withheld at the patient's discretion... Decentralized systems with smaller data sets protect privacy because if any account is broken into, only some information is compromised." And technologies should be implemented to enable patients themselves to track who sees their records.

I will give you some examples of the problems. The HITE-CT (Health Information Exchange) that is now being established defines the unauthorized release of data as a breach, only if it is decided by the processors to be *significant* enough to even notify to the patient. In 5038, how will patients know who will have access to their records, and whether it is the federal government or the private companies that they can sue if there is a breach?

To be more specific, the federal regulations, defining what constitutes the de-identification of patient data, are just not adequate enough to stop the re-identification of the data. The same is true with the proposed use of UPIs, unique patient identifiers, in 5038. There is nothing to stop someone from finding the identity of the patient by cross referencing all the data bases available.

To further quote Dr. Peel, "UPIs would encourage the government and corporations to build massive, centralized databases of health information, rich targets for data theft and abuse. UPIs would become a de facto universal identification system far more harmful than Social Security numbers, enabling millions of government and corporate workers to snoop into

3/7/2012

anyone's medical records," ... Claims that UPIs will be kept separate from personal and financial IDs are wishful thinking. All health records have financial records attached," making it easy to re-identify data.

Thank you very much for this opportunity.

Susan Israel, MD

3/7/2012



Office of the
Healthcare
Advocate
STATE OF CONNECTICUT

**Testimony of Victoria Veltri
Healthcare Advocate & General Counsel
Before the Public Health Committee
In support of HB 5038
March 7, 2012**

Good afternoon, Representative Ritter, Senator Gerratana, Senator Welch, Representative Perillo, and members of the Public Health Committee. For the record, I am Vicki Veltri, the State Healthcare Advocate with the Office Healthcare Advocate ("OHA"). OHA is an independent state agency with a three-fold mission: assuring managed care consumers have access to medically necessary healthcare; educating consumers about their rights and responsibilities under health insurance plans; and, informing you of problems consumers are facing in accessing care and proposing solutions to those problems.

Governor's Bill 5038 concerning an All-Payer Claims Database (APCD) represents an important step in Connecticut's comprehensive health reform efforts. This effort will collect claims data from health insurance payers, public and private, into a single, integrated system, enabling stakeholders to gain unprecedented perspective into trends related to healthcare utilization, delivery, quality and more.

The proposed database will collect medical, pharmacy and dental eligibility and claims data that includes charges and payments, treating provider, clinical diagnosis and procedure codes, as well as patient demographics, into a single, unified database that will be accessible to all interested parties. The APCD will enhance the stakeholder's ability to promote healthier outcomes, improve access to services and reduce systemic costs by drastically improving the transparency of healthcare systems and delivery. This access makes possible vigorous data synthesis and analytics that will facilitate examination of important research and policy questions by and for consumers and advocates, MCOs, providers and state entities. Stakeholders can gain valuable insights into critical system components, such as identifying utilization rates across plans, demographics, diagnosis and cost basis with a degree of ease and precision that has never before been possible. For example, if emergency room utilization by Medicaid enrollees is higher than for those with commercial coverage, what are the drivers? Are there geographic barriers for certain services and, if so, which services and why? Do our residents have access to needed

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preventive services? Are our residents taking charge of their healthcare through the management of their chronic conditions? Answers to questions like these will assist policymakers to develop targeted system improvements and implementation, from insurance and public program benefit design to public health initiatives, designed to eliminate or mitigate these deficiencies.

Indeed, the benefits of this model has been demonstrated repeatedly on multiple occasions by studies performed by Connecticut Voice for Children from the collection of claims data from Medicaid over time. In one example, claim data from the Department of Social Services concerning utilization of HUSKY dental services was examined following the implementation of systemic changes. Analysis of the efficacy, efficiency and quality of outcomes was not readily discernible through traditional models, but the macroscopic examination of the claims data illustrated significant trends indicating that the program's goals were being met. The Comptroller's office also analyzes claims data for state employees and retirees in an effort to continually improve healthcare delivery and contain costs.

Lessons learned from other states that have implemented successful APCDs, as many of our neighbors have, demonstrate the beneficial policy implications that have derived from this tool. New Hampshire's experience includes the identification of key differences in premiums, cost per diagnosis, rates of reimbursement across carriers and facilities, geographic and demographic prevalence of specific diagnosis, and comparisons of ED utilization by carrier and diagnosis. The APCD will permit users to identify important healthcare trends in Connecticut at a level of precision that will enable narrowly focused adjustments to healthcare delivery and payment models.

One area of persistent concern involved in the implementation of the APCD considers patient privacy and the security of the data collected. However, to mask the identity of patients and ensure privacy, the APCD's architecture will encrypt, aggregate and suppress patient identifiers, as well as apply vigorous security protocols consistent with national guidelines developed by the APCD Council and the National Association of Health Data Organizations. Indeed, at least nine states have already implemented APCDs, with several more in the implementation phase, and the literature identifies no data breach. OHA will be part of a working group that will ensure that regulations implementing the APCD safeguard the privacy of individual patients. Prior to implementation of an APCD, OHA will demand testing of all potential uses to guarantee protection of protected health information and patient privacy.

We should not delay the authority to establish an APCD in Connecticut. It is an important next step in our health reform efforts. HB 5038 represents a bold step into the future of healthcare and allows us to harness our technological capabilities, creative innovation and belief in social justice for the personal, financial and equitable benefit of all of Connecticut's citizens.

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Thank you for providing me the opportunity to deliver OHA's testimony today. If you have any questions concerning my testimony, please feel free to contact me at victoria.veltri@ct.gov.

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**JOINT
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**PUBLIC
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PART 6
1695 - 1988**

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person is homeless and unaccompanied and then that is given so that they can apply for federal financial aid. So this process is not new. This is one that's done federally as well, and these same professionals are already doing it.

And then in answer to the question about age, we'd be open to talking about an age. I know last year when this bill was discussed there was an age of fifteen that was put out there. We'd be open to talking about that. I would not want the younger children and youth to be kept or delayed access to medical or mental health care because they don't have access to identity documents, but I understand the concerns. And if the age of fifteen was more amenable, I think that that would be an improvement.

REP. RITTER: Fair enough. And thank you, and thank you also for the background on the other areas where really essentially we're already doing this because I think that was maybe less than clear at the time this morning, at least not clear in our minds. So thank you for that. Is there anything else? Any other questions? It's getting quieter and quieter. Thank you very much for your testimony.

STACEY VIOLANTE COTE: Thank you.

REP. RITTER: Our next person to speak and at least appears to be the last speaker will be Susan Israel.

SUSAN ISRAEL: Hi, everybody. I'm Susan Israel. I'm a physician who's been following privacy issues. After all of this it may seem trivial, but I think it speaks to a bigger problem in terms of some of the laws of the state.

HB 5514

HB 5038

HB 5514

I'm going to address Section 5, subsection (b) in reference to the Connecticut Tumor Registry. And I would hope that it would specifically state that only unidentifiable patient data as it is being taken without patient consent be sent to the Department of Public Health, that no DNA testing be done on the issue without patient consent and only aggregated data be released to the public to further protect patient privacy. Subsection (b) mandates that tissue of tumors may be sent to the DPH, along with demographic and treatment information, and that the commissioner of public health shall promulgate a list of required data items. So the commissioner, as I understand it, has open-ended authority to delve into your medical record without your consent. It seems that the intention must be to have the name of the patient as per the testimony of the commissioner on 5038 about the All-Payer Claims Data Tumor Registry and to quote, "The C T R conducts followup on all cancer patients for vital status. The CTR uses data sources such as driver's license renewal date or hospital discharge date to ascertain that a patient was alive at a certain date. All all-payer claims database, extending to outpatient care and prescriptions, would improve the completeness of the followup." So to me this means that the Connecticut CTR will receive our cancer information and our hospital information and that bill I believe is HB 5652, Public Act 11-61, Section 43(b) -- just two more sentences. Anyway it's attached. So I just wanted to point out that it sounds kind of extreme but let's say you had cervical cancer and the commissioner wants to know your sexually transmitted disease and whether you had HPV which can cause cervical cancer, but it seems to me that hopefully we won't have someone who has an invasive tumor also has an invasive state. So I would ask the committee

to please look at this. Thank you very much.

REP. RITTER: Thank you for your testimony and your extreme patience. Are there questions from the committee? Seeing none, I guess I might ask is there anyone else that wishes to testify? There is someone that would wish to testify. One moment. It's my understanding that Keith Carter -- are you Keith Carter -- would like to testify, and we're looking back at Senate Bill 425, a basic health program. Mr. Carter. Thank you.

KEITH CARTER: Thank you for taking me. I apologize because I had to take off and go back to class. I kind of like didn't want to miss it because I had to go home for my mother's home going, and I missed the other opportunities so I just wanted to make sure I got this done, but I want to thank you for the opportunity.

My name is Keith Carter. I'm a student at the School of Social Work here at the University of Connecticut. I would like to first thank you for the opportunity again to appear before you to testify in support of the basic health plan bill. I would also like to thank you for raising this bill because I feel affordable health care is important to everyone. This is especially true for the over 100,000 individuals that are working hard to survive without health insurance in an uncertain job market, a job market that is in most cases either will not pay health insurance or enough for the employee to purchase health insurance. A neighbor of my inlaws is a good solitary example of those individuals experiencing life without health insurance. David suffered a broken ankle ten years ago and was unable to receive the proper medical care due to a lack of health insurance and now walks with a permanent limp. Just think if his minimum wage

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**PUBLIC
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PART 7
1989 - 2282**

2012

Bonhomme, Penny

From: Susan Israel [susie96@optonline.net]
Sent: Tuesday, March 20, 2012 10 15 AM
To: PHC Testimony
Subject: HB 5514 resubmission

To the Committee on Public Health

March 21, 2012

Testimony on H.B. 5514, Sec. 5, Subsection (b)

Submitted by Susan Israel, MD

I am Susan Israel, a physician. It is my hope that Sec. 5, Subsection (b) of HB 5514 will specifically state that only *unidentifiable* patient data, as it is being taken without consent, will be sent to the Dept. of Public Health, by the hospitals, labs and providers, and that no DNA testing be done on the tissue without patient consent. And only aggregated data be released to the public, to further protect patient privacy.

Subsection (b) mandates that tissue of tumors may be sent to the DPH, along with demographic and treatment information, and the "Commissioner of Public Health shall promulgate a list of required data items." So the Commissioner has open ended authority to delve into your medical record without your consent. It seems that the intention must be to have the name of the patients, as per the testimony of the Commissioner of Public Health on HB 5038, the All-Payer Claims Database, CT Tumor Registry (CTR). And to quote: "The CTR conducts follow-up on all cancer patients for vital status. The CTR uses data sources such as *driver's license* renewal date or hospital discharge date and ... status to ascertain that a patient was alive at a certain date. An all-payer claims database, extending to *outpatient care and prescriptions*, would improve the completeness of the follow-up...". So this seems to mean that the CTR will receive our cancer information and our hospital information *with* our identities attached.

So let's say a woman has cervical cancer. The state may wish to know her history of sexually transmitted infections because HPV may cause cervical cancer. But please let us have laws that would avoid a patient having an invasive tumor and an invasive state.

Thank you very much for this opportunity.

3/20/2012

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**CONNECTICUT
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SENATE

303
May 9, 2012

So ordered, sir.

SENATOR LOONEY:

Thank you, Madam President.

Calendar page 7, Calendar 376, House Bill 5279, move to place the item on the consent calendar.

THE CHAIR:

So ordered, sir.

SENATOR LOONEY:

That may have been placed there previously.

THE CHAIR:

It had been, sir.

SENATOR LOONEY:

Okay. And skipping, Madam President, to Calendar 398, on page 8, Calendar 398, House Bill 5241, move to place on the consent calendar.

THE CHAIR:

So ordered, sir.

SENATOR LOONEY:

Thank you, Madam President.

Madam President, calendar page 15, Calendar 464, House Bill 5344 that -- double check has that been placed on consent previously?

THE CHAIR:

Yes sir.

SENATOR LOONEY:

All right. And Madam President, calendar page 16, Calendar 469, House Bill 5038, move to place on the consent

rgd/tmj/gdm/gbr
SENATE

304
May 9, 2012

calendar.

THE CHAIR:

5368 -- is that 5638, sir?

SENATOR LOONEY:

Five -- 5038.

THE CHAIR:

5038, thank you, sir.

So ordered.

SENATOR LOONEY:

Thank you, Madam President.

And Madam President, calendar page 22, Calendar 475, House Bill 5550 placed -- move to place the item on the consent calendar.

THE CHAIR:

So ordered, sir.

SENATOR LOONEY:

Thank you, Madam President.

Calendar page 18, Calendar 483, House Bill 5355, move to place the item on the consent calendar.

THE CHAIR:

So ordered, sir.

SENATOR LOONEY:

Thank you, Madam President.

Madam President, calendar page 24, Calendar 521, House Bill 5343, move to place the item on the consent calendar.

THE CHAIR:

rgd/tmj/gdm/gbr
SENATE

318
May 9, 2012

(HB 5283)

On page 3, Calendar 240, House Bill 3283; page 3, Calendar 299, House Bill 5437; page 5, Calendar 349, Senate Bill 374; page 6, Calendar 375, House Bill 5440; page 6, 362, House Bill 5011.

On page 7, Calendar 376, House Bill 5279; on page 7, 387, House Bill 5290; on page 8, 394, House Bill 5032; on page 8, 396, House Bill 5230.

Also on page 8, Calendar 398, House Bill 5241; on page 8, Calendar 393, House Bill 5307; on page 9, Calendar 403, House Bill 5087; on page 9, Calendar 406, House Bill 5276; on page 9, 407, House Bill 5484; on page 11, Calendar 424, House Bill 5495; on page 12, Calendar 435, House Bill 5232; on page 13, Calendar 5 -- excuse me Calendar 450, House Bill 5447; on page 14, Calendar 455, House Bill 3 -- I'm sorry -- House Bill 5353.

On page 14, Calendar 453, House Bill 5543; on page 14, Calendar 459, House Bill 5271; on page 15, Calendar 464, House Bill 5344; on page 15, Calendar 465, House Bill 5034; on page 16, Calendar 469, House Bill 5038; on page 17, Calendar 475, House Bill 5550; on page 17, Calendar 474, House Bill 5233; on page 17, Calendar 477, House Bill 5421.

Page 18, 480, House Bill 5258; on page 18, Calendar 479, House Bill 5500; page 18, Calendar 482, House Bill 5106; on page 18, Calendar 483, House Bill 5355; on page 19, Calendar 489, House Bill 5248; on page 19, Calendar 488, House Bill 5321; on page 20, Calendar 496, House Bill 5412.

On page 21, Calendar 504, House Bill 5319; page 21, Calendar 505, House Bill 5328; on page 22, Calendar 508, House Bill 5365; on page 22, Calendar 510, House Bill 5170; on page 23, Calendar 514, House Bill 5540; on page 23, Calendar 517, House Bill 5521.

Page 24, Calendar 521, House Bill 5343; page 24, Calendar 518, House Bill 5298; page 24, Calendar 523, House Bill 5504; page 29, Calendar 355, Senate Bill 418; on page 13, Calendar 444, 5037; and Calendar 507, House Bill 5467.

THE CHAIR:

Senator -- Senator Suzio.

SENATOR SUZIO:



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ERNEST J. COTNOIR
ASSISTANT SENATE CLERK

TIMOTHY B. KEHOE
PERMANENT ASSISTANT
CLERK OF THE SENATE

Bills placed on the Consent Calendar on May 9, 2012

5358
5148
5394
5326
5025
5534
5539
5320
5462
5394
5511
5283
5437
374
5011
5440
5279
5290
5307
5032
5230
5241
5087
5276
5484
5495
5232
5447
5543
5353
5271
5344
5038



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- 5233
- 5550
- 5258
- 5106
- 5355
- 5521
- 5248
- 5412
- 5319
- 5328
- 5365
- 5170
- 55440
- 5521
- 5298
- 5343
- 5504
- 418
- 5037
- 5467
- 5022
- 5259
- 5496
- 5360



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Bills from Senate Agenda Number 3 from the May 9th Senate Session that were placed on the Consent Calendar

HB5304
HB 5342

rgd/tmj/gdm/gbr
SENATE

319
May 9, 2012

Good evening, Madam President.

I just want to clarify. I thought I heard the Clerk call House Bill 5034? Is that on the consent calendar?

THE CHAIR:

Do you know what page that is, sir?

SENATOR SUZIO:

No I -- he was reading so fast, Madam, I couldn't get it.

THE CHAIR:

It's -- yes it's 53 -- I don't know.

SENATOR SUZIO:

5034.

THE CHAIR:

5034, yes sir.

SENATOR SUZIO:

I object to that being put on the consent calendar, Madam President.

THE CHAIR:

Okay, that will be removed.

Senator Looney.

SENATOR LOONEY:

Thank you, Madam President.

Yes, just seeing that -- ask to remove that item from the consent calendar.

THE CHAIR:

So ordered.

rgd/tmj/gdm/gbr
SENATE

320
May 9, 2012

At this time we'll call a roll call vote on the consent calendar.

Mr. Clerk.

THE CLERK:

Immediate roll call has been ordered in the Senate.
Senators please return to the Chamber. Immediate roll call has been ordered in the Senate.

THE CHAIR:

Senator Coleman, we need your vote, sir.

Senator Kissel, Senator Kissel. Senator Kissel, will you vote on the consent calendar please?

All members have voted?

If all members have voted, the machine will be closed.

Mr. Clerk, will you call the amendment -- I meant the tally.

THE CLERK:

On today's consent calendar.

Total Number Voting	36
Necessary for Adoption	19
Those Voting Yea	36
Those Voting Nay	0
Those Absent and Not Voting	0

THE CHAIR:

The consent calendar has passed.

Senator Looney.

SENATOR LOONEY:

Thank you, Madam President.

Madam President, I believe the Clerk is in possession of Senate Agenda Number 6 for today's session.