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Margaret Flinter: Welcome to Conversations on Health Care with Mark Masselli and Margaret Flinter, a show where we speak to the top thought leaders in health policy, health innovation, and technology, and the top thought leaders who are shaping the health care of the future. This week, Mark and Margaret speak with Edward Abrahams, president of the Personalized Medicine Coalition, dedicated to advancing the adoption of personalized medicine concepts for the benefit of patients and the health system. He talks about the growing body of medicine that will allow truly personalized care, treatment, and prevention based on one's own personal genomic profile.

> Lori Robertson also checks in, the managing editor of FactCheck.org, looks at misstatements spoken about health policy in the public domain, separating the fake from the facts.

We end with a bright idea that's improving health and well-being in everyday life. If you have comments, please email us at <u>chcradio@chc1.com</u> or find us on Facebook, or Twitter @chcradio, or you can also find us on iTunes, SoundCloud, or ask Alexa to play the program, Conversations on Health Care.

Now, stay tuned for our interview with Edward Abrahams, president of the Personalized Medicine Coalition here on Conversations on Health Care.

Mark Masselli: We're speaking today with Dr. Edward Abrahams, Ph.D., president of Personalized Medicine Coalition, dedicated to promoting the understanding and adoption of personalized medicine concepts, services, and products for the benefit of patients and health systems. Previously, Dr. Abrahams was the executive director of the Pennsylvania Biotechnology Association, where he spearheaded the state's \$200 million investment in the biotech industry. He was the assistant vice president for federal relations at the University of Pennsylvania and taught health and public policy at Brown University.

Edward, welcome to Conversations on Health Care.

Edward Abrahams: Thank you very much. I appreciate this opportunity to talk about personalized medicine.

Mark Masselli: Yeah. Let's start right there and take a moment, as I assume, not everyone in our audience may fully understand what the concept of personalized medicine truly means. I wonder if you could talk to our listeners about the basic premise of precision medicine. Edward Abrahams: Well, actually, that's a very good place to begin. Personalized medicine actually is an evolving field, in which physicians use diagnostic tests to determine which medical treatments will work best for each patient based upon what the individual brings to the equation. By combining the data from those tests with an individual's medical history, his or her circumstances, health care providers can develop targeted treatment and prevention plans that would lead to better outcomes for patients and also better outcomes for health systems that integrate personalized medicine into what they offer.

Margaret Flinter: Well, Edward, your organization has been advocating for the advancement of personalized medicine, I think since 2004, which puts you kind of back in the very early years that people were working on this. As people started to hear more about accessing one's own personal genome, and we've had so many people going to Ancestry.com and 23andMe, then all of this seems to have brought us to an increase in research for personalized approaches, to treating all kinds of diseases and conditions, but also to a crossroads where it may be on the horizon to see this as the norm and not the exception. What do you think about that? Do you think we're at a new era where it'll move from possibility to a standard part of health care treatment?

Edward Abrahams: Well, first, let me say, it already has moved from possibility to in particular areas standard of care. Clearly, the parameters of the new horizon are becoming more evident every day. The Personalized Medicine Coalition was, as you note, founded at the end of 2004. Just before we were founded, the human genome had been mapped. The mapping of the human genome opened the opportunity that we could better understand patients, based upon their genetic inheritance, and with that new tool, develop new targeted therapies that would, as I say, lead to better outcomes for patients, and also improve the efficiency of the health system, which by employing personalized medicine have become more targeted.

> The Personalized Medicine Coalition, recognizing that we had this golden opportunity, considered what needed to happen to speed up the movement away from trial and error, one-size-fits-all medicine towards one of personalized or targeted therapeutics. We decided that the space between the science and the patient really was and is determinative, how we regulate. How we reimburse, how we educate physicians and other providers makes a tremendous amount of difference.

We were founded as an education and advocacy organization to spearhead the promise of personalized medicine. I think we've made a lot of progress since then, but still have a long way to go. We know from a poll we did earlier this year that fewer than 20% of Americans **Edward Abrahams**

have any idea what personalized or precision medicine is all about. Although when we explain it to them, the overwhelming majorities like what they hear.

Mark Masselli: Well, while there are only maybe 20% of Americans who understand personalized medicine, certainly the policymakers have been engaged in this. I'm wondering if we can talk a little bit about the policy side of the equation. It seems to me that some of the building blocks for moving personalized medicine had been put in place if you sort of look at the Affordable Care Act, which was designed to put multiple pieces in place. You had the shift from paper to electronic health records with the HITECH Act. You had the 21st Century Cures Act. Of course, we have the All of Us Precision Medicine Initiative, a project actually that we've been engaged in since its inception. How important are all of these building blocks to moving the needle forward on personalized medicine and what's missing?

Edward Abrahams: Those building blocks are critical and they provide the foundation that allows us to put in place the vision that we're trying to articulate, that is to say the movement towards targeted or personalized medicine. I agree with you that the Affordable Care Act, the HITECH Act, which encouraged electronic medical records, and especially the All of Us program, which in the future will provide another research tool that allows us to better understand the individual variation, because it incorporates data from hopefully a million people of all different backgrounds, will yield new insights and therefore better health care.

> Personalized medicine is really based on the new information age reaching medicine. It's not easy, which is why those building blocks are important and why the public policies that will encourage personalized medicine are critical.

Margaret Flinter: Well, I'm really glad to hear you reference the All of Us program. We also are so excited about this and have been very gratified by the eagerness of people of all backgrounds to really grasp how important this might be, and to consider volunteering to be part of the program.

Mark, as I look back over the roster of people we've had on the show in the last two years or so, I think the personalized medicine people have been kind of well represented and maybe almost dominant, which is another good marker. Eric Topol has been a recurring guest on our show. Eric has sounded the call repeatedly that this is amazing and wonderful science, and that these personalized interventions and therapies are likely going to be very expensive, and therefore likely not available to all consumers. We have pulled up a quote I think attributed to you in your 2017 publication, the personalized medicine report, that the top challenge in personalized medicine is reimbursement, reimbursement, and reimbursement.

What are you thinking about the evolving role of payors, both public and private, in the personalized medicine equation? Is this something that you see moving into the sort of essential benefits category, if you will? How are we going to rethink business models to pay for it if we need to or is the volume going to ultimately drive down costs as it has in other areas?

Edward Abrahams: Well, I think you've identified a major barrier to the advancement of personalized medicine, which is the emerging perception that personalized or precision medicine is going to be unaffordable. I actually disagree with Dr. Topol on that. I think that while some products may actually cost more, but because they are of greater value, they will provide better benefits not only to the patients who benefit from them, but also the health systems that employ them. Clearly, we need more evidence to show that a more efficient health system can also be more effective one.

I'm pleased to note that there are systems that have studied the implementation of personalized medicine that shows significant cost savings by avoiding therapies to patients for whom they will not work. I recently read a study that said that over \$500 billion annually could be saved if we didn't prescribe particular drugs to patients for whom they didn't work and avoid the kinds of side effects that thereby occur.

Clearly, we need more evidence that this works and we need more targeted therapies, but I think we're on the right path. One thing that could derail it is if payors just say no instead of work with manufacturers to figure out how we can get more value for the money we already spent, getting value and introducing efficiencies into the system, because you're right. Unless we do that, the promise of personalized medicine will not take off or at least will be a longer runway than we would hope for.

Mark Masselli: We're speaking today with Edward Abrahams, Ph.D., president of the Personalized Medicine Coalition, dedicated to promoting the understanding and adoption of personalized medicine concepts, services, and products for the benefit of patients and the health system.

> Edward, I want to pull the thread on that thought that you had about a more efficient system and better health outcomes at more affordable total cost for the health system. I'm certainly thinking about the areas of improving prescribing practices. Currently, it seems

to be really a trial and error. Now, we have pharmacogenomics test, which can help determine medication's efficacy based on one's personal genome. I think that's been sort of a revolutionary breakthrough and maybe it is the building block of people understanding the potential of personalized medicine for millions of people, avoiding a medication that could not only be of no value to them, but could put them at risk for greater harm. I'm wondering, shine a light on this pharmacogenomics area for our listeners, so they can understand it within the personalized medicine field.

Edward Abrahams: Well, pharmacogenomics is really a fancy word for the right medicine to the right patient at the right time. This is an emerging field. One in four drugs approved by FDA in the last three years have had biomarker information on their labels, suggesting that FDA wants to see greater efficacy and safety, which they've determined can only come about by identifying patients for whom any particular therapy will work.

Let me give you three examples. In order to prevent breast cancer recurrence, in the past, chemotherapy was invariably described. Yet we now know 90% of women will not benefit from that chemotherapy, which is painful and expensive. A simple genetic test can tell physicians that fact, knowing who would benefit and who could avoid chemotherapy. I think you can see the beauty in that and the cost savings, by the way, in that, even though the test may be expensive.

Another one is a drug that only works in lung cancer with a certain ALK rearrangement. That expensive drug will only be prescribed for those patients who have that particular ALK rearrangement, which also can be determined by a simple genetic test.

Another one is in cystic fibrosis, a deadly illness where young men and women die in their early 30s, can live much longer if a particular genetic mutation is discovered and a targeted therapy is prescribed. This is not science fiction. This is happening today.

These are the beginnings of personalized medicine and this field holds enormous promise for patients. What we need to do is align all the stakeholders around it, so that the research comes online more quickly, payors, regulators, providers, and also patients who need to be considered in part of that discussion.

Margaret Flinter: Well, I saw another factoid that there's an estimated 65,000 genomic testing products on the market today, which I think is completely astonishing. I think New York Times science writer, Carl Zimmer, when he was recently with us, he put it this way, that all this discovery may

require the health industry to just throw out the old training models and start over. We are very focused on training the next generation and really ensuring that it doesn't take the 15 years. Historically, we've quoted about innovations moving from the lab to the bedside or the primary care exam room. What are you thinking about in terms of preparing both the workforce that's in training today, the ones who will come after them, and most importantly, that big bolus of people out there in the field today who need to access this information, understand it, or at least understand how to connect people to those who do understand it. What's your organization thinking about that big lift? Edward Abraham: Well, that is a big lift. The health care providers are slow to adopt new methods. Education is critical. I would note that as long ago as 400 BC, Hippocrates said that's it's more important to know which person the disease has than what disease the person has. What's different today is that we now have the tools to begin to do that. What we need to do though is convince the medical system that it's worth testing in order to get the right therapy at the right time. The medical system moves slowly absent evidence and evidence is expensive to develop. I must say even when we do have the evidence --They still don't want to change it. Margaret Flinter: Edward Abrahams: -- they still don't want to change. That's not good for patients or the health system. Margaret Flinter: No.

- Mark Masselli: Well, the industry may be moving slowly, but the pace of discovery in personalized medicine is really dramatic. The Personalized Medicine Coalition is holding its annual conference at Harvard in mid-November and some great minds in precision medicine and scientific research as well as policy. Who's coming to grapple with these big challenges and why you think bringing all these entities together is essential to ensuring that precision medicine is done right moving forward?
- Edward Abrahams: Sure. Our conference is at Harvard Medical School. We're bringing together all of the stakeholders with an interest in personalized medicine, including policymakers, payors, scientists, patients, to consider what's necessary to move the field forward. I'm very hopeful that we'll be able to develop some solutions to problems that you've privileged me by giving me a chance to address. That's the purpose of our conference is to see where the field is at the moment and to discuss what we need to do to bring it to patients more quickly, and how we can overcome the barriers that now exist, and I would say

	particularly the barrier of gathering evidence that change people's minds about investment and adoption of personalized medicine. It comes across two days. It includes leading proponents of the field. I'm looking forward to a robust discussion.
Margaret Flinter:	We've been speaking today with Edward Abrahams, president of the Personalized Medicine Coalition. You can learn more about Dr. Abrahams work by going to personalizedmedicinecoalition.org or follow them on Twitter @permedcoalition.
	Dr. Abrahams, thank you so much for your leadership on this really important movement and for joining us on Conversations on Health Care today.
Edward Abrahams:	Thank you for the opportunity.
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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 U.S. politics.
	Lori, what have you got for us this week?
Lori Robertson:	We looked at ads the Democratic Congressional Campaign Committee has aired in House races across the country and found a few that make misleading claims about health care. For instance, a TV ad in lowa misleadingly said that 50% of the non-elderly in the 3 rd district have preexisting conditions. Yet Representative David Young "voted to deny protections for their health care coverage". His vote for the American Health Care Act would have lessened such protection for those on the individual market, where 6% of all Iowans get their coverage.
	The 50% figure comes from the liberal leaning Center For American Progress, which applied Census Bureau population data to an Obama- era Department of Health and Human Services Report. That report estimated how many Americans could be denied coverage charged more or faced coverage exclusion if they were seeking coverage on the individual market before the Affordable Care Act's protections went into effect in 2014.
	Those not seeking insurance on the individual market, including those with employer sponsored insurance, which is where about half of Americans get their coverage, wouldn't lose their insurance because of any preexisting conditions. It's true that while the GOP health care

	Bill, for which Young voted, would have prohibited insurance companies from denying coverage based on health status. It would have allowed insurers on the individual market to price premiums based on health status in some cases in states that allowed it.
	Two other DCCC ads said Republican candidates in Colorado and Pennsylvania cast votes against those with preexisting conditions, even though the lawmakers ultimately joined Democrats to vote against the GOP health care bill in the House. Representative Mike Coffman in Colorado's 6 th District and Representative Brian Fitzpatrick in Pennsylvania's 1 st were among the 20 Republicans who voted against the American Health Care Act.
	That's my fact check 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'd like checked, email us at <u>chcradio.com</u> . 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. Students of public health are often tasked with devising interventions for addressing some of health's biggest challenges. For Harvard T. H. Chan School of Public Health students, Dan Wexler and Priya Patel, their idea netted an award. The students were tasked with addressing food insecurity in underserved parts of the world, including neighborhoods in their own backyard. They thought of the current trend of meal or meal services like Blue Apron and wondered what if we modified that business model to serve the needs of those living in food deserts.
	Wexler and his partner sourced food delivery companies that could provide prepackaged meal kits with all ingredients included, even spices, dressings, and recipes. They designed refrigerated kiosks that could easily be placed in local neighborhoods.
Dan Wexler:	I think the biggest change is that there is no delivery system door to door per se, and that by going and setting up these kiosks in the community, you can have a very lean design. You don't need a storefront. You don't need to have inbox refrigeration. You are very much addressing the need of access by physically saying, hey, here is healthy food. It's convenient because everything you need is in the

	box. The directions are very picture based. There's a lot of literacy issues. Just really thinking about how can we take all those lean design principles to facilitate access, that really I think make it a solution that has the potential for impact.
Mark Masselli:	They also conducted research with local ethnic groups to create recipes that would resonate with their families.
Dan Wexler:	Then we just went down to the community and did taste testing, talk to people and said do you like this? What do you want to be able to eat for dinner? [inaudible 00:23:21] issue is that similar textures, similar spices. One thing that we found is there's a little bit of contention between parents who want to eat more traditional foods and kids who want to eat more American foods. We tried to bridge those gaps. One of our recipes, for instance, is a Chicken Pot Pie Pasta. It's kind of fun sounding, but also we use a lot of traditional seasonings and spices.
Mark Masselli:	Customers can simply walk to the kiosk and purchase their meal kits with the snap cards or cash. The kiosk will be run by the residents of the neighborhood, giving them an opportunity to run them like a franchise, offering an economic benefit to the community as well. Their idea earned them the Rabobank-MIT Food & Agribusiness Innovation Prize and \$15,000 in startup money to launch their enterprise. A low-cost portable, healthy meal service placed in portable kiosks in
	food desert neighborhoods to address the problem of poor nutrition, providing an economic opportunity at the same time, now that's a bright idea.
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Mark Masselli:	You've been listening to Conversations on Health Care. I am Mark Masselli.
Margaret Flinter:	I am Margaret Flinter.
Mark Masselli:	Peace and health.
Margaret Flinter:	Conversations on Health Care is recorded at WESU at Wesleyan University, streaming live at <u>chcradio.com</u> , iTunes, or wherever you listen to podcasts. If you have comments, please email us at <u>chcradio@chc1.com</u> or find us on Facebook, or Twitter. We love hearing from you. This show is brought to you by the Community Health Center.

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