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

Margaret Flinter: And I am Margaret Flinter.

Mark Masselli: Well Margaret, it's National Nurses Week, the week we honor the nursing profession and the nurses who do so much to improve the lives of patients in a multitude of settings, schools, clinics, medical practices, hospitals, and homes.

Margaret Flinter: Well, that's right, Mark. You know, there are some 2.7 million registered nurses in United States and other 700,000 licensed practical nurses, and also growing numbers of advanced practice registered nurses, all serving to improve the patient experience, to improve care, also to research and contribute new knowledge to the field.

Mark Masselli: I really like this year's theme, Margaret, Delivering Quality and Innovation in Patient Care. And as we know, nurses are driving those innovations on the front line of care everyday.

Margaret Flinter: And with the Affordable Care Act rolling out to full implementation at the end of the year, nurses, consistently rated the #1 most trusted profession in the United States, are going to play a vital role in helping people understand the health care legislation and in meeting their growing health needs, especially in primary care.

Mark Masselli: It's also National Mental Health Awareness Month, an area of health care that often gets short shrift.

Margaret Flinter: Not in our setting, I am happy to say where behavioral health is fully integrated with primary care and so essential to improving health outcomes. And the Obama Administration has made a significant commitment to improving access to behavioral health care for veterans but still, as in so many areas in health care, just not enough behavioral health clinicians to meet the need which is great. An estimated one in four Americans has some type of mental health disorder and a majority of these folks don't get the clinical intervention they need.

Mark Masselli: Very often, behavioral issues underlie many of the illnesses that we are treating, and addressing the whole patient is very important, including behavioral health which is so vital to the health and well being of the patient.

Margaret Flinter: Our guest today has been a leader in developing technologies that are helping patient communities in improving their health outcomes and in supporting each other. Dr. Roni Zeiger is the Former Chief Health Strategist at Google, now the CEO of Smart Patients, a new online search engine and social

media site for people diagnosed with cancer, for their caregivers, and for the clinicians treating them.

Mark Masselli: Looking forward to that. Also FactCheck.org's Lori Robertson checks in as she does every week. But no matter what the topic, you can hear all of our shows by Googling CHC Radio.

Margaret Flinter: And as always, if you have comments, e-mail us at www.chcradio.com or find us on Facebook or Twitter because we love to hear from you. We will get to our interview with Dr. Roni Zeiger 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 am Marianne O'Hare with these Health Care Headlines. Acting Administrator for the Centers for Medicaid and Medicare, Marilyn Tavenner, appears to have a green light for approval. Her nomination had been held up by Iowa Senator Tom Harkin, a democrat upset with the Obama Administration's budget proposal, which included taking money from the health care law's Prevention Fund. Harkin, a supporter of the Affordable Care Act, felt money allocated for prevention shouldn't be siphoned off to set up the federal online insurance exchange largely because more than 30 states are going to rely on the federal exchange. Senate Majority Leader Harry Reid says he is not sure now when the final vote for Tavenner will occur, she does have widespread bipartisan support.

Meanwhile, two new studies assert the country's unusual slowdown in health spending growth rates in recent years may be due more to structural changes in the health care system than to the lagging economy, and thus could continue even after business picks up. National health spending grew by 3.9% a year between 2009 and 2011, the lowest rate of increase in half a century. There has been a vigorous debate about whether this slowdown portends a new era of lesser health care inflation or is merely a brief dip caused by the recession. Meanwhile, the slowdown in health costs since the recession hit amount to an estimated \$770 billion in saved health care costs.

Florida State legislature ended its session without a decision to expand Medicaid where more than 1.1 million uninsured Floridians would have gained coverage under the expansion. Governor Rick Scott, a Republican, and opponent of the health care law, did urge legislators to put aside ideology and vote for the expansion. But the legislators refused to vote in favor of aspects of the health care law. The move has cost the state \$50 billion in federal money for the Medicaid expansion. I am Marianne O'Hare with these Health Care Headlines.

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Mark Masselli: We are speaking today with Dr. Roni Zeiger, Internist and CEO of Smart Patients, a clinical trial search engine and online social community for cancer patients, caregivers, and clinicians to improve patient outcomes. Dr. Zeiger was Chief Health Strategist at Google where he developed programs for personal health records, Google Flu Trends and Symptom Search. Dr. Zeiger earned his Master's in Bioinformatics and his M.D. from Stanford University. He's written several medical textbooks and is a physician at Santa Clara Valley Medical Center. Dr. Zeiger, welcome to Conversations on Health Care.

Dr. Roni Zeiger: Thanks for having me.

Mark Masselli: You know Roni, you spoke at TEDMED, announcing your new venture of Smart Patients. Let's start off talking about your six years at Google Health, which ended in 2011. And while Google is arguably the world's most successful search engine, it did prove to be a place where people felt comfortable storing or utilizing their personal health information. (05:37 inaudible) starting off with a postmortem of somebody that didn't work when you have been so successful in so many fields. But can you give us a sense of what the big idea was at Google Health and why you didn't think it took off?

Dr. Roni Zeiger: Well I think it's a great place to start actually, and we have to learn from everything that we do whether it's successful or not. I actually think the story with Google Health is probably quite a bit simpler than many people make it out to be. We had a really good idea trying to help consumers be more involved in their health care as a result of having better access and control of their information. The problem is that we didn't do a good enough job of solving tangible straightforward problems in a way that was easy enough for most people to do something about. What we didn't do is not only get people the access to their data but make it really useful for them to want to bother doing so. I think we will see the more successful and be much more focused on specific use cases and not looking at health records as a whole. I think we would even ask the question about who cares about a health record, the question is what problem are you trying to solve and how are you going to help me solve it.

Mark Masselli: Very good one.

Margaret Flinter: Well, before I move into the future, just ask another question about that experience. You were not only building a platform that didn't exist before and one that would allow people to securely store their data as you said, but you also were creating an opportunity for people to volunteer their health records for research in the medical community, something that I don't think was available anytime prior to that. What did you learn from that aspect of the experience?

Dr. Roni Zeiger: When we look at efforts whether they are in Google Health or otherwise that ask people to volunteer their data, the same question comes up and that is, not just to whom and for what purpose and how are you going to protect it, but how is this going to make me, if not help me directly which I think actually the answer is it should, but how is this going to make me satisfied for having done so. I think too often we are asking patients to join us but as a passive donor of information as opposed to as an active collaborator, and I think that's one perhaps subtle but very important difference between where we have been in the past and where we can go in the future.

Mark Masselli: And I want to pull the thread on a comment you made earlier about how does the medical record help the patient. And I note that the Pew Internet and American Life Project noted that about a third of all online searches have to do with researching some specific kind of medical condition. And so let's talk about how these searches are enabling patients to become experts in the very specific aspects of their own conditions, something you call microexpert. How can this expertise be most efficiently used to accelerate improvements in patient care?

Dr. Roni Zeiger: We are starting to see that people have more sophisticated questions, understandably if they or their loved ones are sick with something serious. They will very quickly want to graduate beyond the one or two pager, and there is a lot of good information online. There is also a lot of less than good information. Science is moving so quickly and personalized medicine is actually arriving with things as futuristic sounding as drugs that target specific mutations in different patients with what we used to think of as having the same cancer will get a different treatment based on which mutations are found in their cancer. As things get that sophisticated, the static web pages that we are used to dealing with on the Internet aren't enough because the web page about my particular cancer and my particular subtype and given the other conditions I may have, that web page doesn't exist. And so that's when we start thinking about how do you layer the social aspect of the web on top of the content that's out there but the power of the human network that we can lay on top of all the content out there in different places.

Margaret Flinter: Roni, that's a great lead into something that you talked about at this year's TEDMED Conference where you officially launched Smart Patients so a clinical trials search engine and social networking and information sharing site for cancer patients and their caregivers and clinicians who are looking to accelerate their research. You are cofounder, I understand it is Gilles Frydman, if I am saying that correctly, who is founder of the Association of Cancer Online Resources or ACOR, and one of the first developers of online patient communities. And I know you have partnered with other entities active in the cancer communities. And have you created a new platform that enables them to work together effectively?

Dr. Roni Zeiger: Well that's what we are trying to do. And yes, my cofounder, Gilles Frydman, is a pioneer in the space. He has been building online communities, in particular in the cancer world for patients and caregivers for the better part of two decades. He and I met a couple of years ago and many, many conversations later realized that the timing seemed to be just about right to take all the learning that he and others have been doing in the space of connecting people online and provide them with the more modern tools to help them learn together faster. Imagine that there is a group of 1000 patients with a given subtype of lung cancer. Well a new patient comes to the community and says, "I have a question about how often I should be getting scanned to check for recurrence. One of my doctors says this, another one says something else, and I can't really find consensus by looking online." Well a certain subset of that 1000 person network has looked carefully at that problem. These are smart people, who because they or their loved ones are sick, have become quite expert in their specific slice of medicine. And there will be a very collegial and frankly somewhat academic discussion about what the data suggests, and you might ask your doctor to follow on couple of questions to decide what's best for you. You have this network but depending on the question, a different subset of the network lights up and leads the conversation. And eventually, I think that we will be practicing medicine a little bit more like this. Perhaps this is how we will do referrals in the future. But patients are less encumbered by business processes and are more interested in experimenting and are unbelievably motivated and they are learning how to work with each other in new dynamic ways.

Mark Masselli: We are speaking today with Dr. Roni Zeiger, internist and CEO of Smart Patients, a clinical trials search engine and online social community for cancer patients, caregivers, and clinicians. Dr. Zeiger was Chief Health Strategist at Google for six years. Roni, I want to sort of explore a little more about the work at Smart Patients. I was sort of thinking about some patients whether or not we might see the day where there is sort of an informal meet-up and people design their sort of own unofficial clinical trial in that context. Do you see the field expanding where people take this to another level?

Dr. Roni Zeiger: I think the idea that's been proposed by many, and that you are alluding to, of patients doing more of a self-organizing clinical trial, I think there are some really interesting possibilities. There obviously are also some concerns in particular about safety. So I imagine that there are aspects of that that will be part of our future. But I think we are missing something important. And it is very tempting when something isn't working well, which I think is fair to say of our health system, including how we do research and clinical trials, and it's tempting when things aren't working to say, "Let's throw it away and build it again, and maybe this one we will build as a totally patient-centered system where the patient get to figure things out themselves". And it's sexy and exciting to talk about it that way but there are things that the current research system do really well. And the one thing that we have completely failed to tap into is to tap into not just the willingness of the patient and caregivers to participate as subject in

trials but the willingness and energy they have to be collaborators, including collaborators in figuring out well what should the trial look like, bringing patients to the table when the trial protocol is not yet finalized.

Recruitment takes a long time. It's getting even more difficult as we slice up. So one of the challenges I think is that when we design clinical trials today, we design them with no notion of user-centered design. We are building a product and we are putting it on the shelf, and the very first time we get any feedback from the "customer" is after the product has already been designed. So just the simple idea of asking patients what they think about the design of a trial is one of many possibilities where we can do a lot of collaboration and have a more open discussion with all the stakeholders including the patient in order to make science move faster. And I think that's just a low hanging fruit before we get to the slightly more sexy topic of a totally patient-run trial.

Margaret Flinter: Roni, there have been so many health-related tools, I am going to go back to Google for a second, that are really interesting to people such as Zygote Body or Google Flu Trends which we have certainly used during the various flu epidemics here on the East Coast, and Symptom Search which changed the way people think about their health and also how clinicians gather data and also how data is used in the public health space. Maybe talk for a moment about how you see these and similar projects reshaping ways in which patients and providers share information about medical or public health conditions.

Dr. Roni Zeiger: The democratization of health information that the Internet brings in general I think is finally catching up to us both in a good way and in an uncomfortable way in the health space. There are so many of us I think as physicians, that often wish our patients would just stay offline because the web is this big unorganized not necessarily trustworthy space, and it takes extra work and extra thinking to deal with the questions that come up if the patient also has several printouts from various searches that they have done. Imagine a future where a patient has the right tools in front of him or her, whether those tools are because the doctor specifically suggested five websites that he or she generally finds trustworthy, or they found themselves in a community of people who can give them real time guidance about what resources are the most useful. In any of those scenarios, the patient can show up to the visit, their next appointment with their doctor not with three misguided questions that the doctor feels, "Boy, now I have to waste half of our precious minutes unlearning some things", but instead, the patient shows up with the three smartest questions that in fact some times the doctor wouldn't even have thought to ask because the patient has already gone through some of the basics.

I welcome the possibility of having more efficient, more informed conversations, and while it's a little bit painful to get there because the tools are far from perfect, the possibilities are really exciting. And I think we sometimes fool ourselves into

thinking how important the doctor's visit is. But for most of our patients, they spend a trivial amount of time with the physician and all of their health, for the most part that's happening the other 99% of the time, and it's unrealistic to expect that they are going to remember the most important things to share with us, as it is unrealistic for us to be the perfect clinician at that moment. So eventually, we will have a more dynamic ability to interact with our patients asynchronous but, we are going to need to depend in the future more on our patients being informed and we are going to need to tap into the talents and motivation of the patients much more in the future.

17:08

Mark Masselli: You serve as a Clinical Instructor at Stanford University School of Medicine, and you have written and edited several medical textbooks. We have looked at how technology is working to improve patient education and engagement. But what about the medical training environment; what impact do you see these technology platforms having on professional medical training?

Dr. Roni Zeiger: On end of the spectrum is the use of simulation technologies to get more realistic experience, realistic from a technical perspective than what we use to get from textbook. You now get the training on a really fancy dummy. Obviously, a more realistic experience is going to lead to better learning; it's just closer to the real context. And another area that I think is one of those that we may be ignoring, imagine this, when I was a medical student, instead of just reading about the common manifestations of non-small cell lung carcinoma, I eventually sometime in the next couple of years am seeing my first patient with that illness, instead the first time I read about it, not only do I have the statistically accurate picture from the textbook but I also have the story of the real person who is currently dealing with this disease and their variant which is not necessarily representative but is real how it happened to manifest for them. We all talk about how important it is to start seeing patients early on in the process so you can put the clinical facts and acumen that you are developing in the context of real stories and real people; we all remember some of those earliest patients that we saw. And I think now the fact that there are so many contexts in which people are getting together in virtual spaces like in the communities that we are building and growing, that I think there is some untapped potential there from a learning experience. We have already asked the question of several members of our community, because this is such an interesting possibility, if they would be interested in some way, not yet defined way, collaborating with medical trainees so that the trainees could start to learn their medicine in the context of real people's experiences, in a way that's more scalable and more accessible than necessarily having to see that person on your rotation in the hospital.

Mark Masselli: Roni, some of the most innovative projects from Google started off as a 20 Percent Time projects. Can you explain to our audience what 20%

Time actually is and will use the idea of 20% Time at Smart Patients and how do you think 20% Time might yield in the broader health care environment?

Dr. Roni Zeiger: The basic idea, as it was at Google when I was there, is that software engineers in particular who are the ones who really have all the tools to tinker and build new things, should give them permission of approximately one day a week or 20% of the time to pursue something that isn't necessarily on the formal agenda. They have an idea and they should feel free to prototype it, build it and do a non-officially sanctioned or supported project because you never know where the next best idea is going to come from. And where better to look for it than the people who have the raw talent, understand the focus and the goals of the company. And people do their best work when they are excited about it. Many great projects at Google and I am sure at other companies too came out of that kind of thinking.

Margaret Flinter: We have been speaking today to Dr. Roni Zeiger, CEO and Founder of Smart Patients, a clinical trial search engine and social networking site for cancer patients, caregivers and clinicians to share best practices in cancer care and to accelerate the pace of research. You can learn more about his work by going to www.smartpatients.com. Roni, thank you so much for joining us on Conversations on Health Care today.

Dr. Roni Zeiger: Such a pleasure to be with you.

Margaret Flinter: Yeah, really appreciate speaking with you.

Mark Masselli: Yeah, really appreciate it.

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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 non-partisan, non-profit 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 health care law and premiums, in particular, what the law will mean for premiums on the state or federal-run exchanges where people who buy their own insurance will shop for coverage. That starts next year. 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 companies say premiums will go up because they will be required to accept all customers including those with preexisting health conditions.

Advocates of the law say there will be a much larger pool of policyholders, including more young and healthy people, who will buy insurance because they will be required to do so.

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 that 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. 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, e-mail 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. By now, it's a good bet that a majority of health-related New Year's resolutions have fallen by the wayside. An international aid organization has devised a novel idea for improving health outcomes for the kids they serve in third world countries while improving the health and fitness of folks here at home. CURE International provides orthopedic and reconstructive surgeries for impoverished children in 27 countries around the globe.

Joel Worrall: And we are there to provide the highest quality surgical care to them and then follow-up care afterwards to help them deal with things like club-foot or twisted spine. We treat a lot of burn contractures and cleft lip and palate.

Margaret Flinter: Joel Worrall, vice president of cure.org says that the surgeries to repair club feet and other physical deformities average around \$1,000 per child and they thought what if they could tap into the American desire to attain fitness goals here and tie that goal to raising funds needed to help children in need around the world, and they launched the Champion Campaign. The campaign seeks folks to sign up on their website and become part of Champion teams, to all make a commitment to lose weight, to increase their fitness, whatever that fitness goal might be.

Joel Worrall: You are not just sort of out there on your own; we are actually partnering you with an entire team of people who are all hoping to achieve similar goals.

Margaret Flinter: Team members are there to support one another's goals and each team member solicits sponsors to support them in their endeavors, and when the fitness goals are attained, the funds raised go to help a specific child in need.

Joel Worrall: And we are giving you an opportunity to actually see the result of what your hard work is doing in the lives of specific children.

Margaret Flinter: Cure.org's Champion Campaign, a unique platform to help folks seeking to improve their own health while providing funds to help the health of others, 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.