Phil, thank you very much for that introduction. It is a pleasure and an honor to be this year’s Waggoner lecturer. I am delighted to join you. There is, in fact, a connection between my talk this morning which focused on informed consent issues in research settings and my talk here this afternoon which focuses on issues of confidentiality in the medical setting. And the connection is simply this, that in research we have taken it as a matter of policy that patients, potential research subjects, will be given the opportunity to make their own decisions about whether or not to participate in research, that they will control the situation. They will make the determinations regarding what happens to them, even regarding what happens to their information and whether or not it should be employed in research settings. In general medicine and psychiatry in particular, we have generally taken the same approach with regard to who has control over patients’ medical record information. The answer to that question has been the patient who gets to determine where the information goes, who gets to use it and whether or not it is employed for research purposes, administrative purposes or to other ends.

We are, however, on the verge of what could be, a major change, a revolution you might say in the way in which medical record information is
handled and in the answer to the question, who has control over the information that is collected about patients’ medical situations. And it is that potential revolution that is really, in a number of ways, the subject of my presentation to you here this afternoon.

Confidentiality has, as many of you know, always been a cornerstone of psychiatric treatment in particular, but medical treatment in general. You all know the words of the Hippocratic Oath, which depending on which translation you use, that the practitioner will not speak of that which should not be spoken of to other men. That is, what the practitioner, what the physician learns in contacts with his or her patient will remain with the physician and not be further disseminated. Psychiatry in particular won a major victory two years ago in the U.S.--I guess it is now three years ago in the U.S. Supreme Court decision in Jaffee versus Redmond which declared a psychotherapist/patient privilege to exist. In the federal courts, Justice Stevens writing for the unanimous majority of the court, noted that effective psychotherapy depends upon an atmosphere of confidence and trust, and therefore the mere possibility of disclosure of confidential communications may impede development of the relationship necessary for successful treatment. And you could probably substitute psychiatry for psychotherapy and probably medicine in general for psychotherapy and still have a valid statement regarding the importance of confidentiality.
Despite these words, however, threats to the confidentiality of medical treatment seem to be coming at us from every direction. And you do not have to go far to find them. For example, I have an article here that came from the Washington Post not very long ago. It’s a story written by a reporter who was walking down the street headed to his house when he found papers blowing down the street, an unusual occurrence in his suburban Maryland neighborhood. He stopped to pick one up and discovered it was part of a medical record and he gathered more of them and sort of Hansel and Gretel like traced the trail back to where they were coming from. And there was a large dumpster outside a house that was being renovated from which these records were being blown out by the wind. He took a pile of them home, looked at them more closely and discovered that they were, in fact, psychiatric records including patients’ names, diagnosis, problems that they were having in treatment, and the like including one ironic note describing a particular youngster thought to be a suicide risk who was described as, “very concerned about people seeing him as crazy and knowing that he was in psychiatric treatment.” Well, the reporter dug into the story a little bit and discovered that the house that was being renovated used to belong to a psychiatrist. Psychiatrist had retired, moved across the river to Virginia and somehow the records left in the house made their way into the dumpster and were being blown across the street. He called the psychiatrist, tracked him down in Virginia. The man said, “Oh, I have no idea how this could happen. I destroyed all my records, of
course, when I retired from treatment. It must be that one of my employees stole the records and that’s how they ended up in the dumpster.” Well, if the employee stole the records, he or she stole them and then left them in the same house and it all seems rather improbable. It seems like one of those instances where it was all too easy for a practitioner to ignore the question of patient confidentiality and to not give a second thought to what would happen to the records that he had accumulated over a lifetime of rendering clinical care.

So the threat that your medical record may be blowing down the street one day is a clear and obvious threat. But other threats to our medical record confidentiality are lesser known and they stem from activities that have been going on in Washington that have gotten us very close to the point of essentially overturning centuries of tradition with regard to the control of information that derives from the delivery of medical care and may lead us in just a few months into a very different world, a new order, if you will, in which medical record information is no longer controlled by patients but controlled by the government instead. And I will describe a little later to you exactly what the dimensions of that change might be.

Now since I can’t possibly provide a comprehensive overview of all the issues related to the current status of confidentiality, my goals today are a little bit more modest. I’d like to review with you three of the major forces that are threatening confidentiality. Today, computerization of medical
records, the creation of medical record or medical information databanks, and access to records by managed care companies and these are probably all issues with which you’ve had experience. And then I would like to update you on the current legislative initiatives and tell you a little bit about where things stand because they change day to day. But this is a critical time, really. Whatever you believe about the importance of confidentiality or the importance of access, what goes on in Washington in the next four to six months is probably going to shape a generation, the next generation of how we deal with medical record information. It may shape the next hundred years of how we deal with such information.

So let’s start with a look at the issue of computerization which is really what’s driving a lot of the current situation. What is going on in the world now of medical record computerization? Well, many medical entities are considering adopting computerized records and some already have. And in the last day I have talked with people here at the university and discovered that you are really in the lead as far as these developments are concerned having developed both a computerized medical record system and made some special provisions which we’ll talk about in a broader context with regard to psychiatric records per se.

An example of the debate that is likely to ensue when these efforts are not done well came from Massachusetts in the last three years where one of our leading health plans, then called the Harvard Community Health Plan, now
known as Harvard Pilgrim Healthcare, a non-profit HMO at one point affiliated with Harvard, now quite independent and the largest HMO in the state went to a computerized medical record system giving relatively little thought to the question of what information would be included in that system and deciding that everything would be included in that system including information that some people might consider to be particularly sensitive, particularly in this case medical—\(I\)’m sorry, psychiatric record information. The Boston Globe picked up the story and revealed to its readers that this million plus member system with tens of thousands of people in its employ and literally thousands of physician and non-physician caregivers had created a system where from any clinic or affiliated physician’s office, anybody with a password could punch in a patient’s medical record number and see their entire medical record, whether or not that person was involved in their care and no matter how sensitive the information was, and the Globe focused in particular on psychiatric record information because there is an intuitive sense I think that most people have that that is particularly sensitive. That is the kind of medical information that perhaps along with information about sexual transmitted diseases, abortion, and perhaps still cancer with the stigma that that carries, people would very much not like to have bandied around.

In the face of a public outcry, Harvard Community Health backed down and went to a complete segregation of its psychiatric and medical records and
took their psychiatric records offline and made it back into a paper record system which they continue with to this day. And they are running two separate parallel medical record systems as a result and they have spent enormous effort trying to contain the fallout from their initial move. So clearly there are dangers both for the entities that are moving to computerized records and to patients themselves in the process.

Where’s the push coming from for computerization? Why do we see one entity after another adopting a computerized medical record? Well, there are, to be sure, powerful forces behind this move. In a very influential 1992 Institute of Medicine report, computerized medical records were endorsed as the future of medical record keeping. It was, although this may be hard to remember now, part of the Clinton healthcare plan of blessed memory and some aspects of it were adopted in little known provisions of a bill called the Kennedy-Kassebaum Health Insurance Portability Act which I’ll discuss in just a moment. It has been the focus of intense lobbying by the information industry, which is eager to facilitate this. Hardware companies, software companies, data management companies all see enormous profits to be made in this process of conversion to computerized medical records. Nobody forgets that Ross Perot’s money came from being the man who had the contract to computerize the Medicare billing and payment system. And there are more millions or billions to be made as the nation moves towards a computerized medical record system.
Now to be sure, it’s not just money that’s at stake here. There are valid arguments made for the good that can come from increased computerization. And I presume it was arguments that, like these, that led to the adoption of a computerized system here. Computerization, it is argued, probably rightly, will increase the availability of information in ways that are beneficial to patients, at other sites in a system if a patient turns up, people who turn up in emergency rooms, when care is shifted to new providers or even people who turn up in an emergency room across the country and need rapid access to information about a patient’s medical situation. It as well provides an increased ability to detect patterns of care, patterns of presentation and response, patterns of use or misuse of medical interventions. There’s greater efficiency of record management. At some point, our medical record rooms, if we keep using paper records, will get bigger than our hospitals and the hospital will be, especially given the current trend toward downsizing in patient beds, will be a little wing off the back of the medical records facility. Clearly at some point we need a way of being more efficient about how we keep our records. And it is argued as well, and again legitimately, that there will likely be cost savings from the increased ability to track utilization in a system and potentially on a regional or national basis.

Well, you might ask, if computerization can be so helpful, and it probably can be, why should we be concerned about it? And I think the answer can be illustrated by another case that happened in my backyard in Boston at the
Beth Israel Hospital, one of the major Harvard teaching hospitals, in which a man who worked at the facility, a janitor or somebody in the building staff, got access to their computerized medical record system and sent a very personalized, sexualized letter to a woman whose medical record he pulled up at random there. She was appropriately outraged. He was appropriately fired but it helped to demonstrate just how vulnerable people are. Now even with paper records there’s always the opportunity for that kind of intrusion. Witness the story I started with about the records blowing down the suburban Maryland street. But the ease of such invasions of privacy and their potential scope are increased enormously when records are computerized. Records can be scanned remotely. You don’t have to be in the medical record room where it’s easy to catch you while you’re doing it. It is easy to search by patient name, diagnosis, age, or for particularly embarrassing diagnostic data. There was a well known incident that occurred in Florida where a man was reported in a bar with a computer diskette in his pocket, one of those three and a half inch diskettes, bragging to his friends that before they went out on their next date they ought to check with him because he had the list of everybody in Florida who was HIV positive. And in fact, he did. The Department of Public Health kept that record. He worked for that agency. He somehow got access to that list and ultimately it came to light. He was picked up and the information was confiscated. But it does, again, illustrate just how easy it is to pass information around in this new information age. And you can imagine
pedophiles or rapists or other offenders making great and illegitimate and unfortunate use of access to databases of that sort.

Moreover, as record systems are linked together, the risk multiplies. It is not just one hospital now. Now we have hospital systems. HMO’s cover millions of patients often across many states. And if you look at national, for example, in mental health care, behavioral health management companies, the managed care organizations that control essentially the delivery of mental healthcare in this country today, the largest of them delivers them care or controls the delivery of care to more than 60 million people at this point. And although their data systems are not completely linked and integrated yet, you can certainly see the potential for that to happen.

Moreover, in addition to these actual risks from breach of confidentiality, there’s also the perception issue. When patients learn of computerization, they may become reluctant to reveal important information to us, information that we rely on to make accurate diagnoses and provide appropriate treatment. And not just in systems that are already computerized. The lack of trust that may result can generalize to all medical and psychiatric care systems.

Just last month I picked up another article from the Washington Post and interestingly--I mean, if you’re interested in this area, the leading sources of
information are our daily newspapers. The scholarly literature has not caught up yet in any systematic way and there is very little careful empirical study of risk to confidentiality. It is the Washington Post, New York Times, your local paper as well that are more likely to carry these kinds of stories. Let me just read to you the lead of a story in last month’s Washington Post. The headline is, “Long Reach into Patients’ Privacy; New uses of data illustrate potential benefits and hazards.” Two months ago, a 42-year-old woman named Mimi walked into her pharmacy in Fairfield, Connecticut to pick up a refill of the medicine she had taken for years for her migraine headaches and stormed out with a headache larger than she'd ever imagined. She could not get a refill, her druggist told her, because a company that manages pharmacy benefits for her managed care company had decided she was taking too many kinds of medication. Mimi, who herself is a mother and part-time psychotherapist called two of her doctors, only to discover that the company had written a letter to each of them listing every medication she was taking for asthma, joint pain and allergies, along with the migraines. And she responded in the following way. And she said, “I felt violated because the company did all this behind my back. It made--it looked like they were insinuating I was a drug addict.” And the article goes on to talk about the impact that that experience had on her trust in the security of her medical record data. I suspect most of us do not know sitting here today whether the companies that insure us or manage our care or the pharmacies at which we have our prescriptions filled are part of these extensive medical
information databases and whether there is somewhere a file that sits on each of us with all our medications, all of our diagnoses and all of the information about the care we’re getting. And the evidence suggests that that is true to a much greater extent than any of us imagine at the moment.

Well, what can we do about it? What should we do about it? I don’t think we can stop computerization of medical records in general, and I am not sure we should. The pressures for cost saving and the other advantages of computerization are really too strong. But we do need to decide how we deal with computerization and whether there are some kinds of information that we ought not to computerize or ought to protect in special ways. The question that Harvard Community Healthcare didn’t ask itself before it put all its records online. It may be, for example, and I would maintain as a psychiatrist that in fact is that psychiatric records, per se, should be dealt with differently. Now not all of my colleagues in psychiatry even would agree with that. Many psychiatrists value the integration of psychiatric and general medical care and fear that treating psychiatric records differently will impede that process and by segregating psychiatric information off on one side will reduce the quality of that care.

Now others point out that compromising information can be found throughout a patient’s medical record. Are you HIV positive? Did you ever have a sexually transmitted disease? Have you a history of substance abuse? Were you once suspected of child abuse when you brought your son or
daughter into an emergency room? I can tell you from experience our oldest was one of these kids who was breaking a bone every other month. And after the fourth or fifth broken digit, toe, arm, or whatever, we got very unusual looks from the emergency room personnel when we brought him in for the next one. Well, is that in his medical record as well? And some of my colleagues are perhaps appropriately concerned that singling out psychiatry or any other area of medicine for special treatment will lead to greater stigmatization of that area and of those patients.

Granting the legitimacy of those arguments, I do think nonetheless that psychiatric records still need special protection as other sorts of information in those records may as well. There are, after all, some kinds of information that are still more likely to contain sensitive information, more likely to be stigmatizing, and more likely to dissuade patients from seeking care if they think that information is insecure. And I understand that here at the University of Michigan you have taken the step of segregating, partitioning, if you will, your psychiatric record information from the general medical record. And the system that has been described to me seems to me to make a great deal of sense. We are now just moving into computerized records at the University of Massachusetts and are doing the same thing. I would actually like to move to a much more sophisticated system than our technical people tell me is possible at the moment. Rather than having one firewall and all the psychiatric information on one side and the general medical
information on the other, with anybody in psychiatry able to access any of
the psychiatric records, I would like to create special access to each patient’s
record to those people who need to see that record. And the rest of our
seventy-odd psychiatrists who have no business looking at that record need
not have access to it. I think that the potential for doing that exists.
Technically it is certainly feasible. We just need the software written and
these programs that are being developed on a commercial basis constructed
to take those kinds of needs into account.

Moreover, I would suggest that there are other things we should be doing as
we moved into this world of computerized medical records. I think patients
should always be told whether or not computerized records are being used.
There are some patients who may elect to seek care elsewhere. And that
seems to me to be their right and they cannot exercise that right unless they
have knowledge of the situation. They may also elect not to reveal certain
information. Now the medical profession tends to react adversely to that
prospect. We have a belief imbued in our medical training that we have the
right to know everything about our patients and patients who withhold
information from us are bad patients in some way. But I doubt if there are
any of us in this room, and I will include myself here, who have ever fully
disclosed everything we could to our caregivers. I think we all have used
discretion at times regarding what we have or have not communicated. And
I think if we do so knowledgably, that is appropriate. That is, if we are
willing to trade off some measure of care for a greater degree of confidentiality, that seems to me to be a reasonable option for us to have.

Some organizations have been willing to give patients the right to opt out of computerization and retain paper records for certain purposes. And if systems can be constructed that way, again, at least at this point where we don’t yet have the kinds of computerized record system safe guards that we might want to have, that is not an unreasonable option either.

We need to develop more experience with partition of sensitive information and I suggest to you there are a number of ways we could do it. We could partition records based on the nature of the caregiver, psychiatrist versus not, the nature of the treatment, substance abuse treatment versus other, the nature of the disorder, HIV positive versus other, the type of information, suspected child abuse versus something else. Technology in this case should actually help us in achieving that kind of fine grain differentiation among various kinds of medical record information. We don’t know yet which of these approaches will work best and we are at the stage where experimentation is needed. And clearly appropriate security measures need to be developed. We were talking yesterday, when we were talking about the Michigan system about audit trails, which I understand are built into the system, you can track everybody who has ever had access to the record. And that is fine but if you talk to technical people, what they will tell you is audit trails only take you so far. Somebody has to look at the audit trail to
determine whether unauthorized access has occurred, and if you have got 100,000 records in your system, that's hard to do on a systematic basis. Moreover, the person who is looking has to know whether or not the access that is documented there was appropriate or inappropriate and that implies a fair degree of knowledge about who should or should not be going into any particular record. It is not as simple a solution as it sounds. It may be something of a deterrent to unauthorized access, but it is not a great system for people who are dipping into records without proper authorization.

Above all, I would suggest to you that as a profession we need to be vigilant about these developments. The software exists for medical record computerization. It is being marketed aggressively. HMO’s, clinics, hospital systems, even individual practices in the long run will have a strong incentive to move over to computerized records and if we do not pay attention to the implications for privacy, we will wake up one morning and discover that neither our patients’ privacy nor our own privacy when we are patients is well protected.

The next level of concern here after computerization of records at an individual location is the assignment of these record systems into regional or national databanks. What would something like this look like? They would be regional or national depositories of data concerning all medical services and presumably would be linked with individual identifiers so that the information that you generate when you see your OB/GYN for your annual
pap smear could be linked with the information that comes from your primary care physician who treats your allergies and asthma.

Interestingly, the Clinton plan, that’s almost five years ago now, proposed required reporting of every medical contact that took place, whether or not you paid for it out of pocket or it was covered by the Clinton plan insurance component. Even if you didn’t want that information to be tracked, you had no option to withhold the information from the system. It’s an astonishing provision in many ways. It’s the ultimate big brother as far as medical records are concerned, but to my amazement, the entire aggressive campaign against the Clinton health plan--Harry and Louise on TV discussing how the future would be bleak if the Clinton plan were adopted never mentioned the issue of medical records privacy. This was a non-issue although it was there in broad daylight and certainly played no role in the defeat of the Clinton plan.

With the defeat of that plan, the impetus for the creation of these databanks ebbed just slightly but the forces--the proponents of it have regrouped and are moving forward again. Again, there is a similar coalition, software, hardware data management companies, this time supported by managed care companies and researchers who literally drool over the prospect of access to such data, huge banks of data involving medical care of all of us around the country. Think of the outcomes research. Think of the epidemiological studies that could be done.
But this really is big brother. For data to be useful, they’ll have to be linked individually over time. Someone will have the key. There literally will be no place to hide. And if reporting is mandatory, even patients who pay out of pocket in an effort to protect their privacy will not be able to do so.

Where do things stand now? Well, this is sort of interesting and in a way illustrates the stealth way in which these issues have moved forward in Washington. Several years ago you will recall that a measure passed Congress called the Kennedy-Kassebaum Health Insurance Portability and Accountability Act, HIPAA for short. HIPAA was best known for providing some small measure of parody for psychiatric treatment and also for insuring the so-called portability of health care insurance, if you lost a job and were moving to a new job and it limited the use of pre-existing condition restrictions on health insurance provision. But buried in the Kennedy-Kassebaum bill was a measure provision dealing with so-called administrative simplification. Now I will tell you that although administrative simplification sounds a lot like motherhood and it is difficult to be against it, how many of us are for administrative complexity after all? In fact, it’s a code word for computerization of medical record information. The administrative simplification provisions required within 18 months of adoption of the bill, which has long since passed, the secretary of HHS had to come up with standards for electronic transmission of information, including claims or in counter information, billing and payment information.
It didn’t require electronic transmission, but if electronic transmission were used and HMO’s and insurers increasingly are looking for claims to be submitted by modem, they would all have to conform to a single standard.

Moreover, within 12 months of adoption, the secretary of HHS had to propose recommendations with regard to privacy to Congress, including how a national plan for a unique identifier system could be implemented. The unique identifier meant that each of us would be assigned a number as the lawyers in this debate say from sperm to worm that would be with us forever and would be the number under which all of our medical record information would be compiled. You could not escape scrutiny of your medical encounters.

Now just over a year ago, a year ago August when the national commission on Vital and Health Statistics started holding public hearings on this issue in Chicago, there was finally, although this had been enacted in law two years before that, a huge outcry regarding national unique identifiers. And a one year moratorium was passed in Congress on any further action and Vice President Gore on behalf of the administration announced that they were putting a hold on any further development. But there is no legal impediment at this point to further movement on unique identifiers and it has always struck me as unusual that so few people know about this issue. There are, after all, people in Montana who are scanning the skies looking for black helicopters sent by the United Nations as the lead force to take over the
country for a one-world government who believe that there are signals on the back of all road traffic signs directing the United Nation troops where to go. And yet these people are oblivious to the real threats to individual privacy in this country such as the creation of a unique identifier system that would encompass all medical record information.

Well, why a unique identifier? Why uniform data transmission? Why should the government care why data is sent? Well, there is only one purpose in creating a unified standard and that is once it exists, data from different systems can be merged into national or large regional databanks. And since there will be little purpose to having such databanks unless all data are included, the provisions on electronic transmission may well become mandatory as they were in the Clinton proposal.

What should we in medicine be doing about this? Well, this is going to take a major effort if we are truly concerned. I am truly concerned about it. But it must be coupled with public education. There is a general tendency for people to be infatuated with computers and cyberspace and to see developments there as generally positive, or at least, irresistible. We need to convince people if we think that medical care will be harmed by such a threat to privacy that not everything that can be done with computers should be done. And I would suggest that as soon as an action like this is taken becomes general knowledge and the first leak occurs, we are going to see patients’ medical information just dry up and people just simply are not
going to reveal to their physicians anything they think might be embarrassing. And physicians are not going to put it in the medical records and therefore the utility of these records for tracking care or doing research will be vitiated as well.

Let me skip over in some regards the managed care company issues. You know what is going on there. Companies are demanding extraordinary access to actual medical records. They are not accepting summaries. We have no idea where these records go or what is done with either the physical record or the information once it lands in the managed care company’s lap nor are there any regulations for the most part governing, certainly no national regulations governing what is done with that information and is a matter for legislative attention. But because I want to save some time for your questions and comments because you may well disagree with my concerns here, I want to tell you a little bit about the current legislative efforts that are going on in Washington.

For the last several years, essentially since the collapse of the Clinton plan in 1994, legislation has been introduced every year in every congress by a number of major players on medical records confidentiality. And they are usually labeled something like, “Patient Medical Confidentiality Rights Bill,” or “Medical Record Confidentiality Act of 1999.” In fact, what these bills often do--in fact, typically do is remove many of the protections of medical record confidentiality that have traditionally existed and they might
better be called Medical Record Access Bill of 1999 because they are being written and promoted in an effort to increase and facilitate access by all kinds of people to medical record information. Let me give you some examples.

A typical bill of the numerous bills--there are about three in the House--I’m sorry, four in the House and three in the Senate right now is the Jeffords bills. Senator Jeffords is chair of the subcommittee of the Senate Labor, Health, and Pensions committee that has jurisdiction over this legislation. Senator Jeffords is from Vermont and is a moderate Republican. The Jeffords bill would do, among other things, the following. First it would remove effective patient control of medical record information. It would no longer be the case that patients would have to release information from their records or it could not be released. In fact, the bill would require employers’ health plans and providers to obtain blanket releases at the time of enrollment to a health plan as a condition of entering the health plan which would allow disclosure to take place for purposes of treatment, payment, or health care operations.

Now, consider what some of these things mean. Treatment, right now you determine whether your medical record information is transferred from, for example, your psychiatrist to your primary care physician or to your dermatologist for that matter. And if you think your dermatologist needs to know that you are taking lithium because you are bipolar, which he or she
might in order to give you good care for your rash, well then you authorize the release of that information. If you think it is irrelevant to the tinea that you have between your toes, then you might not want to release that information. Under the Jeffords bill and all of its Republican-sponsored colleagues in the Senate right now, you would no longer have that choice. Information that was deemed relevant to care would be available to all of your caregivers whether or not you authorized its disclosure.

And what about healthcare operations? Well, that is a very vaguely defined term that is included in all of the Republican bills. Remember Republicans are in the majority in both houses right now and so it is their legislation that gets the primary focus because it is most likely to move through Congress. They would allow information to be released for a wide variety of purposes that in some way relate to the functioning of the insurer, the managed care company or other entities that are responsible for providing or managing your benefits, for example, pharmaceutical benefit management companies. Now this raises the prospect again of an episode similar to what occurred on the east coast last year when patients began receiving letters in the mail urging them to change from one medication to another for the condition that they had. And some patients began wondering, “Well, how on earth does the pharmaceutical company that sent me this letter know what my condition is or what medication I’m taking?” It turned out that CVS, a large--I don’t know if you have CVS out here. It’s a large pharmacy chain up and down
the east coast sold that information which it had in its computers. Now whenever you go into a chain pharmacy, there is a computer. They enter in all of your prescription information. Sometimes it is very convenient because they have your pharmacy benefit information there as well and they know what your co-pay is or whether it is free or whether you have to pay the full price. But that all goes into a data bank. And CVS decided that it could mine those data and sold it to drug companies that were interested in persuading consumers--patient consumers that they do better with one drug rather than another. And the privacy issues were completely, completely neglected. Well, the outcry ensued. It was inevitable and CVS said, “Oh, we’re sorry. We’ll never do it again.” But in fact, much of this congressional legislation would appear to permit such actions to be taken as a matter of course.

The Jeffords bill would also allow parents access to minors’ records--all minors’ records. No more saying to parents, “Look, if you want me to treat your son or daughter for their problems, I need to have some confidential relationship with them. We’ll talk to you when it’s appropriate, but basically you have to trust that I am going to be treating your son or daughter appropriately.” Researchers would get almost unlimited access whether or not you wanted them to have it. And in the initial version the police, when the records were likely to contain relevant information regardless of state laws, controlling their access to that information could
just ask for it. The latest version of the Jeffords bill now requires a warrant, but Senator Bennett’s bill--Senator Bennett is a Republican from Utah, still has no warrant requirement and is, in fact, the bill that has been endorsed most strongly by the Association of American Medical Colleges because it most easily and most completely makes medical record information available for research purposes. And the AAMC, which in some respects should be representing us, has chosen to focus on one interest here which is the interest of researchers and getting access to data and completely neglected the interest of caregivers and patients in maintaining some control over that medical record information.

Moreover the Jeffords bill and all of the Republican measures, in fact, preempt all state laws on medical record privacy. The Jeffords bill preempts them going forward. The Bennett bill just preempts everything that exists right now.

Some of the bills in the House and Senate now are a little better than Jeffords. Some are a little worse. The best bills from a privacy perspective are the Democratic bills that echo each other that are submitted in the Senate by Senators Kennedy and Leahy and in the House by Markey and Condit. But there is no possibility that the Democratic bills will move in a Republican Congress.
I would suggest that if one looks at this from the viewpoint of a medical practitioner that there ought to be several principles that guide this legislation if we’re going to have national legislation and that those principles are not hard to discern. If we want patients to come clean with us and tell us the information we need to make diagnoses and provide treatment, we ought to generally allow patients to control access and disclosure. And that has always been the case. Exceptions to that rule which need to exist in some circumstances should be very narrowly defined. Identifiable information should be released only when non-identifiable information is inadequate for the purpose, and this is something that the congressional bills completely fail to address. Somehow the legislators on Capitol Hill just don’t get it that for many of these purposes you can use non-identifiable data. I’ve testified at three different Congressional hearings on this privacy legislation and it comes as news to the senators and representatives each time that that ought to be possible as a general rule.

When you need to release identifiable information, it should be the least amount of data needed to achieve the goal at hand. And states should be allowed to experiment with higher levels of protection. National legislation should be a floor on patient protection, not a ceiling. Given that technology is moving as rapidly as it is and how difficult and how long it takes to get legislation passed in Congress, we’re much better off allowing the states
some flexibility here so they can experiment with more rapid adaptations to changing circumstances.

Well, where do things stand right now? Because of the difficulty of dealing with these issues, Congress has been stalemated. And though they set themselves a deadline of August to complete work on a bill, they have not done so. The statute that they passed--actually, it is HIPAA again, the Health Insurance Portability and Accountability Act actually empowers the Department of Health and Human Services to set its own binding standards. HHS is now at work and unless Congress either passes a bill in the next couple of months, and there may be renewed pressure to do that because Congress would much rather do it itself than allow HHS to set the standards. But if Congress either doesn’t pass a bill or extend the deadline, we will have new guidelines governing all medical record information in the country and it will be promulgated by HHS.

Now having met with Secretary Shalala and with the president’s chief medical advisor, health advisor Chris Jennings, I can tell you that there is no greater sensitivity towards issues of medical record confidentiality at that level than there is in the Republican side of Congress. The focus is on cost. There is a belief in HHS, which after all oversees a large amount of federal entitlement dollars, that more availability of information will lead to greater potential for reducing costs by identifying patterns of expenditure that could be pressured to contract.
I would suggest, in closing that however you feel about these issues, we are at a time that will set the pattern for the next generation at least, century perhaps and maybe even millennium for how medical records are being dealt with. And it is too important for us all not to pay careful attention and to weigh in. And the next couple of months are likely to be a critical time for your senators, representatives, and even the president given that the executive branch is now at work on this to hear from you how you feel about these issues.