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Mark Masselli: This is Conversations on Health Care. I'm Mark Masselli.

Margaret Flinter: And I'm Margaret Flinter

Mark Masselli: Well Margaret interesting development in Washington this past week acting administrator of the centers for Medicare and Medicaid, Marilyn Tavenner was on track to finally being confirmed by the Senate a year and half after being installed but that is now being held up by a surprising player.

Margaret Flinter: Well Tavenner was chosen to replace Don Berwick who is the acting administrator before her. His confirmation you remember was blocked with the Republicans who are really angry over Berwick's appointment during a Congressional Recess, but now a Democrats holding up the confirmation of the President's choice for CMS Administrator which is a very influential position.

Mark Masselli: Just when it look like there might be some rare Bipartisan Agreement on Capitol Hill, Democratic Senator Tom Harkin announce that he was with holding support for Tavenner he's using his appointment to register his disapproval of the Obama Administrations budget proposal, which is taking several hundred billion dollars out of the Affordable Care Acts prevention fund to pay for other parts of the program.

Margaret Flinter: And as we know Mark that prevention fund is providing support for some very important community level prevention strategies across the country. It would be a shame though to see more uncertainty in leadership and avoid CMS Tavenner's full appointment continues to be held up.

Mark Masselli: And that it would be speaking of prevention, interesting policy changes could be underway because of the Affordable Care Act which provide support for screening of all kinds of diseases.

Margaret Flinter: And the US Preventive Services Task Force which we think of is something of the Bible of preventive services is likely going to recommend that testing for HIV/AIDS be included as a standard screening that all patients receive.

Mark Masselli: So this is a significant shift in policy, HIV is still a big health problem in this country of the 1.2 million Americans who have HIV 20% don't know it.

Margaret Flinter: That's right, Mark. And just to put another number on it there are 50,000 new cases of HIV infection each year reported in this country. So this would be a great step forward in reducing transmission because knowing you're positive is the first to making sure you don't transmit it.

Mark Masselli: Our guest today is working to improve the collection of meaningful health data that could impact public health around the country. Dr. Kenneth Mandl is Director of the Intelligent Health Laboratory at Boston Children's Hospital.

Margaret Flinter: Dr. Mandl is a pioneer of consumer health information and bio surveillance technologies and he's been exploring ways to create truly integrated health information systems that allow for much better sharing of health data.

Mark Masselli: FactChecks.org's Lori Robertson tries to clear up some confusion over who will get tax credits for purchasing health insurance once it's required in 2014.

Margaret Flinter: But remember what the topic you can hear all of our shows by going to CHCradio.com

Mark Masselli: And as always if you have comments e-mail us at CHCradio.com or find us on Facebook or Twitter we'd love to hear from you.

Margaret Flinter: We'll get to our interview with Dr. Kenneth Mandl in just a moment.

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'm Marianne O'Hare with these Healthcare headlines. The sequester in healthcare, well Congress had hurriedly moved to remove sequester cuts from the Federal Aviation Administration. Folks in the healthcare sector are warning of greater calamity due to the entrenched cuts forced by a Congress, refusing to authorize funds to cover programs that ran out of funding in March. When the cuts cost the FAA to enact mandatory furloughs leading to thousands of flight delays, certain members of congress booked and move to restore funding for the FAA alone.

Cancer clinics across the country have seen their fund slash due to this sequester and many clinics are having to put Medicare and Medicaid patients on hold, for necessary chemotherapy and they're having to turn away thousands of potential new patients. The irony is those patients being turned away by clinics are turning to hospitals for care where the treatments are far more costly. Advocates are calling for another act of congress to restore funds to those patients in need, at the nation's cancer centers.

And in the speech this week President Obama word of dire consequences a thousands of medical research programs across the country funds that are necessary for many of those research programs have been cut off since the beginning of March. His fears have been echoed by many including National Institutes of Health Director Dr. Francis Collins, who led the team that mapped the human genome, he said for every research dollar the government spent on that four billion dollar quest, it's yielded roughly a 120% return.

And grooming or the kiss of death of report out of the University of California Berkeley looked at 32 of the most common lipsticks and lip-glosses on the market. They detected lead, cadmium, chromium, aluminum and five other toxic metals some of which were found at all levels that could raise potential health concerns, you might want to read the label before you packer up.

I'm Marianne O'Hare with these healthcare headlines.

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Mark Masselli: We're speaking today with Dr. Kenneth Mandl, Director of the Intelligent Health Laboratory, Boston Children's Hospital's Informatics Program. He's also co director of the Smart Platform Project sponsored by the Department of Health and Human Services which is seeking to create an app store for health, Dr. Mandl is also co director of CDC's Center of Excellence and Public Health Informatics which focuses on consumer technologies like personally controlled health records. Dr. Mandl is the Associate Professor at Harvard Medical School and is considered a pioneer of consumer information in biosurveillance technology. Dr. Mandl welcome to Conversations on Health Care.

Dr. Kenneth Mandl: Well thank you so much.

Mark Masselli: Kenneth you've been called the pioneer in the emerging world of bioinformatics that is use of real time observational data to monitor those with acute or chronic disease. You and your colleagues in the informatics program at Boston Children's Hospital created the -- indeed, all the electronic health record system back in 1995 real pioneers, and interactive EHR that allows patients to managed their health records. Medical practices have slowly transition to the use of electronic health records and you say we're at this critical juncture in health information technology. So, could you give us an assessment of where we are with health information technology in this country or more importantly where we aren't?

Dr. Kenneth Mandl: As you know almost 18% of the gross domestic product is spent on healthcare, we have the highest per capita spent on healthcare in the world. And sadly even with that use of our treasure out outcomes don't compare well to other nations. If you talk to the folks at the headquarters of Wal-Mart they can tell you nationwide how many boxes of Oreos are on their shelves in real-time. In healthcare, we don't collect and store data in a way that makes it easy to analyze and in fact on many patients we don't collect electronic data at all. Another problem is that when a hospital does collect data electronically they store it locally, this leads to medical errors and also duplicate testing, both of which are unhealthy and expensive for patients. There's over 700 different electronic health record products and each one can be customized, so under the stimulus the American recovery and reinvestment act, a massive federal investment health IT adoption has moved the needle from around 5% to around 50% of healthcare settings that are equipped with electronic records and as a result data are accumulating

rapidly. So now the challenge is can we actually begin to align around achieving specific goals?

Margaret Flinter: Ken, we're promoting that they need to become unified and integrating the data to become a learning system. So perhaps for the benefit of our listeners, talk to us about what you mean by this learning system and how as the electronic health record systems that you've worked with facilitators research at Boston Children's as well.

Dr. Kenneth Mandl: Well it would surprise many people to know that the healthcare system has few mechanisms to improve itself based on its successes or failures. So when a physician makes a decision about what therapy to give to a patient that is largely based on her own experience. If a therapy doesn't ameliorate the patient's condition, that physician may get wiser and refine her practice when treating the next patient. But what's not happening is that the health system isn't getting smarter as a result evolving individual physician's experience. So we want to create a learning health system and therefore we need to learn to collect data on all the patients all the time, you know, very few patients are actually on research studies well under 1% and in terms of feeding back data into a quality improvement process that tends to happen very focused areas within healthcare it's not happening globally. So we need to be able to collect data and not just from patients in hospital, but also from patients at home. Most patients are having their outcomes and their improvement's not in the hospital but at home, we need to be able to take the results of what we've learned in this learning health system and deliver it back to the point of care and to patients at home so that better decisions can be made.

Mark Masselli: Ken, I want to pull a thread a little on that because you wear a number of hats and one of those is that you're co director of the CDC Center for Excellence in Public Health Informatics, so I guess the question is how is electronic health records in the aggregation of real time health data and all of these center for excellence impacted public health analyst and prediction it institutions where they may be deployed, there's a little bit of disconnect out there between just having electronic healthcare records, you are saying earlier in the ability to make some big transformations in healthcare. Can you talk more about that?

Dr. Kenneth Mandl: Yeah. So it turns out that even very small amounts of data collected on whole populations can have an enormous impact on our understanding and our treatment. We were looking at the spread of influenza and we found using very simple data stream that was what the patient told the nurse they had come to seek care for, it's called the chief complaint and we process these chief complaint and we aggregated them and we were able to actually use those little strings of information to conduct surveillance across wide areas for the flu.

First of all it turned out to be a better way to do surveillance for the flu than anything that was being done through much more heavy and overburdened systems that were producing results that were not very timely. We were able to actually make very

interesting discoveries about the flu, for example we were able to show using data from pediatric institutions and adults institutions and outpatient practices combined, we could see this three and four year olds were the ones spreading the flu. And I realized looking at these data that the spread of flu was happening partly because there's this tremendous opportunity for it to incubate in daycare centers where kids are just coughing all over each other, and spreading it very effectively through the daycare and then bringing it home. And it turns out that the rates of flu and the patterns of flu in three or four year olds were highly predictive of the elderly dying of the flu three months later, because we can collect it uniformly and universally we were able to figure out something very important and it had an impact because four months after we published our findings the CDC added three and four year olds to the immunization schedule for influenza.

Margaret Flinter: Sure we have the opportunity to identify -- I think President Reagan used to call them the thousand points to look around the country where exciting things are happening and one that we've focused on is the Blue Button Initiative, which was ruled out as you know with the veterans health administration first and he's been quite successful in getting veterans interested in managing their health records electronically. How does your system differ from Blue Button or build upon ---

Dr. Kenneth Mandl: Absolutely Blue Button is a very simple and very well marketed concept it means that a patient can get a copy of their electronic health record data and I'm thrilled to see that it's there. It's called the Blue Button because in order to make it very easy for a patient to understand what they're doing, the graphic on the web browser of a patient accessing their health record in the veteran's administration looks like a shiny blue button. They can push it and actually get an extract of their data, now it's a very interesting piece of the -- sort of health information economy that has not been fully addressed which is what about patients getting their own information. So something called HIPAA or the Health Information Portability and Accountability Act which was passed in 1996 was actually supposed to get patients copies of their data. There's been various blockades to something we call data liquidity and the high tech act which was passed in 2009 was also supposed to get patients copies of their data right away, but there were various impediments again to the data actually becoming liquid. Finally at this point in time with efforts like Blue Button demonstrating at least that there's feasibility of patients accessing their data, we're looking at federal requirements in 2014 that really should finally promote export of data from electronic health information systems out to the patient.

Mark Masselli: We're speaking today with Dr. Kenneth Mandl, Director of the Intelligent Health Laboratory in the Boston Children's Hospital Informatics program, he also co-leads a program funded by the department of health and human services the smart platform which is seeking to create an App store for personal and public health. Ken, the ultimate goal of the smart program is to create a unified system that will allow a single medical app to be enabled for use across multiple electronic health systems. So tell us a little more about the system your team has developed in -- how does this system

compare to the way the apple iPhone promotes innovation in the app development world.

Dr. Kenneth Mandl: To leverage that investment and then to -- and to transform healthcare into a data driven enterprise. The medical industrial complex must be able to freely innovate at the point of care and with patients at home, so what happens is right now let's say there's an innovative application developed by a small company that's really understanding how to help the patients managed their medications but it would like to have access to data from the electronic health record after all we have invested all these money in electronic health record data, shouldn't those data be available. But what happens to a company like that now, is that they try to integrate at each side of care and integration at each hospital or practice and it can take a very long time. So instead wouldn't it be interesting to take the kindest model that Steve Jobs was so successful at, a platform for apps. So that this innovative company could simply put their app into an App Store just like a Smartphone users can download an app use it right in their electronic health record system. They compete with each other for ratings they compete with each other on price, there's really nothing like that going on in healthcare information technology now. So what we're trying to do is create an ecosystem where the innovators get a broad market for those apps, because they were in an app store so they put it in the app store, and anyone can access it.

Margaret Flinter: Well I think we look forward to going to the app store and finding something in the electronic record division that doesn't have six zeros after the three that you just talked about ---

Dr. Kenneth Mandl: Right when I first started the project I thought that these apps might cost, you know, a hundred thousand dollars instead of having six zeros. But now I think they might cost just like other things in the app store, you know, \$4.99.

Margaret Flinter: Well there you go, we're going to look forward to that one but, you know, we're obviously scaling up to full implementation of the Affordable Care Act. But certainly within the Affordable Care Act beyond coverage there is this push for more efficient care delivery and the accountable care organization. So when we look at the ACO you've been I think quoted as saying that you can't have accountable care if you cant's count. So tell us how do you envision the smart system empowering the accountable care organizations to really share that health data and innovate in a way that does been the cost cur vent and get us better health outcomes.

Dr. Kenneth Mandl: So what the app store for health projects smart platforms what that does is it allows us to have a universal façade on top of this very diverse ray of electronic health record product, this provides a tremendous economy of scale for reforming, reshaping the healthcare system, we'll have new delivery practices certain types of care will be shifted into outpatient settings or retail health clinics and an important outcome of the investment in health information technology was suppose to be that we could provide decision support to doctors. To help them provide better and more effective care, and we don't have good way to change the data we collect let's say

the centers for disease control is investigating a pharmacy that compounded a steroid medication that ended up getting contaminated and was distributed very widely causing a large number of infections when that steroid was injected. The CDC had to go out there and a national scale conducts an investigation and also alerting physicians. So if you have an app based approach the CDC can release one app and it could be used in emergency departments and outpatient settings all over the country at once.

Mark Masselli: Ken, you know, I wanted to go back to your answer around influenza which I found quiet fascinating about the work that you done and people are using social media in so many different ways, we've had Jamie Heywood from Patients Like Me on the show speaking about the limitless potential and medical research when you have a group of people motivated to find cures for certain illnesses and willing to share their real time data. What are some of the social media tools you're interested in that will be able to facilitate more rapid meaningful research in healthcare?

Dr. Kenneth Mandl: You know crowd sourcing of information is proving to be an extremely powerful tool. And also people are in social media all the time, they're both on the standard mega platforms like twitter and Facebook and they're also on health specific social media sites, like Patients Like Me, like a site that we have done research with under the CDC center of excellence called two diabetes where we've actually been able to crowd source intelligence from across their population of 35,000 people with diabetes, who are willing to actually enter and share information with us. So the ability to just reach out and essentially take the pulse of an online social network enables really new approaches to what might be called participatory medicine, it's not just the data in from laboratories that are important in understanding and improving health. It may well be that there are other sources of big data like twitter, like Google flu trends that are actually very important to get to our doctors at the point of care. So social media is producing knowledge and it's also engaging patients, and its engaging patients at a much higher rate than other forms of health information technology have done to date.

Margaret Flint: We've been speaking today with Dr. Ken Mandl, Director of the Intelligent Health Laboratory in the Boston Children's Hospital Informatics Program. He's also the co director of Harvard Medical School Smart Platform Program. You can learn more about his work by visiting Children's Hospital. Org/Mandl, that's M-A-N-D-L. And Ken, thank you so much for joining us on Conversations on Health Care today.

Dr. Kenneth Mandl: Thank you, it's been a pleasure.

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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 healthcare 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 Mark and Margaret there have been plenty of questions about the healthcare law and premiums. In particular what the law will mean for premium on the state or federal around exchanges, where people who by their own insurance will not for coverage. These exchanges change the way the individual market operates, now this has been a market with hard to predict premiums as it was and the bottom line is that no one knows exactly what premiums will cost when the exchanges are up and running. Insurance company say premiums will go up because they will be required to accept all customers including those of pre existing health conditions. Advocates of the law say there will be a much larger pool of policy holders including more young and healthy people who will buy insurance because they'll be required to do so.

A 2010 survey by the Kaiser family foundation, found an average annual premium of seven thousand one hundred and two dollars for a family of two or more. Premiums do tend to be lower than premiums for the employer sponsored plan but the individual market folks also tend to pay higher out of pocket cost, one thing we do know many of those buying coverage on the exchanges will get federal subsidies to help them do so. The most recent report from the non partisan congressional budget office projected up by 2023 80% of the 25 million people buying on the exchanges would get subsidies. How much will they get well the Kaiser family foundation has a subsidy calculator on its website that can give people a sense of whether they might be eligible and how much they might get it does give some estimate of what you might see in 2014.

And that's my FactCheck for this week. I'm 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 chcradio.com, we'll have FactCheck.org's Lori Robertson check it out for you here on Conversations on Health Care.

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Mark Masselli: Each week, Conversations highlights a bright idea about how to make wellness a part of our communities and everyday lives. America is aging and along with that fact managing more and more chronic disease while many of these illnesses are manageable outside the clinical setting some put patients at higher risk for medical emergencies while conducting the business of their lives. Inventor Cesar Camacho thought why not make a bracelet that can be comfortably worn with a portable software program and USB plug that can be used to input all of the essential medical data into any computer. He developed the care of medical history bracelet on which a patient's medical data is stored things like blood type chronic illness descriptions, medications even copies of x-ray images or CAT scans.

Cesar Camacho: So, you have a general information about yourself like insurance policies, your telephone numbers, and addresses for all your doctors.

Mark Masselli: The care of medical history bracelet can also store other vital information if the patient is having a medical crisis or can't speak for themselves.

Cesar Camacho: It is important to have the right information at the right time, and you know and nowadays as you know we got the best doctors in the world, but they're only as good as the information that you provide them.

Mark Masselli: The care of medical bracelet also has been program to process data from brail text in currently comes in bilingual versions both in English and Spanish, a simple wearable USB device that can offer critical medical information for patients who are unable to speak for themselves, assisting medical professionals coming to their aid in a crisis, now that's a bright idea.

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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.