

Susannah Fox

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Female: 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 Susannah Fox, former Chief Technology Officer at the Department of Health and Human Services an expert on how Americans utilize the Internet and social media to gain knowledge about their health. She talks about how digital health is transforming the health care experience.

Lori Robertson also checks in, the Managing Editor of FactCheck.org, looks at misstatement 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 wellbeing in everyday lives. If you have comments, please e-mail us at chcradio@chco1.com or find us on Facebook or Twitter @CHC Radio. We love hearing from you. 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 Susannah Fox on Conversations on Health Care.

Mark Masselli: We're speaking today with Susannah Fox leading health industry researcher with a special focus on health consumers in the Internet. She previously served as Chief Technology Officer at the US Department of Health and Human Services under President Obama. Prior to that, she spent 14 years at Pew Research studying the impact of Internet technology on consumers in health care. Ms. Fox also served as Entrepreneur in Residence at the Robert Wood Johnson Foundation. She earned her BA in anthropology at Wesleyan University right here in our backyard. Susannah welcome back to Conversations on Health Care.

Susannah Fox: Thank you.

Mark Masselli: Obviously we're calling you from the home of Wesleyan University at WESU. I'm sure you're familiar with Go Wes.

Susannah Fox: Yay.

Mark Masselli: You've been charting to behaviors of American consumers in their interface with the Internet for nearly two decades with a special focusing on how they access health information. During that time access to the Internet has become ubiquitous. You say that at no other time in history have we been able to communicate across the world in an instant with anyone who has knowledge or experience to share. I'm just wondering if you could tell our listeners what you've learned.

Susannah Fox

Susannah Fox: If you think back even just 20 years ago if you had a question, you were limited to asking your friends and family or going to the library, you might be able to have research of health question in a medical library. Now that's really blown open. People have access to medical journal articles in every language. There's so much information that has been digitized, and even more importantly people have access to each other, meaning, they can put a question out on the network, whether it's on social media or even just using email and they can get answers. But so often, people are able to connect with other people who share the same health condition, who are at the same life stage, who can answer their question in what, I like to call, a just in time someone like you. Someone who knows exactly what you're going through and can help you at that time.

Margaret Flinter: Well, Susannah when you'd last joined us you were serving as the Chief Technology Officer at HHS that was created to foster more rapid adoption of digital technologies in health care, specifically, to facilitate the speed of sharing health data and to give people access to their own health records. I think we'd all agree it's been a challenge for the health industry to provide what they think patients will want. At the same time patients seemed to be very interested in health care apps which might not have anything to do with what the traditional health industry is providing. How might health care get better at actually devising solutions that patients want to use?

Susannah Fox: I love this question because it calls on the history of what we have been trying to create at the federal government level and at the industry level, and that is to open up the data warehouses. Big organizations including the federal government might be forgiven for getting really excited at the beginning of the data revolution to open up the warehouses that we already had. It did feel really different to allow people to have access even to just to a small stream of data, but consumers aren't really sure what to do with the information.

For example, I'm still a fan of Blue Button which was a revolutionary program started in the Obama Administration first at the VA and now for Medicare beneficiary. They're actually opening it up to an API so that veterans and Medicare beneficiaries cannot only access the information, their health record, but direct it to an app of their choice. That's where I'm starting to see a bridge to the future. A bridge to where consumers are already using health apps and so much of health happens outside the clinic.

What we need to do is figure out a way to marry the streams of data, the stream of data that comes from the clinical encounter as well as the stream of data that a consumer might be generating with their wearables, or even better what is the data that could help someone navigate the grocery store in a smarter way, to make better choices

Susannah Fox

about their food. How can people sleep better at night? That's actually where health really lives.

Mark Masselli: That's very fascinating. Margaret, when Susannah was talking about liberating data you think about Todd Park who's part of that sort of revolution along with you and others. But as an anthropologist by trade, you're fascinated with the human behavior in society. One of those demographics you've been most focusing on is the youth population the so called digital natives. I think it's fair to say that many adults would love to have greater insight into what's going on in the minds of their teenagers.

You've really taken a deep dive into this group as they're clearly the most agile navigators of this space. You recently did a study for Hopelab a company designing digital tools to help facilitate healthy behaviors. Your report yielded some fascinating insights and tell us more about what you've learned.

Susannah Fox: Well, we went into this wanting to make space for the teens and young adults themselves to tell us in their own words what they think. We designed it to be a traditional survey where we asked some questions, statistical numerical data and we left plenty of space for open-ended responses. One of the most important findings is that there really is a significant existing market for digital health tools in this age group 9 and 10. 14 to 22 year olds have looked online for health information. Two-thirds of teens and young adults have used mobile apps related to health and they're mostly focused on things like fitness. But there are a lot of them who are using the health apps to track sleep and meditation.

The other thing that I was surprised by is that 6 in 10 teens and young adults say they have read or listened to or watched other people share about their health experiences. They're talking about podcasts, they're talking about watching TED Talks or YouTube videos. Video especially emerged in the open-ended questions as a huge potential for health education among teens and young adults.

Margaret Flinter: Well, you know, Susannah, it's not surprising really given the amount of time the average American teen spends engaged with their smart phones. There's been a lot of high profile stories about screen time not being good for kids in the long run, some studies that have linked to rise in anxiety and other mental health conditions to digital exposure. But I was really struck by one of your findings in particular that teens are starting to very wisely sensibly use online platforms to help them deal with real behavioral health issues. Tell us a little more about how young people are using digital tools to help them address the very important and significant personal challenges in a way that they couldn't before and potential of this to democratize in some ways access to health that hasn't been there for kids face a lot of

Susannah Fox

barriers to getting the help they need?

Susannah Fox: In a lot of ways. The Internet and a teenager's phone can be a lifeline as they navigate adolescence and young adulthood. The two groups who are in particular need of support when it comes to emotional wellbeing are teenage girls and young women. They are much more likely than males their age to go online for information about anxiety or depression. The other group is LGBTQ youth. Three out of four say they've looked online for information about depression compared to 32% of straight cisgender youth. But again, in talking with young people directly and giving them space to tell us. When you're feeling low, do you go online or do you avoid going online? Do you use social media? If you do, how do you use it? What emerged in their answers, young people are not helpless pawns of social media, a lot of them are actively curating their social media feeds to get inspiration, to find humor and emotional support.

Other people recognize that it's not a good idea for them to go online when they're feeling bad and so they self-regulate and they stay away from social media. There are people who say, I know that social media makes me feel worse, but I can't stop myself. It's these vulnerable youth that we need to be concerned about. We need to make sure that we are approaching this with the understanding that young people's experience of social media is nuanced.

Mark Masselli: We're speaking today with Susannah Fox, leading health industry researcher on health consumers in the Internet. She served as Chief Technology Officer at the US Department of Health and Human Services. Susannah, you wrote recently about something that we're very interested in our practice where one of the early participants in the All of Us precision medicine initiative. You've noted the rise of Bios-Citizens and we recently had Larry Smarr on who was probably the most measured man in the world.

There seems to be this growing tide of consumers who are gaining deeper insight into their own health through accessing their personal genome as well as other health information from wearables. You say it's spurring a whole new trend in DIY a Do It Yourself health care and signals another dramatic shift in consumer behavior. I wonder if you could tell our listeners more about this emerging trend.

Susannah Fox: Well, I've always been interested in going out to the edges of any field to see what the hackers and the cowboys are doing. I got to say Larry Smarr is in that category.

Mark Masselli: He certainly is.

Susannah Fox: In health care people who live on the edge of health care are often people with rare conditions because they so often have to engage in

experimental treatments which really looks like DIY's medicine. One trend that I noticed because I started meeting people who were not only experimenting with tracking data, but they were also making or adapting physical objects, assistive devices like a writing tool for someone with low dexterity, hacking a wheelchair. I saw how the maker movement is running parallel to both the Empowered Patient Movement and the Biohacker Movement.

What I see is this really interesting confluence where manufacturing tools and the tools of scientific discovery are becoming cheaper. We're seeing more and more people experimenting, creating a DIY lab. It's this access to the personal genome to access to crowdsourcing to experiment in ways that we didn't really have 20 years ago. What I'm interested to see is how this is spreading into the more mainstream population because there are a lot of people who have health mysteries that they would like to solve. It's not just people who have access to the highest end tools like Larry. I personally think it's exciting, but it's also intimidating because there's potential for mischief. My rubric, my ethos in general is to open up access to the information data and tools that people need to solve problems. I hope that it doesn't result in creating problems.

Margaret Flinter: Susannah, we've talked about the teens and we've talked about the tech savvy people, but coming in from the edges to a incredibly large going to grow population. We think about the older population and the older of the older population, you know, the 85 plus who are increasingly not living in nursing homes. There's a whole incredibly exciting focus on really supporting that life and providing the opportunity not to get on a keyboard, but with their voice, get support in their own home for doing some of their own activities of daily living, for monitoring, for connecting with other people.

What are you excited about with this group? What are you hearing from friends who may be caring for elderly parents across the country or people that you've come across who are focused on this particular age group that we know is only going to grow?

Susannah Fox: It certainly is only going to grow. My personal observation, having been a caregiver and my observation based on research, is that caring for a loved one, especially in older adults, is still a very hands-on activity. One aspect of care giving that I turned up in my research is that caregivers are challenged by the complicated schedule of medications that their loved one is on. We have all these wonderful advancements in the pharmaceutical world, but how are we asking people who maybe have some forgetfulness, who maybe have some dexterity problems to remember to take these tiny pills in the right order. I think that's a place where technology can really be helpful. The other place that I see is very important is that elders and

Susannah Fox

caregivers are two groups that are challenged by feeling isolated.

Margaret Flinter: Right, absolutely

Susannah Fox: That's again, something that technology can help with. There's a lot that could be done with telepresence. There's a lot that can be done in terms of online support groups. I'm really interested in the connections between peers. You don't have to leave your loved one to go to an online support group to get that crucial advice or word of encouragement that you might need. Now the consumer electronics always has amazing gadgets on display and I love seeing what people come up with in terms of, frankly, the spying that you can do and smart toilets and other gadgets like that. But really I am a big believer in listening to the people who are, frankly, listening to the people who were doing the wiping and the swabbing and asking them what do they need. I don't know that it's going to be that they need more surveillance and smart toilets. I think they're going to need more help with the medication management.

Margaret Flinter: Yeah very practical.

Mark Masselli: Susanna, you're anthropologists and researchers, and I think our listeners have heard today you're forward thinking, visionary. We just had Noelle LaCharite on the show and she's done a lot of voice applications in healthcare. I'm wondering what your thought is about voice and what's happening in that realm. The keyboard is a little clunky. Is there any breakdown by age of people who were thinking about voice applications or do you think that's a whole new frontier for us? There may be a whole new interface for us.

Susannah Fox: I think voice activation is a wonderful forward step, I think that it's an example of assistive technology for people living with disability that is going to move into the mainstream and it really can't move fast enough. Among the hackers and the cowboys of health care, I also put in that category people living with disability.

Margaret Flinter: Absolutely.

Susannah Fox: They make a way out of no way. What we're seeing in terms of the assistive technology that grew from screen readers and the ability to take dictation essentially. I will say that my husband recently had hand surgery and so is unfortunately living this where he has to actually dictate every memo in every email. I wouldn't say he's happy with the technology that he was being offered right now, so we still have a long way to go. But in terms of telehealth and telepresence, one of the findings of the Hopelab and Well Being Trust survey of teens and young adults gives a little bit of an indication of a possible future. 20% of that age group say they have already interacted with a clinician online, whether it was via text via video. This is an age group

Susannah Fox

that is very ready for telemedicine.

I'm intrigued to see how that grows because we really need to find a way to revolutionize access to primary care and mental health professionals. I think the future of clinical care is home-based more than we can even imagine right now. Again, I'll put in a plug for peer to peer health care that there's this invisible network that surrounds us, of people who could give us advice if only they knew what questions we were struggling with. There might be people in your father's network who are waiting to help, but they just haven't found a way in yet. For me it still comes back to humanity. I think most people do want to help and we'll provide that just in time advice if we give them the chance. As the clinic moves more into the home, how could we tap into that invisible network that surrounds us to stay healthy?

Margaret Flinter: We have been speaking today with Susanna Fox, leading health industry researcher on health consumers and the Internet. You can learn more about her research by going to susannafox.com or follow her on twitter @Susanna Fox. Susanna, thank you for your ongoing and important research in this emerging sector of health care for your kindness and humanitarianism and for joining us today on Conversations on Health Care.

Susannah Fox: It was my 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 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: In our latest quarterly update of Trump's numbers, we looked at various statistical measures under Trump's presidency. For health insurance coverage, the number of people lacking health insurance has barely changed since trump took office, but millions are expected to drop or lose coverage this year and in subsequent years. The most recent report from the National Health Interview Survey estimates that 28.5 million people were uninsured during the first six months of 2018. That's about 100,000 fewer than in 2016. Only 8.8% of the population lacked health coverage during that time down from 9% during Obama's last year.

That's a reversal of the trend in Trump's first year when the number who lacked coverage rose by 700,000. Trump failed to repeal and replace the Affordable Care Act as he promised to do. But in

Susannah Fox

December 2017, he signed a pack bill that will end the ACAs tax penalty for people who fail to obtain coverage. That took effect this year. Earlier the nonpartisan Congressional Budget Office estimated that the end of the mandate penalty will cause 4 million people to lose or drop coverage this year, rising to 12 million two years later and 13 million in 2025. 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 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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Margaret Flinter: Each week Conversations highlights a bright idea about how to make wellness a part of our communities and to everyday lives. While more than 20 million Americans have gained coverage under the Affordable Care Act, some 30 million remain uninsured, and many of these are either immigrants or without the resources to purchase coverage. While most can access primary health care in the nation's community health centers and safety net hospitals, many more with complex conditions simply can't afford access to specialty care. Entrepreneur Jayanth Komarneni decided to create a virtual way to bypass the system and founded the Human Diagnosis Project. A network of volunteer specialist offering virtual consults for the neediest patients.

Jayanth Komarneni: The Human Diagnosis Project is an online system built by the world's doctors to understand the best steps to help any patients. In the process of developing the Human Diagnosis Project, we realized that there is an opportunity to develop a system that can ultimately help solve the problem for those people who won't have access to specialty care.

Margaret Flinter: Dr. Santanu Nandi is Director of the Human Diagnosis Project. He's a frontline primary care provider in a safety net clinic who saw the opportunity to provide specialty care in a cost effective way.

Dr. Santanu Nandi: The way the system works is safety net providers like myself can freely exchange electronic consultations with volunteer specialist from around the country, so that the expertise of those specialists have that are uninsured patients currently can't have access to, becomes available.

Margaret Flinter: It's estimated that roughly 35% of specialist visits can be done virtually. The Human Diagnosis Project offers an opportunity to create real savings in the health care system.

Jayanth Komarneni: There is a very real and large portion of situations in which providing

Susannah Fox

an electronic perspective on that given problem will actually solve that problem for many patients.

Margaret Flinter: Online portal, linking safety net providers, serving underserved populations to specialty care expertise, improving outcomes for millions of uninsured and vulnerable patients. Now, that's a bright idea.

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Mark Masselli: You've been listening to Conversations on Health Care. I'm Mark Masselli.

Margaret Flinter: And I'm Margaret Flinter.

Mark Masselli: Peace and health.

Female: Conversations on Health Care is recorded at WESU at Wesleyan University, streaming live at www.chcradio.com, iTunes, or wherever you listen to podcasts. If you have comments, please email us at chcradio@chc1.com, 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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