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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 innovation, health policy, care delivery and the great minds who are shaping the health care of the future. This week Mark and Margaret speak with Dr. Donald Rucker, National Coordinator for Health IT at the US Department of Health and Human Services. He discusses a recently announced initiative at HHS to make everyone's electronic medical records readily available to them on their smart phones at no cost to the patient. They're seeking true portability of one's own health information.

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 wellbeing in everyday lives. If you have comments, please email us at chcradio@chc1.com or find us on Facebook, Twitter, iTunes or wherever you listen to podcasts. You can also hear us by asking Alexa to play the program Conversations on Health Care. Now stay tuned for our interview with the National Coordinator for Health IT at HHS Dr. Donald Rucker on Conversations on Health Care.

Mark Masselli: We're speaking today with Dr. Donald Rucker, National Coordinator for Health IT at the US Department of Health and Human Services. Prior to joining ONC, Dr. Rucker was Clinical Professor of Emergency Medicine in Biomedical Informatics at Ohio State University. He began his informatics career at Data Medic Corporation where he developed the world's first Microsoft Window based electronic medical record. He earned his undergraduate degree at Harvard, his medical degree from U Penn and his MBA and MS in medical computer science from Stanford. Dr. Rucker welcome back to Conversations on Health Care.

Dr. Donald Rucker: Thanks.

Mark Masselli: ONC's job is to build a private and secure nationwide health information system that supports meaningful use of health data. You just recently, I think at the HIMSS conference, shared some exciting new bold initiatives that have come out of the secretary's office, Secretary Azar and chief among them is a proposed rule to support seamless and secure exchange and use of electronic health information by giving patients in their healthcare providers secure access to health information. I wonder if you could share with our listeners about the new role and what you think is very significant about this exciting new direction.

Dr. Donald Rucker: Sure, what we're doing and proposing as a rule, it's out for public comment is to actually allow patients to get their medical records on

their smart phone. If you think about it, in the last couple years, we've allowed patients to get access to their data through patient portals, right? But we haven't really allowed patients to control their data, taking it, moving it somewhere else. It really is not been possible in a practical way that sort of reflects our daily realities. We're really putting the medical record into that consumer space where we live, right, where we do whatever it is, Uber or Lyft, or banking, or airline reservations type of thing. This role requires providers to actually have a URL end point, the browser address, that patients can download their medical records securely using standards based application programming interfaces. That's a lot of technical jargon, it means you can take an app of your choice that ingest medical records, pointed at your provider and get your data on your smart phone, pretty exciting.

Margaret Flinter: Pretty exciting. Don it reminds me of so many things in health care over the last decade or so where all of a sudden health care ago, well, that's amazing and revolutionary and the patients go what took you so long to figure out that this is -- but we know, of course, there are concerns and complications. I understand that the rule still leave some unanswered questions as to the how, of course, how we make all this health data seamlessly accessible to all patients, and at no cost to them. I say that that's remarkable, because that's such a far cry from what we see today, where patients seeking access to their information often find out they have to come in, in person and sign a release. There's a long standing tradition of allowing providers to charge. Tell me what congress defined as information blocking? What's the vision around that?

Dr. Donald Rucker: One of the things that you pointed out, with modern application programming interfaces, we have a whole set of technical opportunities to do this much more readily than we have in the past. Congress has heard a lot of complaints, exactly along the lines, you outline Margaret, and the providers don't want to provide the data. In the law now, the law being the 21st Century Cures Act, signed into law by President Obama, I assure you, the White House are absolutely on top of enforcing this access for patients. It is prohibited for providers to do what's called information blocking, to not provide you with your medical data electronically.

We were asked at the Office of the National Coordinator, again, part of Health and Human Services to define allowable exceptions. The baseline assumption is providers will provide the data to patients electronically through these endpoints, so you can download it on your smart phone. Once it's on your smart phone, you can do with it as you desire. But the exceptions, so we've crafted out for proposed rulemaking some things around privacy, security, potential patient harm, this would probably be with underlying mental illness type of

issues. Then also some technical allowances on what the EMR vendors can charge the providers who have to provide these application programming interfaces, as well as some common sense provisions. The computer request can't be acted on, that's an exception or if the server is being rebooted. But the base assumption is that providers, so doctors in hospitals, through their EMRs are going to provide an endpoint that an app of your choosing will be able to download your medical record.

Mark Masselli: Well, that is just exciting news I think for everybody, all consumers listening. I think we live in this world of worries about hacking and cyber security and the like, and that platform might be one that's vulnerable. To what extent are you working with the companies or making sure we're going to put it into an environment that safe and secure and works for the patient?

Dr. Donald Rucker: Yeah, so whenever you hear something about cyber security, you sort of really dig into what exactly is the issue, is this just somebody hijacking a password? Is this a deep vulnerability in the software because of a bug? Or is this something that where we've actually consented to allow the data to be reused, right? So the Facebook type of or Google type of questions. When you look at for the patient record on the smart phone, the technical stuff is quite secure under something called **oh off to [PH 00:07:42]** that's a note alert term for the encryption security protocol. It's the same thing that's used by banks with your financial data.

We're using state of the art security there, and patients have to give consent. It's actually very similar to the type of security that's used today, if you log on to a patient portal from your provider. But it's actually more empowering to the patients, because they actually can revoke consent, they can control it. It's actually a much more empowering thing for the patient. Then patients, I think we'll have to make an assessment of what apps they use to hold their medical data, just the same way you decide, do I want to use a banking app? You have to sort of figure out is this an operation that I trust? People will make that determination, it'll be under their control which apps they store their data on, or use to access their data. But they will have to, as with every other choice they make on their smart phone think about what are the privacy implications here, right?

Of course, we give up lots of privacy. Anybody who uses Facebook, anybody who uses Google, anybody who uses a credit card, right? We've already made many choices, where we've said, you know what, we understand they have our data, then we want that convenience. I think different patients will draw that line in different places depending on their clinical issues, the opportunities for the smart phone to give them better ways of treatment, new ways of treatment.

I think the biggest issue in all of this, that is often underlying interoperability is so much health care is unaffordable in America. So many people have massive issues, affording health care. One of the big benefits here is to inject competition into health care delivery systems that have often configured themselves to prevent patients from taking their data and shopping. I think all of that will come into the patient side of what they do with their data, but the technical side is secure.

Margaret Flinter: I hadn't thought about that patient sort of comparison and shopping. But I wonder if I can go back to the information blocking piece for a moment. My understanding is that the team at ONC has actually proposed seven exceptions where the patient or another provider might request health information and the request can be denied. I wonder if you would tell us what the other exceptions are. I'd also loved if you could comment on did you within ONC can be in any kind of focus groups of consumers or get any feedback on what those exceptions ought to be?

Dr. Donald Rucker: The exceptions again, I think the exceptions I would look at them as fairly narrow and fairly specific. The baseline assumption is the providers are going to release the data to patients, and that the patients are in control. I think for too long the American medical establishment has been extremely paternalistic. You know we've all grown up with other people deciding the health care we get since the start of Medicare, and maybe even the World War II provisions around having health insurance, and so patients can't decide they're not smart enough to have their data. I don't buy into that at all, it's just not true and it's not right.

The exceptions are designed to be narrow, the specific exceptions are, if there's something where we think there would be harm coming to a patient or another person, this will be very, very narrow I would think. The second exception is something where we think that the release of the information was violate privacy. Again, with all these exceptions it can't just be like a blanket excuse, there has to be very specific. The other exceptions are security, very similar to privacy, in terms of cost, obviously interfaces, software, access, all of this costs money. But we've heard a lot of complaints, we've actually met with many, many folks, in putting these roles together, in particular with a lot of entrepreneurial firms that would like to provide new services to the American public, often at much lower costs.

We hear that the vendor community often is charging a million dollars for them to have access to the data, charges that bear no relationship. You can obviously price an API out of existence. You're only allowed to charge reasonably incurred cost and there's also a second provision of the seven, if you're claiming intellectual property that you have to

license it on reasonable and nondiscriminatory terms. We've heard complaints that these APIs are only opened up if the vendor feels that this might want to compete in this line of business. Then they won't let this competitor have access to the data.

Then the final two of the seven, because think about feasibility, an app is going to an endpoint and asking for something while the other demands could be infinite, right? It has to be something that can actually be provided. Then finally, if there's downtime, these are servers, and as we all know computers need to be rebooted, those types of things. Those are the seven exceptions to information blocking, we think it's going to free up the information for patients.

Mark Masselli: We're speaking today with Dr. Donald Rucker, National Coordinator for Health IT at the US Department of Health and Human Services, which is tasked with building a private and secure nationwide health information system. Don, it's kind of an exciting new era that we're going into. I think one of the things that we've heard from our patients is that they're smart, but the information tends to be boring, and not in context. I'm wondering what's going to happen in terms of the entrepreneurial aspect of Facebook, but really a lot of people are sharing information regularly.

I take it what might be occurring is that they have an app that they've developed, it may be one where they're sharing it with a whole community of people. It may be a community of their family and friends, that we're going to see the entrepreneurs thinking about ways that if you want to slice and dice this or you can pour something off and send it off to one of your relatives, you're going to be free to do that. When you talk about sitting with those entrepreneurial organizations, are you hearing people starting to discuss this development as well?

Dr. Donald Rucker: Yeah, Mark, those are going to be some of the things we've already seen some of these from, obviously, a number of small companies. Apple obviously is a large company that have done that first step. As you point out, it can be pretty dry. But I think the real win is going to be in what I think in the software world is called a mash up. Right now if you look at the app, and I don't know, I've heard numbers of 200,000 health apps, I have no idea, I haven't done personal count. But if you look at that app universe, you find there's a very small handful that have access to medical data, and then there is a whole other set of apps about health that have no access to medical data, fitness apps, diet apps. I think the win in the entrepreneurial is going to be when people figure out new ways to blend streams of information to come up with entirely new products.

Let me go back to the ride sharing services. If you just checked out Uber or Lyft, think about all different things that they've mashed into

that service, right? They've put in APIs to mapping to credit card to traffic to your consumer database, probably 10 other things under the covers, right? The win is they've taken a bunch of things that before were not connectable, right? In the old days if you wanted a cab, if you'd even find one you'd call a dispatcher, you never know when they were coming. We're in that old school era, where your stuff is sort of just locked in the chart. I think it's going to be tremendously exciting, it's kind of play out over the years. The winners here will be combinations that the three of us on this phone call won't have ever even dreamed of.

Mark Masselli: That's true.

Margaret Flinter: Well, that's a very exciting future. We'll do one now to the past, Mark, I think and say that we have enjoyed learning from talking to your predecessors at HHS and ONC, and that have worked so long and hard to get it to this point.

Mark Masselli: A font of creativity.

Margaret Flinter: Really, so I just want to take a moment and really celebrate all those people.

Dr. Donald Rucker: Absolutely. My predecessors have laid the foundation for this and it's taken a number of years.

Margaret Flinter: It absolutely hasn't. One of our favorite lines that came out of almost two decades of this was Todd Parks [PH] in his liberate the data, liberate the data for a lot of different purposes. But one of them absolutely was for the possibility of research to have data sets that we never dreamed possible to think about ways to improve health, prevent disease, promote well being. How does this most recent direction increase access to data for research purposes? Are you excited about that dimension as well?

Dr. Donald Rucker: You know, I think this is one of the things that the new technology has opened up in some other work we're doing at ONC with the National Institute of Health on think for science and think for genes, where we're using these modern APIs to hook up patient records for research, allow patients to participate in these research trials. It's very exciting, right, and of course the patients who are most interested are the patients with major illness. For them, this opens up some real possibilities for new treatments that would actually change their life in just stunning ways. The beauty of a technology here of these fire fast health care interoperable resource type of application programming interfaces, is that we can broaden the entire research pool of data.

Historically, research has been these heavily controlled clinical trials where they've used a lot of statistical work with a small number of

patients to extrapolate to the rest of us that's expensive. It often doesn't include minorities or people who are older or younger, or different genetic makeup. We think this is going to allow us to rethink the enterprise. Interestingly enough, this open Application Programming Interface part is part of the 21st Century Cures Act that also rethink how the FDA handles data. It's really in harmony.

Mark Masselli: We've been speaking today with Dr. Donald Rucker, National Coordinator for Health IT at the US Department of Health and Human Services. You can learn more about this new proposed rules and are invited to submit comments on the rule by going to healthIT.gov or you can follow them on Twitter @ ONC_Health IT. Don thank you, and as Margaret said, thank your team for the contributions that you're making and for joining us today on Conversations on Health Care.

Dr. Donald Rucker: Mark and Margaret, thank you very much.

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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 aims to reduce the level of deception in US politics. Lori, what have you got for us this week?

Lori Robertson: In a February Town Hall event on CNN presidential candidates Senator Bernie Sanders repeated a few claims about health care that we've debunked before. Sanders said that President Trump thought to, quote, throw 32 million people off of the health care they had. But that figure includes some who would choose to no longer purchase insurance if the individual mandate penalty were removed, which occurred this year. The figure Sanders sites is a government estimate of what would happen if congress repealed the Affordable Care Act without replacing it. President Trump supported the republican backed American Healthcare Act, a bill that sought partial repeal and replacement of the ACA. But when that plan faltered, he also advocated for an immediate repeal of the ACA with a replacement at a later date.

A 2017 analysis by the nonpartisan Congressional Budget Office which fits that replace later strategy did find that approach would increase the number of uninsured by 32 million people over 10 years, but not all of them would be thrown off their insurance as Sanders said. Sanders also claimed the US is spending, quote, almost twice as much per capita on health care as any other country. Estimates do show the US spend almost double what many other countries do, but not all of them. The US spent $10,209 per capita in 2017. That's more than double the 2017 OECD average of $4,069 per capita. However,

Switzerland spent $8009 per capita, and Norway spent $6,351 per capita. 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 everyday lives. Stanford based bioengineer Manu Prakash has a simple goal. He wants to create a portable medical lab small enough to fit in a backpack and he's already developed a tool that fits the bill. While sitting under a tree in Uganda he notice that the local medical clinics door was propped open by an expensive centrifuge machine, one that was reliant on electricity now broken and no longer in use. He wondered how could he create a portable centrifuge that would be inexpensive to make, easy to operate and easy to replace? His inspiration came from a simple childhood toy, the Whirligig, a toy that functions by pulling two ends of a string threaded through around object like a button.

Manu Prakash: We spent a significant portion of this time truly understanding the mathematical phase for how you can convert linear motion into rotational motion.

Margaret Flinter: He took this simple try idea to another level creating a human power centrifuge made from simple components, paper, twine and plastic. All together each paperfuge as he calls it, can be constructed in under two minutes and costs only 20 cents. And yet remarkably, it works extremely efficiently.

Manu Prakash: With this set of principles we're able to essentially make a centrifuge that spins all the way to 120,000 RPM. In the lab we can separate and pull out malaria parasites from blood, separate blood plasma.

Margaret Flinter: It's currently being tested for malaria diagnoses, but it's being readied for far more complex diagnostic challenges.

Manu Prakash: This is a tool that requires no electricity, you can carry them around in your pockets for a price point of 20 cents.

Manu Prakash: The paperfuge achieved a highly effective field for clinicians providing a portable solution to diagnostic challenges. 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 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.