(Music)

Mark Masselli: This is Conversations on Health Care. I am Mark Masselli.

Margaret Flinter: And I am Margaret Flinter.

Mark Masselli: Well Margaret, we are seeing a flurry of activity across the nation as states jockey into position with the health insurance exchanges, even those states who have declined to set up their own state-based exchanges.

Margaret Flinter: And in states like Texas and Oklahoma, the so-called Red States where opposition to the Affordable Care Act has been fierce, there are marketing campaigns underway now from various non-government sectors seeking to inform residents about the health care law.

Mark Masselli: Blue Cross Blue Shield is going to offer plans in all 50 states in both the state-based exchanges as well as the federal exchanges and the insurance company is focusing its promotional effort in those states deferring to the federal government where there is little or no promotion underway due to political resistance.

Margaret Flinter: Well it's particularly important in those states like Oklahoma where 20% of the population is uninsured and most of the folks will qualify for some kind of subsidy on the exchanges. So getting the message out about Obamacare continues to pose perhaps the biggest challenge as we roll towards full implementation.

Mark Masselli: And of course they are still talking in Congress about holding up the national budget on October 1st, if any of the budget has funds dedicated to the promotion of the Affordable Care Act.

Margaret Flinter: Some day Mark this will all be a memory and hopefully near universal insurance will be the law of the land. But it will be interesting to see how consumers navigate the exchanges after October 1st when they officially open for business. In Connecticut, exchange director Kevin Counihan expects that we are not going to see significant participation in the exchanges until after the first of the year and more likely closer to the March deadline for signing up for the exchanges. That's when he thinks folks will get to either that comfort level or necessity level with the online insurance marketplaces.

Mark Masselli: And they will also be motivated by the promise of a tax subsidy as well. The bottom-line here is that many millions of Americans who have existed outside the protection of decent health coverage will soon have the confidence of knowing they are covered both for preventative as well as catastrophic care.

Margaret Flinter: And Mark, there is one area that we really haven't spent a lot of time talking about on the show but it's critical to patients and providers as well and that's the entrusting of data to the system, the assurance of patient privacy, and that's something our guest today has been analyzing for years.

Mark Masselli: Deven McGraw is Director of the Health Privacy Project at the Center for Democracy & Technology. She will be talking about their effort to promote legislation that will protect patient health data while also enhancing systems that will effectively share data to promote research and quality improvement.

Margaret Flinter: And we get to have another visit from Lori Robertson, Managing Editor of FactCheck.org who is always on the hunt for misrepresented facts in health policy.

Mark Masselli: But as always, no matter what the topic, you can hear all of our shows by Googling CHC Radio.

Margaret Flinter: And if you have comments or questions, please reach out to us at www.chcradio.com or find us on Facebook or Twitter because we love hearing from you.

Mark Masselli: But first, here is our producer Marianne O'Hare with this week's Headline News.

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Marianne O'Hare: I am Marianne O'Hare with these Healthcare Headlines. Michigan and Medicaid expansion, the state's leadership had originally refused expansion of Medicaid under the Affordable Care Act to include half a million uninsured low income residents but they have since changed their tune and recently voted to expand Medicaid in that state. The vote positions Michigan to become the largest state controlled by Republicans to support a major component of the new federal health care law. Meanwhile, Medicaid expansion and the rural poor, it appears many will be left out in the cold when it comes to coverage. A study published in a recent edition of The Economist shows many of the nation's rural poor live in states that have opted out of Medicaid expansion to cover more low income residents. More than half the nation's low income residents live in these rural settings.

Meanwhile, in Texas, where they are not expanding Medicaid under the Affordable Care Act, the move is going to generate close to a 10% increase in insurance premiums for the uninsured. About 1.3 million uninsured low income or self-employed Texans would have qualified to gain coverage under Medicaid expansion. The premium hike is expected because folks in the low income

bracket tend to be less healthy and their health care costs will have to be shouldered by the industry.

Good news under the World Health Organization, women are living longer globally but there is still much work to do. While life expectancy has grown globally for women around the world who are over 50, still far too many die early from preventable causes like undiagnosed early stage cancers and uncontrolled heart disease. While the report suggests more comprehensive preventive care is needed, we can look to Japan for some answers. There, women live on average longer than any other nationality. I will have the seaweed and sushi please. I am Marianne O'Hare with these Healthcare Headlines.

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Mark Masselli: We are speaking today with Deven McGraw, Director of Health Privacy Project at the Center for Democracy & Technology, which is focused on developing workable privacy and security protections for electronic personal health information. Ms. McGraw was appointed by Health & Human Services Secretary Kathleen Sebelius to serve on the Health Information Technology Policy Committee. Ms. McGraw holds a Master's in Public Health from Johns Hopkins and a law degree from Georgetown where she was the Executive Editor of the Law Journal. Ms. McGraw, welcome to Conversations on Health Care.

Deven McGraw: Thank you very much. I am very glad to be here.

Mark Masselli: So Deven, you have been at the forefront of one of the most fluid areas of health reform, and that's the protection of patient health data and privacy. And the HITECH Act, which was part of the Stimulus Bill, provided billions of dollars and incentives for hospitals and practices to make the switch to electronic health records. So first, give us an assessment of the scope of changes that has occurred in terms of electronic health record adoption and why these convergent policies to protect the privacy of patient health information are so vital to the success of building this new HIT infrastructure.

Deven McGraw: Sure. I think people don't realize that efforts to reform the health care system really began back in 2009 with the enactment of the Stimulus legislation which included billions of dollars in tax incentives to facilitate the adoption and use of electronic medical records by health care providers, doctors and hospitals. And we are well into the implementation of that program, which began in 2011 and what we have really seen has been a pretty astronomical rate of adoption, much more than was expected of digital health records by hospitals in particular and even physicians. I think well more than three quarters in fact of hospitals, of eligible hospitals, have adopted, and physicians eligible for the program we have about half of them having implemented electronic health records, and that's a really good sign. But obviously, the digitization of data that used to be kept customarily in paper records raises a number of privacy issues

and security issues as well. And it's when you digitize a record, it really magnifies the potential when a mistake or a misuse of a record occurs.

So breach of records is a perfect example. Back in the paper record days, if you lost a paper file, you lost one patient's record, or a box of files might have been 20 patients' records. Now if you have an issue with respect to data breach, it's often thousands or tens of thousands or even hundreds of thousands of patient record. So the magnitude of the potential for inappropriate access really increases with the digital records, and so it was pretty critically important for Congress to address gaps in privacy rules at the same time that they provided a lot of taxpayer money in order to facilitate adoption of electronic records. Because at the end of the day, patients and health care providers as well, but the patients in particular need to trust that the information that's being uploaded or downloaded or shared protects their privacy at least to the degree that it was protected in a paper-based environment.

Margaret Flinter: But Deven, you carry many titles, but among them, you are the Chair of the Office of the National Coordinator's Tiger Team, a team that I don't think most of us were aware existed so we are going to want to hear more about that Tiger Team, finding workable solutions to a wide range of privacy and security issues that relate to this health information technology domain. Now you recently outlined four key areas of health information technology that you think require very targeted attention in terms of privacy protection. Tell us about these key areas that you think really need this particular focus and attention.

Deven McGraw: I think four of the top areas are better education about what the rules are for protecting health data and also what patients' rights are with respect to their health information, paying more attention to health data security which has never been as much of a priority as it should be for the health care industry, dealing with the fact that HIPAA doesn't cover all health data, that it only covers health data when it's in the hands of entities that are sort of part of our traditional health care system, right, doctors, hospitals, health plans but health data that's shared for example by a patient on the Internet isn't covered by HIPAA at all, and then what are the rules for data analytics or analytic use of data that's collected initially for purposes of treating you for example but then the need to sort of examine that data in order to improve our health care system and being able to sort of analyze treatment patterns and figure out what works best and what population is going to really be critical to reversing those trends. And so those are the four areas.

And the education piece is really, really critical in context of health privacy. We want to actually encourage the sharing of health data where doing so is going to improve the health of an individual and improve the health of populations. So it's always easier and less risky to say well I am worried about the privacy of that information so I am not going to share it, because that's the only way I am going to guarantee my patient's privacy, oh and by the way I don't think HIPAA allows

me to share it. Believe it or not, that excuse is used a lot, and that's not true. And it doesn't help the patient at all to have privacy be used as an excuse for not sharing information in circumstances when it should be shared. Patients have long had the right to be able to access their health information but they are frequently told HIPAA doesn't let you. And that's not true either. The security issue, the health care industry focuses a lot on delivering you good care and maybe less on protecting the information that comes out of that care because that's not necessarily what they have training and expertise in, and so as a result, we have seen a lot of breaches, largely due to inadequate data security.

Mark Masselli: Deven, I want to sort of pull the thread a little on your comment about data breaches, and it is clearly an area that's got lots of people, patients as well as providers, very nervous. A day doesn't go by that I am not reading the front page of either the New York Times that I don't read about this sort of breaches that are going on daily, so. But you have also noted that one in six patients will actually keep some data out of their electronic health record because they are afraid of discovery. So tell us what you think some best practices are.

Deven McGraw: Well the good news is that in fact there are technologies that keep data very secure. And right now, those technologies are encryption technologies, using encryption standards that are customarily required actually of government contractors for example. I mean encryption means that even if somebody is able to figure out your user name and password and get into your account, they can't read or understand the data unless they actually have the encryption key. So encryption, encryption, encryption is the way to go. Health care has been very slow to adapt to encryption technologies, and so, as part of the Stimulus Legislation, Congress established a right for patients to be notified of breaches of their health care information, they actually included an enormous incentive for the health care industry to encrypt, by saying, hey if you encrypt this data then you don't have to notify of a breach incident because essentially nobody will have been harmed unless you haven't used encryption properly. Well even with that incentive we still see the health care industry very, very slow to encrypt data.

An industry that I would point to that's been encrypting data for years is the financial services industry. You don't hear about breaches, in the way that you do in health, of banking. So they figured this out and yet the health care industry again has been very slow to encrypt. And to be honest, I am not a 100% sure why. When I have asked entities within the health care system why they don't encrypt, some of the common excuses are it costs too much, it slows down access to data, when I come back to my encryption experts, they look at me like I have six heads, right. Because encryption maybe used to be expensive but the costs have been reduced significantly and in fact it's not that costly. And we are seeing that disconnect on a daily basis with respect to the breaches that have occurred.

Margaret Flinter: Well Deven, it has been just unprecedented how fast things have changed. Mark and I were recently at a national meeting of community health centers. I think the figure that was quoted was more than 90% of the 11,000 health centers across the country. We probably implemented it maybe seven years ago in our organization but Kaiser Permanente and the VA of course have more than a decade of experience in that arena. What do you point to in terms of the success of electronic health record and this technology in improving the health not just of individuals in health care but the population as well?

Deven McGraw: There definitely are pockets of evidence that in fact moving to digital records improves care coordination which has an enormous impact on the quality of care as well as ultimately on cost. But I think the evidence on cost savings in the use of electronic health records, we have not seen it yet, and there is a couple of reasons for that. One is that the very early stages of the Stimulus Program focused primarily on getting people just to do the initial steps on the adoption curve and to start using it at least internally in delivering care for your patients. And to some extent, that's going to result in an uptake in costs because diabetics for example who haven't been getting their foot exams, now we have an electronic record system that is going to be able to identify who they are for the physician, which results in more care.

Now, we are playing a little bit of catch-up in terms of the electronic systems identifying patients and getting them the care that they need. But later stages of the incentive program are focused on actually sharing data for care coordination, making sure that transitions in care such as when a patient leaves the hospital that all of the information about their medications, what kind of care they received in the hospital can in fact be acted on and are acted on in order to ensure that they don't end up back in the hospital. So we may be sort of seeing some short term increases but over the long term we should be able to see decreases in care, and in fact some of the systems that have been operational with health care records for a longer period of time like Kaiser Permanente, like the VA, are already showing the evidence and have been showing the evidence for quite sometime. The other evidence I would point to is the ability of patients to get their data and to get it in a form that's usable for them, that they can take action on it.

Mark Masselli: We are speaking today with Deven McGraw, Director of the Health Privacy Project at the Center for Democracy & Technology, which is focused on developing workable privacy and security protection for electronic personal health information. We want to let our listeners think a little more about HIPAA which is the acronym HIPAA for the Health Insurance Portability and Accountability Act. So talk to our listeners, who are consumers, a little more about what the red letter issues are around HIPAA but also to some of the practices really are kind of afraid of sharing this data.

Deven McGraw: HIPAA is, in the view of someone like me who is a privacy advocate, HIPAA is a wonderful wall. It really sets some boundaries for how your doctor and the hospital that you might go to, there are specific rules that they need to follow about what they can and cannot do with health data. And while the rule is not perfect, it certainly is far better to have those rules in place than to have the type of environment that patients face when they do health searches on the Internet for example, or they share health information on Facebook because it's valuable to them to be able to network with other people who have their disease, or they are using a mobile app to manage their health care. Those technologies are not covered by HIPAA. It's just an artifact of HIPAA really being about getting the health care industry to use standardized claims and to bill electronically. And so it was never enacted as an overarching privacy law, and the privacy rules as a result only apply to the entities that are within that ecosystem. And so when you as an individual are entering health data into the less regulated marketplace, it's really incumbent on you to read the policies of the entities with whom you are sharing data. So whether you download a health app on your phone, the extent of your protections are in that privacy policy, and if you read it and you don't understand it or you see information sharing language in there that makes you uncomfortable, your recourse is really not to use it. I call it being aware before you share.

Now, in terms of getting your data from your health care providers, you are exactly right that a lot of providers are really reluctant to do this. Some of them genuinely think that HIPAA doesn't allow them to share data with patients and others would just prefer not to share data with patients out of fear of what the patient might do with that data. And the reality is that the providers don't have the ability to say no. HIPAA gives patients a right to their information, and when you make a request, they need to comply with that request within 30 days. If you go to your health care provider and you ask for a copy of your record and they say no, they are wrong, and you can complain actually to the Office for Civil Rights, which is in the Department of Health and Human Services that your HIPAA rights have been violated because that information you have a right to access it. But at the end of the day what's really going to move the needle on patients being able to access their data is when more and more physicians and hospitals realize that sort of patients are partners in delivering good care and it's actually to their advantage to provide patients with their data. Because most patients don't sue, right? Patients want to get their data because it's about them and it's relevant to their health care, and at the end of day, most providers that have taken steps to look at patients as equal participants in their care and provide information regularly, really see the gains in terms of how well their patients do and how their patients feel about the doctor-patient relationship. It makes a difference and it makes a positive difference in those circumstances.

Margaret Flinter: We have been speaking today with Deven McGraw, Director of the Health Privacy Project at the Center for Democracy & Technology. You can

learn more about her work by going to www.cdt.org. And Deven, thank you so much for joining us on Conversations on Health Care today.

Deven McGraw: Thank you.

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Mark Masselli: At Conversations on Health Care, we want our audience to be truly in the know when it comes to the facts about health care reform and policy. Lori Robertson is an award-winning journalist and managing editor of FactCheck.org, a nonpartisan, nonprofit consumer advocate for voters that aim to reduce the level of deception in US politics. Lori, what have you got for us this week?

Lori Robertson: Well, Representative Louie Gohmert claims that a poor guy out there making $14,000 is going to suffer under the Affordable Care Act. Gohmert wrongly says the person earning that amount would pay extra income tax "If he cannot afford to pay the several thousand dollars for an Obamacare policy". But this so-called poor guy would be eligible for Medicaid or heavily subsidized private insurance depending on where he lives, and he can't be penalized if he decides he can't afford it. The law expands Medicaid to include those earning up to a 138% of the federal poverty level. $14000, the figure Gohmert uses, is a 122% of the poverty level, making this hypothetical person eligible for Medicaid. Of course, not every state is going to expand Medicaid. 21 states are opposed to the expansion, including Gohmert's home state of Texas. In those states, someone earning $14000 would be eligible for significant federal subsidies to help pay for private insurance on the exchanges. But if this person decides not to buy that insurance, he can't be subject to a tax penalty for not doing so. He is eligible to receive a hardship exemption from the individual mandate. The Department of Health and Human Services published a final rule on July 1st that said anyone who is ineligible for Medicaid, because a state decides not to expand it, would be exempt from the requirement to have insurance. And that's my fact check for this week. I am Lori Robertson, Managing Editor of FactCheck.org.

Margaret Flinter: FactCheck.org is committed to factual accuracy from the country's major political players and is a project of the Annenberg Public Policy Center at the University of Pennsylvania. If you have a fact, that you would like checked, email us at www.chcradio.com. We will have FactCheck.org's Lori Robertson check it out for you here on Conversations on Health Care.

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Margaret Flinter: Each week, Conversations highlights a bright idea about how to make wellness a part of our communities and everyday lives. When Derreck

Kayongo was a young refugee living in Africa, he learned the true meaning of survival.

Derreck Kayongo: Child of war can be simply described as a kid caught between a rock and a hard place. It's finding all your pieces and trying to put them back together.

Margaret Flinter: Rescued by an aid organization and brought to the United States, he knew he had to do something to make a difference in the lives of those many children left behind, children displaced by war, orphaned by disease, living in extreme poverty. 2.4 million children die each year from lack of access to basic sanitation.

Derreck Kayongo: We have about two million kids that die of sanitation issues mainly because they don't wash their hands.

Margaret Flinter: And when Kayongo learned that hotels around the United States dispose off 800 million bars of soap every year, he knew that was a resource to tap into.

Derreck Kayongo: 800 million bars of soap that the hotels throw away in the US alone every year.

Margaret Flinter: He founded the Global Soap Project. The discarded soaps are gathered and processed at a plant that sanitizes, melts and reforms new bars of soap that will be distributed around the world to children and families living in poverty or in disasters zones like Haiti. And with it, the children are given lessons in basic hygiene, some learning for the first time how to thoroughly wash their hands and why. The Global Soap Project earned Kayango the distinction of one of CNN's Hero finalists, and he was also a winner in the Annual CLASSY Awards, which support philanthropic work that improves health and wellness around the globe. A simple idea, repurposing the waste of soap and providing one of the most simple tools of hygiene to those in need around the world, now that's a bright idea.

(Music)

Margaret Flinter: This is Conversations on Health Care. I am Margaret Flinter.

Mark Masselli: And I am Mark Masselli, peace and health.

Conversations on Health Care, broadcast from the campus of WESU at Wesleyan University, streaming live at www.wesufm.org and brought to you by the Community Health Center.