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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, the negotiations continue in Washington over the much talked about fiscal cliff.

Margaret Flinter: And it's interesting to know Mark that words like compromise and common ground are cropping up more frequently in the discussion over what to do about those fiscal changes looming on January 1, 2013.

Mark Masselli: It rings in the New Year and also it might ring out the Bush era tax cuts which expire January 1st and spending for a number of social programs, including Medicaid will see an instant reduction unless some kind of negotiation is found.

Margaret Flinter: The President wants to see taxes increase only on the wealthiest Americans while the Republican leadership is still calling for those social programs to be put on the table for discussion, including the Health Care Law, hard to see those as social programs.

Mark Masselli: It's true. Déjà vu, all over again because there really hasn't been much progress from either side on their respective ideas about how to solve the problem, but it is interesting to note that more politicians in the GOP are backing off of their no-tax increase pledge. Mr. Nordquist may not be happy about that.

Margaret Flinter: So we'll see how the negotiation progresses in Washington with fewer politicians perhaps strong armed into just saying no.

Mark Masselli: Whatever the outcome of the fiscal cliff discussions could have a big impact on the areas including health care education and infrastructure rebuilding and probably even social security.

Margaret Flinter: But it's also unlikely that the Affordable Care Act will be dismantled or in my opinion, tempered with to any significant degree to make way for that tax compromise, but we'll see if I'm wrong.

Mark Masselli: That would be good news for today's guest, Dr. Joe Selby who is the executive director of the Patient-Centered Outcome Research Institute, also known as PCORI.

Margaret Flinter: PCORI is one of the not so well-known provisions within the Affordable Care Act and Dr. Selby is one of the nation's top health care researchers and is using his expertise and particularly his focus on the patient experience to advance PCORI's mission of promoting research that gives us the data on health care practices that yield the best outcome for patients.

Mark Masselli: And we'll hear from Factcheck.org's Lori Robertson who looks at claims on Capitol Hill on the Health Care Law, but no matter what the topic, you can hear all of our shows by Googling CHC Radio.

Margaret Flinter: And don't forget, if you have comments email us at CHCRadio.com or find us on Facebook or Twitter because we love to hear from you.

Mark Masselli: We'll get to our interview with Dr. Joe Selby in just a moment.

Margaret Flinter: 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 health care headlines. The Health Care Law continues to be a topic of contention, legally and politically. Discussions are under way this week on how Congress plans to deal with the upcoming fiscal cliff when a number of social programs see their financial support ending and a number of Bush era tax cuts are due to expire.

Republican House minority leader John Boehner says, "There can be no discussion about compromise on revenues without the Health Care Law being part of that discussion." And the Supreme Court has cleared the way for another legal challenge to the law; Liberty University and Christian College in Lynchburg, Virginia claims the law forces their organization to subsidize abortions and the contraception. The High Court has decided to allow their challenge to be heard in oral arguments in the 4th District Court of Appeals, paving the way for the challenge to move closer to a hearing before the High Court. There are numerous other religious-based challenges to the Health Care Law waiting in the wings.

Meanwhile, the American Academy of Pediatrics is weighting into this controversial territory. They issued a statement this week, urging pediatricians to pre-prescribe emergency contraception, known as Plan B ahead of time to all teenage girls under 18. Plan B is available without a prescription for those 18 and older. This would eliminate the need to seek out a doctor for teens worried about the possibility of a pregnancy.

When you think of foods that seem synonymous with a healthy diet, grapefruit comes to mind but folks taking any number of medications should take note. A study out of Canada shows that properties in grapefruit can alter or inhibit the efficacy of as many as 85 different kinds of drugs, including statins; commonly prescribed for cholesterol and high blood pressure. The side effects occur when fouranocoumarin, a chemical in grapefruits, binds with enzymes and prevents them from properly breaking down the drugs. ABC News has posted a full list of the drugs at list on their news website.

I'm Marianne O'Hare, with these health care headlines.

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Mark Masselli: We're speaking today with Dr. Joe Selby, executive director of the Patient-Centered Outcomes Research Institute, known as PCORI, an independent nonprofit health research organization, authorized by the Affordable Care Act. PCORI was created to provide patients and providers the most informed prevention, diagnosis and treatment options in health care by conducting rigorous research on national patient outcomes. Dr. Selby is a family physician, a clinical epidemiologist and recently served as the director of the Division of Research at Kaiser Permanente where he oversaw 500 research clinicians and 250 ongoing studies. Dr. Selby is an author of more than 200 peer-reviewed articles and continues to focus his study efforts on diabetes and quality improvement. Dr. Selby, welcome to Conversations on Health Care.

Dr. Selby: Thank you very much, Mark and Margaret. It's a real pleasure to be here.

Mark Masselli: Well, we saw that President Obama is re-elected, which really bodes well for the continued advancement laid out in the Affordable Care Act which established PCORI to shift the focus in health care research to really take into account the patient-centered experience and to evaluate patient outcomes so that improved quality on patient outcomes, government health policy and practices. Could you tell our listeners a little more about PCORI and what's new and innovative about your approach, and what kind of impact you expect to have on patient outcomes in health care?

Dr. Joe Selby: Yes. PCORI's brand new and I want to emphasize that PCORI is a research funding organization, so we will be providing funding to researchers, to clinicians, to patients; particularly when they join together to apply for funding and we are interested in research questions that provide useful information to patients and their caregivers and their clinicians as they face critical health care decisions. It's the existence of PCORI and its placement in the Affordable Care Act recognize that despite the fact that we actually spend $150 billion or $160 billion a year on clinical research in this country alone, it's still the case that patients often get to a decision point and don't have practical information that really compares two or more options that form a decision that patients have to make. So, we focus on trying to fill that void, provide that clinical information and we pay particular attention to what works for whom. So we recognize that the same treatment doesn’t work exactly as well for every patient and sometimes, one has to tailor these treatments to who the patient is.

Margaret Flinter: So Dr. Selby, the PCORI model set out to establish a new format for researching outcomes to involve patients and their providers, and to do it using comparative clinical analysis and in an article in Health Affairs, you outlined really two very different research approaches; investigative generated research such as clinical drug trials by pharmaceutical companies or testing of surgical devices, but also a patient-stakeholder led approach. Tell us about the difference between these two research protocols and how does that play out in a research protocol. What does it mean to have a patient-stakeholder approach?

Dr. Joe Selby: Well, we’re trying to get the patient’s voice and the clinician’s voice into the research process, and we think that if we do that it’s more likely that when the research is done it’ll answer the right questions. Often times, the research is done; it’s a very elegant research, it just doesn’t quite answer the question that clinicians were asking or patients were asking. So, we have two approaches to getting those right questions.

They can both be just about any kind of clinical questions and we really think both pathways are important. We send out broad announcements, explaining the kinds of research comparisons that we’re interested in. We say, send us the most compelling questions and when you do, join with patients, join with the relevant clinicians and tell us why this question is important to patients. So we’re very open and interested in what researchers and patients and other stakeholders come up with on their own and submit to us, but sometimes patients and clinicians and others aren’t really prepared to just sit down and write a research proposal, and so we engage patients and their patient organizations, clinicians and their organizations in a kind of ongoing brainstorming session that looks for the right questions, and then we invite them to join us in prioritizing them and helping us decide which questions, if answered, would be the most likely to provide information that’s lacking now; the most likely to change practice, the most likely to improve outcomes.

Mark Masselli: Dr. Selby, you bring a nice combination of qualities to your position; you are a brilliant research leader and you are a tireless patient advocate. You’ve identified five key target areas in particular. Can you tell us a little more about what they are and how will they govern where PCORI grants go in the future?

Dr. Joe Selby: The statute itself told us that before we get started funding research we had to get together with the stakeholder community and identify the priorities that would guide our research. Now they could’ve been very narrow priorities. We could have focused in just on five diseases, if you wanted. We didn’t. We named five broad priority areas and I’ll them to you in just a minute but I’ll just say that we think they fit together nicely. So here is the first one; it’s called Assessment of Options for Prevention, Diagnosis and Treatment. That really gets at questions at the patient level about which treatment or which preventive measure works best for me. That's kind of the classic comparative effect in this research paradigm, and that's only one of our five priorities.

The second one is called the Improving Health Care Systems, and so that just recognizes what I know, you two know, that the system where patients get their care has a lot to do with whether they hear the options, whether they get the options, whether they get follow-up, whether their care is coordinated. Best for whom, so improving health care system is the second.

The third is called Communication and Dissemination Research and that just recognizes the fact that once you get the evidence collected and established, you've got to find ways to get it out so that people are aware of the evidence.

The fourth is Addressing Disparities, and that just is based on the widely recognized fact now that treatments don't work the same for everybody. So, we start from the fact that there are disparities and we say, we will fund research that addresses ways to eliminate those disparities.

And the fifth is a priority about building the infrastructure to do more of this research. We really think we need to change the culture in this country so that out in the clinics, out in the hospitals, out in the health care systems we are asking and answering these questions all the time that patients and our clinicians come to recognize that when you don't know the answer; when you're making decisions and advising patients on what to do and you realize you don't really know the answer, the best thing to do is ask the question and get the answer, and for that you need an infrastructure. You need to put clinical data together into large databases. You need to find ways to analyze those data more effectively so you need better methods, and we need to train both researchers and clinicians, and patients to participate in this research. That's the fifth one, our infrastructure priority.

Margaret Flinter: That third piece; the community participatory approach can be very challenging. I wonder if you could share with our audience what you've seen around the country in terms of best practices of how people are bringing communities of patients together, what are people using as strategies to get at that patient-stakeholder involvement that you've seen as being successful.

Mr. Joe Selby: Well, first let me say Margaret that I completely agree with you. I like to say sometimes that what we do here at PCORI is community-based participatory research applied to clinical questions. We are not by and large studying issues in the community as much as issues in clinical decision making, but we use all the principles that led to the development of this community-based participatory research movement and we've started, we have a very active website with lots of ways for patients to get engaged with us. We talk about building a patient and patient advocacy community across the country and that's growing rapidly.

We have online ways for patients to submit questions that we then process and put into the prioritization scheme.  Very exciting, patients have a hand in formulating the questions and in collecting and looking at the data, and that is just one of many, many examples.  Many online communities are already formed; often organized around a particular disease, often around rare diseases and those patients have come together in substantial part because they want to contribute to research.  So, we're looking for ways to partner with them, we're looking for ways to link these kinds of online communities with the clinical data that exists for them in electronic health records.  So we think that's a part of the solution.

We think that surveys and particularly social media type of surveys are a good way to keep our finger on the pulse.  We look for a lively, vibrant, two-way program of communication.  We also are forming advisory panels.  So these will be smaller numbers of people but selected from large pools of applicants to be representative to help guide PCORI and advise PCORI.  So they'll watch with us over time and keep us hopefully on the cutting edge of patient engagement. There is a lot to be learned, just about how to do it right.

Mark Masselli:  We're speaking today with Dr. Joe Selby, executive-director of the Patient-Centered Outcomes Research Institute, an independent nonprofit health research organization, authorized by the Affordable Care Act.  PCORI was created to provide patients and providers the most informed prevention, diagnosis and treatment options in health care by conducting rigorous research on national patient outcomes.

I want to sort of pull the thread on one of the five priorities that you talked about before and that was really on communication and dissemination.  I know we're engaged with the Dartmouth Institute on the clinical microsystems change process and I know one of the biggest problems and challenges that we have; there are a lot of good practices and important things for people to do, but that change process is very difficult out in the clinical setting.  So past sharing the information, what other tools in the tool belt are you giving practices to help them with this transformation that they are all going to go through over the next many years?

Dr. Joe Selby:  It's a very good question Mark, and you are right that systems and the clinicians that work in them don't feel like they have a lot of time on their hands to sit around and discuss change.  It's happening on the fly; as they are very busy seeing patients and trying to make decisions.

I think one principle that we're pretty convinced is important is that there has to be something in this for everybody.  So, clinicians and patients have to feel like they are getting something out of this process of change. It can't in any way be a top down approach. So that takes us back to our principle of involving these key players from the beginning. Often, these ideas are not one size fits all ideas. So the same intervention doesn't necessarily work for 100% of patients, and if you're not careful your interventions will improve care for some patients but they could actually worsen disparities or differences between patients. So we think that is done better with patients at the table.

The third thing to say is that we will be funding implementation research, so we're very interested in how you take evidence and put it into practice, but a lot to be learned as you suggest.

Margaret Flinter: But Dr. Selby, I think one of the dichotomies certainly that we've seen historically is that the research lives within academia, the practice lives within the community and the gap and the chasm between the two can be very broad because it takes of course skill and resources, and training to do the research. Maybe you could speak to us a little bit about how are you seeing people bridge that gap, how are the universities and the traditional centers of research connecting with the community-based partners to do this critical work of designing the research studies that address the five key areas that PCORI is focusing on?

Dr. Joe Selby: I think it is going to be a change, having been one of those researchers I think it does represent a change. In our very first announcements issued last May, we laid out these instructions that you must have relevant patients and other stakeholders involved in the team and we've got on the order of 1,300 letters of intent, people saying they were submitting applications but when the application deadline came, we had just 488 and that's a remarkable fall-off. And when we polled people; the applicants who had said they were going to send us proposals, they told us that the main reason they didn't was because it was taking more time than they thought to establish these connections.

So, that's a signal to us that you're right, it's difficult but on the other hand the availability of research funding and the requirements we put in are having an effect and over time, we're going to waste a tremendous opportunity if we don't study these interactions and learn from them what works the best, but we are clearly seeing these partnerships. I mean they were there before we came on the scene and our funding is strengthening those partnerships. We really hope also that we see some new players at the table in terms of who is leading these and we'll be delighted to see applications come in from community clinics and neighbor health centers, patient organizations; we'll be delighted to see them in the lead of these applications and bringing researchers along to make sure we get the message right.

Mark Masselli: Dr. Selby, we'd like to ask all of our guests this final question; when you look around the country and around the world, what do you see in terms of innovation and health care that our listeners at Conversations should be keeping an eye on?

Dr. Joe Selby: There is a lot of things going on. I think this appreciation is we've been talking about already of the critical care of systems and the potential for systems. Most people still get their care in settings that really you'd have to admit are not part of organized systems. So there is just a huge potential for organizing care more thoughtfully for aligning the incentives of the various players so that the people are talking to each other and they are on the same page; they are trying to accomplish the same thing which is improved outcomes.

So I think systems have just an amazing amount going for them and the Affordable Care Act recognizes that in many, many ways. And the second is this relatively new idea that whether we're talking about pills or surgeries, or systematic approaches to care or health education, they are not going to work the same for everybody and we have to pay a lot more attention than we have to the fact that patients are different. So whether we're talking again about medication, surgeries or system interventions; more attention to the patients and in tailoring those interventions, I think it's going to lead what some call personalized medicine but it's also going to just lead to smarter medicine and more efficient, and goodness knows we need more efficient medicine.

Margaret Flinter: We've been speaking today with Dr. Joe Selby, executive-director of PCORI, the Patient-Centered Outcomes Research Institute which is an independent nonprofit health research organization committed to providing patients and providers the most informed prevention, diagnosis and treatment options in health care by conducting rigorous research on national patient outcomes. You can find out more about his work by visiting www.PCORI.org. Dr. Selby, thank you so much for joining us on Conversations on Health Care today.

Dr. Joe Selby: Thank you, Mark and Margaret.

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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: Mark and Margaret, we looked into claims about the Affordable Care Act from a conservative group called Americans for Tax Reform. The group had posted an image of what it said the IRS would require from individual tax payers because of the law but it makes false claims. The group said that tax payers would have to disclose personal health information to the IRS to prove they have coverage and that failing to comply with the law would result in “interest against your property” but the law says the IRS can’t file liens or levies, such as seizing property against those who don’t have insurance, and IRS officials have said the Agency won’t collect any personal health information, nor would it need to.

We don’t know the exact forms or procedures the IRS will use to determine whether tax payers have coverage or should pay a tax for not having it, but so far we know that health insurance companies will send the tax payers a proof of coverage form that individuals will then attach to their tax returns. As the former Commissioner Douglas Shulman explained in 2010; “The IRS will simply ask its individual tax coverage and name of the company,” he said and “match that information with the report from the health insurance companies themselves. Shulman said the IRS’s role has been “way overstated,” and that’s my fact check for this week. I am Lori Robertson, Managing Editor of FactCheck.org.

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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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Mark Masselli: Each week, Conversations highlights a bright idea about how to make wellness a part of our communities and everyday lives. Low literacy rates have been linked to poor health outcomes around the globe, so Nicholas Negroponte decided he should do something about that. The chairman emeritus of the MIT Media Lab has been on a mission since 2005, the year he launched one laptop per child whose mission is exactly that. Negroponte figured his organization could meaningfully change the lives of about 100 million children living in the world without access to education. He felt that such a sturdy child-friendly laptop, relying on solar power could change that statistic. What they found in this stage of the project was pretty astounding; not only were children learning to read and acquiring knowledge but they were also teaching their illiterate parents how to read.

Nicholas Negroponte: What if we go these parts of the world where there are no schools, there just aren’t any, there are no literate adults and of course the children are illiterate. 100 million, what can we learn from the kids teaching their parents is that we can try and experiment where the kids teach themselves, and that’s the new story.

Mark Masselli: Negroponte was so inspired by the children teaching the adults that he tried an experiment in an Ethiopian village that had no teachers, no schools, no literacy. That brought boxes of computers to the village, left them there with no one to instruct the children in any way.

Nicholas Negroponte: Within five days, they were using 47 apps per child, per day. Within two weeks, they were singing ABC songs in the village, and within five months, they had hacked Android.

Mike Masselli: Negroponte, speaking at a recent M-Tech Conference at MIT says this could enable a whole new way of teaching around the globe that effectively has the power to eliminate illiteracy and one hopes improve the economic and health figures of these children as well. The One Laptop Per Child Organization now has deployed three million computers in 40 countries in 25 languages. Distributing a simple durable laptop into the lives of children who would have otherwise been left illiterate, changing their world for the better and offering the promise of a bright future; now, that’s a bright idea.

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Margaret Flinter: This is Conversation 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 wesufm.org and brought to you by the Community Health Center.