

PUBLIC HEALTH INSTITUTE
DIALOGUE4HEALTH WEB FORUM: MAKING DATA WORK FOR THE PUBLIC'S HEALTH
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[Webinar in progress...]

>> I'm attending this Web Forum...

A, individually.

B, in a group of 2-5 people,

C, in a group of 6-10 people.

Or D, in a group of more than 10 people.

And, again, please click submit so that we can get your answers.

Once you're done answering the poll question, click on the Media Viewer icon again to bring the closed captioning back if you need it.

It's my pleasure to introduce Shell Culp, who has been a complete joy to work with since we started putting together this series many months ago, Shell speaks on performance improvement for government, change management and open data movement across the country, as well as the unquestionable expertise, her general spirit enthusiasm and willingness to dive right in have made her a favorite here. As this particular series winds down I want to give her a huge public thank you for all the work she has done and also let her know that for better or worse, I will be scheming ways to get her back on the microphone. Shell, go ahead.

>> Shell Culp: Thank you, Diana. Welcome toll Dialogue4Health, private health institute Dialogue4Health shares strategies to improve the public health.

PHI partners share critical resources. This series on Making Data Work for the Public's Health is sponsored by the California Healthcare Foundation, dedicated to improving the health and well-being and quality of life for people around the world. Learn more about PHI at www.phi.org. This Web Forum series take as a look to improve.

Using newly available data sources range from infrastructure, privacy issues and specific innovations that advance particular initiatives.

With support from the California Healthcare Foundation, Dialogue4Health is excited to bring you this Web Forum and I'll be looking forward personally to new and innovative Web Forums to participate in with Joanna as well.

We are considering...

[audio interference]

Dr. Dave Ross.

Shell, I'm sorry to interrupt, but we're having trouble hearing you. Could you get closer to your phone? You seem to be fading in and out.

>> Shell Culp: How does that sound?

Hello?

>> Hello.

>> Shell Culp: Can you hear me now?

>> I can. That sounds much better.

>> Shell Culp: I'm sorry, where did we leave off?

>> You were introducing folks. Thank you.

>> Shell Culp: Great, so pleased to introduce our distinguished panel, Dr. Dave Ross is director of public health, Dr. Coelius is director for Code for America.

A family emergency has prevented Dr. Shah from joining the forum. Let's jump right in.

It's my pleasure to introduce Dave Ross from the Public Health Informatics Institute. I met Dave at the listening tour in San Francisco last December and it was like we had always known each other. Dave is not with us but we have a recorded version of his presentation to frame the third in the series of data for health webinars in forecasting the future.

>> Dave Ross: I would like to welcome everyone to the third installment in the making data work for the public's health series, and today's installment is forecasting the future.

Before we begin, I really want to thank also the sponsors of this event, the California Healthcare Foundation without their generous support, these wonderful events could not take place, so we thank them.

Let me first, our listening audience introduce myself, I direct the public health informatics institute, which is a program located at the task force for global health. The task force is a non-profit located in Atlanta Georgia, specifically in Decatur, and we work throughout the United States and around the world. We have a broad reach in the range of areas, including the information role that is public health.

And so the informatics institute supports practitioners and ministers of health in various countries in helping them develop information capabilities needed to play their role effectively.

My job in this brief introduction is to talk a bit about my forecast, our speakers today are very well qualified to take a glance into the future. My look into the future is informed by several different activities I've been involved with recently. One was last year, I was co-chair of Robert Wood Johnson Foundation Data For Health initiative and had the good fortune to visit cities on the west coast and the southwest, the southeast, the midwest and the northeast. We traveled the country, and in those travels listened to large groups of community members of people from various industry, sectors of industry from the healthcare sector and the public health agency staff.

We brought them together as a community and asked each community a series of the same questions, the questions essentially focused on what did they see the needs for data were to inform the actions that they felt like taking to improve the health of their community. And we left the definitions of some of those words like community and

health open so that they could interpret them as they wished, but to speak about what their vision for their community was.

We heard a number of common themes, but at the core of the themes across the board was the desire for data that are factual, the desire to turn that data into information that allows them to understand problems in a pretty granular way, specific to their community, to act, and they were all across the board in every community, prepared to take actions. What we saw was their desire to have tools and help and support and turning data into useful information.

That was a very interesting experience. For me, and a few remarks I have to make this morning. The other is I'm involved on the National Committee of Vital and Health Statistics, which is an HHS advisory committee and the national committee is now working to formulate recommendations to HHS about its role in improving population health and community health.

I suppose in a way those are one in the same. It depends on who you're talking to as to how you interpret that.

So let me first talk about this issue of population health.

We look into the future. What are we saying.

I think what we are now saying is communities becoming mobilized to ask questions, questions that can only be answered with data that cross sectors and are granular to their community. People want context, so they want statewide and nationwide context in which they frame their understanding of their own community, but they want community data. And that is a more granular level way of looking at problems than we've ever seen in the past. So the expectation of the public, I think, is changing.

So I look into the future, one of the things I want to point out is that we have a change of expectation. All of us, ask yourself, nowadays, with the mobile computing devices that we all carry around, we expect instant communication with many people and we expect almost immediate answers to almost any question we think we could ask. Search engines changed our way of thinking.

So now when you get into public health related issues or population related issues, what we know is that if there's an outbreak, the public wants specific answers and almost in there realtime. So as I look forward and say the challenges and opportunities for public health, one is to inform populations at a granular level in a very timely way.

There's another trend that I want to just briefly speak to and that's this whole notion of digital health.

I would just ask -- too bad we can't see a show of hands, but ask all of those in the listening audience today, how many of you are carrying a device that are monitoring your health.

For example, a Fit Bit. I happen to be wearing one right now.

I tell you, a year ago I wouldn't have thought I would be doing that. But here it is sitting on my wrist. And I imagine quite a few others are doing that.

This notion that we are thinking about our own health in a very direct and measured way is already upon us and I think that's one of those trends that is going to change and transform. Because awareness about one's health leads to a broader awareness about the health of others and I think that's going to shift our attitudes. That to me is a trend that is going to be important because it's going to open the door for us to

think about other ways to use data or other kinds of data that we might want. That's going to influence heavily, I think, how public health should work in the future.

So in closing with my opening remarks, I would like to just make my glance into the future is that we have public health agencies that are effectively the information custodian or intermediary if you will, to the community, that helps the community hold up the picture of their health status by using data that reflect all aspects of the social determinants and really timely and granular and accurate and believable picture of health status in ways that the community wants to respond and together takes actions. I think these trends together are moving to a very interesting future. I think today's program will enlighten you further, that the past series, looking at where we are today, but now looking forward, it makes this three-part series on making data work for the public health a wonderful contribution and thanks to the California public health foundation for making it possible. I hope you all enjoy this fascinating program.

>> I would like to add my thanks to Dave Ross...

[audio interference]

Before we move on, I would like to take an opportunity to comment on his rashes and perhaps draw a circle around some things that we've heard over the period.

The first notion of privacy and confidentiality and I asked Sandra Hernandez, the executive director of the California Healthcare Foundation with comments on blog posts... [audio interference]

>> Shell, I'm so sorry, whatever you did earlier to fix your audio, if you could do it again, we would be so grateful.

>> Shell Culp: How is that?

>> Better.

>> Shell Culp: Where did I leave off?

What is the last thing you heard, Joanna?

>> I lost you a little after Sandra Hernandez.

>> Shell Culp: Let me start over. Some of you may recall that I asked Dr. Sandra Hernandez at the beginning of our first Web Forum, Sandra is the executive director of the California Healthcare Foundation, to comment on a blog post she made regarding our collective notions of privacy in this social media. It's important again distinguishing between data that can be shared without negative consequences and data that should not be shared at all. As was pointed out we are in greater numbers, understand and manage our own health with devices as Fit Bits and others, for example I use my phone. The data from these devices is the same data that can be used to right [audio distortion]... and we'll hear about these in a few second from Dr. Coelius. These help paint a complete picture as Dave pointed out and Daniel will elaborate upon on those factors that contribute to our wellness and the environments in which we manage that wellness. It's important to note that these data have collective value beyond our personal use and to extend that value to neighborhoods in communities that we live in and to be used for common good. And while it may not be with our Fit Bits increasingly we can contribute to that greater understanding and then hopefully collective solutioning for some of our biggest problems.

Now let's take a few seconds for our second poll.

Do you collect data about your own personal health, such as Fit Bit, blood

pressure, et cetera? A, yes, diligently.

B, sometimes, but it doesn't always happen.

C, no, but I have been meaning to start.

D, no, should I be doing that?

E, no, and I will not.

F, other.

And please let us know what "other" means to you.

Now we turn to Dr. Rebecca Coelius, director of health for Code for America.

I met Rebecca at the second California health and human services open data fest in Sacramento where she talks about health, economic development and justice and public safety, all of which contribute to the broad notion of wellness. She is a strategist and leads Code for America's investments in promising new digital health services while she cultivated new partnership in the Code for America health lab. welcome, Rebecca.

>> Rebecca Coelius: Hi, thanks so much for having me today and thanks especially for all the attendees that have joined us. I want to repeat thanks to the healthcare coalition because not only do they support the series but a major supporter of our work at Code for America.

Without further ado, I thought I would give a background on what Code for America does, and some of you in the audience may not be familiar with us.

Talking about recent work and the work impacts the public's health and uses data, things we've learned and a few more general productions.

So Code for America, it's an organization nonprofits that work on a national scale and started about five years ago with the belief that government actually can work for the people, by the people, in the 21st century. The emphasis can work because although many of you on this call work for government, work with government and already believe this, unfortunately, across large portions of our country in particular, where Code for America is based, that notion may actually cause a large debate. You know, whether or not representatives are working in the United States today. So we believe that it can, but it only can as it moves into the digital age and develops muscle and starts to practice into things we actually call practices. This is our list.

Government starts with people's needs. Many have heard of student design and research. Ensures everyone can participate, coming to where people are to participate and ensuring all are inclusive. We believe that government should start small and continuously improve learning and applying a lot of the work in development. We believe government can use realtime data to inform decisions and it can default to open, not just data but word processes and that it needs to build the right team. So that means having people that are digitally savvy and adept in things like product development in house and not always contracting out and it also has the muscle to choose the right technology for the job.

I thought it was important to represent what we actually mean when we say "21st century government."

Shell mentioned Code for America's work is organized around focus areas. Health, safety and justice, economic development and communications and engagement. And in those areas we have a series of programs that does mission-driven product development that it develops in communities of people looking at similar things and also develops a

lot of content and around the practices that I talked about earlier.

Now we get more health specific. The way that Code for America defines work around health is focusing on delivery of health and human services by increasing program access and usability. And we say health and human services, it's much more on the side of healthcare in public health simply because Code for America focuses on local government, so city/county, sometimes but not often the state, mostly the public health and healthcare side, people employed by government are directly delivering many of the services.

So what we've done and learn over the last couple years in HHS, one of our major programs is the fellowship program that has been with us since the beginning, five years ago. And this is a program where we challenge the teams of technologists, an engineer, designer, researcher and product manager for those complementary skills. Across the country they align around a particular problem framed around a human outcome that community wants to reach and a few different practices, they want to build muscle and moving towards that outcome.

So projects that we've done recently are starting to get through a future data and digital technologies and such in health and human services, especially public health, a great example is address IQ. I know that was addressed earlier in the week. Address IQ is a project that came out of the 2014 fellowship in Long Beach, California. And when the fellows got to Long Beach, the city of Long Beach, which uniquely has its own health department shared that they knew they were searching locations, people that were very significant utilizers of healthcare services and it was an issue of individual but also costly to the community and they were inspired by a lot of the work that was spearheaded in New Jersey and this concept of hot spotting this locations and bringing better services to those individuals, those addresses to help ameliorate the high utilization. So they built in partnership with the city a tool called address IQ that pulls in data from the police department, as well as the fire department on calls that were made, generally at the address level only for larger facilities, things like nursing homes and housing that has enough units, any personal health information for an individual. It identifies a number of calls and the reason for the call. So it creates a dashboard constantly updating and sending out alerts when the data changes across the city. This could be logged into from multiple departments within the city of Long Beach because it identifies for better targeting and identifies they had trouble collaborating with each other around what plan was going to be put in place to address these locations, high utilization. So also in the product is something very similar to what any of us experience when we're using things like Google Chat where people across departments can collaborate and share what they're doing around a given address.

I should know in addition to address IQ, it was built and up and running in Long Beach, California, but we are now looking at piloting and doing additional market research in additional cities and counties, particularly across the state of California, but really nationwide. So I will remind you all if you're interested in being part of that, please be in touch.

A current project in Richmond, Virginia, we're looking at the problem of how different safety nets and hospitals, sliding scales can share patient financial eligibility information. So a lot of the documents that verifies a person was in a certain place at a certain income level, that sort of thing. And this project came

about because the fellows went to Richmond and city and county partners there shared that Richmond, luckily, as compared to other communities in the United States, doesn't have an issue of scarcity in their healthcare Public Health Services. They rather have an issue who are eligible for them not availing those services, especially in the human services public health side, versus emergency care.

So they had them come in and do a good deal of research to understand why that is happening and they identified that there were a large number of people in the community that were actually trying to avail themselves of these services, especially on the primary care side, but we're having such trouble proving that they were eligible for the reduced cost pair and even when they did submit documents it was taking multiple months to be processed and once that happened at one point they would have to go do it at another clinic if referred or at a hospital or something of that nature, that many people just gave up because there was too much friction in the process.

So this tool helps the individual submit that information only once and then it's stored in the system and the data can then be shared across the different community health clinics and safety net hospitals. It's currently in pilot stage, so I can't talk too much about outcomes, but I am particularly excited to see where this goes because this is a problem I've seen of national relevance, not just healthcare but across human services as well.

This is just another screenshot from the project.

Another current project this year, which is much more on the healthy eating side, our team in west Sacramento, California, went into the community and was asked to work on a joint health and economic development project. So there were many, many new farmers in West Sacramento and the wider region, the Sacramento region is interested in helping farmers stay in their community but also really interested in helping people in the whole community better access fresh and seasonal food. So one that I find particularly interesting is they've set up a tech space system for a few different farmers markets where people can text a certain number and then the farmers market will respond with what is most seasonal and also working on prices at this time.

Because they did hear from a number of people in the community that if they knew that even a few of their favorite fruit or vegetables have come in and available they more likely would be able to go to the farmers market to purchase their groceries.

I know there's a lot of interest in this community, you know, looking towards the future. Not just from within, but working closely with community members, technologists and developing some digital services and working with data.

This work is called the brigade program, the largest program by number of people involved, they have over 105 brigades across the United States and over the world. One of our most active and successful brigade programs is in Japan, 4500 plus volunteers participate. You can follow the link below, but one particular example of a brigade community and is in the city of Chicago. The brigade program started in 2012 and pretty early in the cycle they had a hack night and worked on a project called Chicago flu shots. You can go to Chicagoflushots.org and they basically put the different locations people could go and get flu shot vaccines during certain times of the years. It was a success and deployed to three other cities in one month. One of the interesting things about this project is that not only was the work useful to residents but also was very successful in sort of convincing people of their value of

opening up and standardizing and sharing flu shot location. And, you know, a couple other things building off of that was in large part inspired by that work and some of the people do that work.

I won't go into too much detail, but Chicago, which is not well known, an app, food poisoning, that comes through in service requests to inspect the restaurants, a lot of those partnerships, and now the Chicago's department of innovation and technology is making some significant and long-term investments for identifying food violations.

Certainly not saying this is due to Code for America, but early work with the brigades program brought people together and got people thinking about using data and providing services in different ways that perhaps wouldn't have happened without that.

That's just a screenshot of the Chicago flu shots locator tool.

This is another Code for America project that came out of the 2013 Indiana fellowship and this is not created with the intention of being a health project specifically, and it's not currently used for health reasons. I think it is actually really interesting an example, public health can pull from an engage in the community and some of its work, because looking to the future is certainly one of the trends that we're seeing, community-driven research but also people wanting to be more participants and having their voice heard, enter data, that sort of thing. City voice is a place-based call-in or text system to collect and share community feedback, and these communities are using it for feedback and information around the quality of parks, safety of parks, that sort of thing.

Now, sometimes in our work at CfA we can do year-long projects and they turn into useful tools and interesting things that can be taken forward right away, and sometimes we find it's the first layer of a pretty tricky onion. We like to call it the onion of friction, users accessing services in the community. One pretty good example is the work is still ongoing came out of our fellowship in San Francisco, California in 2013. Many on the call may be familiar with a tool that got a lot of press and that tool was designed to be a simple text-based identification system for people on the program in -- SNAP program in California, also known as food stamps, and basically people fall off the program because perhaps they miss a letter notifying them they need forms or something else happened. It's very costly in the system and disruptive to a lot of families. So it was successfully notifying people that there were at risk of being turned off the system, but we found when they actually tried to call in to local human services agency, they were having to wait on hold for such a long time, often up to an hour, hour and a half, that people were pretty quickly hanging up. So even though we were successful in notifying people and getting them to take action using data, we were not so successful in actually solving the problem, because there were deeper problems and technology that we go at.

We are working on a tool now called connect. You know, we do have the great pleasure -- they have the ability to put on hold for a few hours, they will call you back as soon as somebody is available and bringing that technology also to the local health system which a lot of the community members like because they don't have people falling off.

About the layers on that problem, we spoke to many people that are already enrolled in groups in California and they shared a lot about their initial experience of simply getting on the program and how that was. This is produced for animation, but we

like animations. But if none of you have tried to apply for something like food stamps in your state, I encourage you to go to the website and check out that experience. California actually has one of the poorest participation rates in the country, only about 60% of the people that are eligible for the food stamp program here are actually enroll, and we believe the application is one of the reasons why. It's about 40 screens long and takes an hour to two hours to complete. And you have to bring verification documents, an interview, which is often difficult to schedule, et cetera. So this traces all the way back to the San Francisco fellowship several years ago, the application process, the ability to get those documents by text and notification system for your interview so you don't miss it.

Another one of our projects that grew out of that San Francisco experience was called EBT near me. This is a cool example of working with the states to use data that wasn't previously opened, but making a case for why it should be opened and building a tool that people needed. So one of our hypotheses is that one of the reasons that people were often using their EBT card, which is a card that holds their dollars on it, most effectively they're often using it at corner stores, more expensive, et cetera, was because they didn't know the variety of places where they actually could go and use that card. So we put it on the map using data that is open and released by federal governments. Pretty quickly found that people were actually trying to use the tool not for locations related to EBT card but trying to figure out where they could find ATMs that didn't have high surcharges for them to call out their cash based benefits. Because in California, the system is used.

They had an agreement with Xerox saying they would not release the location of ATMs or whether or not they had surcharges. So it was a really big deal.

California was spending \$20 million a year on surcharge fees coming directly out of taxpayers' pockets but coming directly out of the cash benefits given to people, so it had a pretty significant impact. But by showing the states there was this real user need and they also were paying quite a bit, you know, out of the programs, some things also administered, we convinced them to share data with us and they're looking hard whether or not they should be signing things like this with vendors in the future because the data might become immensely valuable for reasons like this.

So a couple things to generalize that we've learned looking forward, we've really found that as much as open data is important and as much as we've gained in creating a culture, open data is doing the expectations, we have a lot of work to do recognizing that understanding user needs, to drive what data is open and how it's used, a lot of work, doing research and sort of getting out in the community and interacting with people is not there in the same way it often is.

So really spend time with users in the process on the data collection and analyzation process.

I know in the first phase, a lot of the times you prioritize open data that probably is more politically expedient and sometimes useful and sometimes not. If you're starting with a human problem, it's going to be quite obvious how to use that open data how it's released, but you're probably going to have a whole set of people inside government, outside government and for profit and nonprofit companies to use that data because there's an immediate problem to apply it against.

These are things people are saying in the community, but I'll say it again.

We need to measure our success in terms of human impact, not the number of data sets we released or asked and developed, just whether or not that application is solving a problem for residents or internal business process needs.

One pattern we've seen in a lot of this work, and I hope other people have seen this, so you don't just think I'm crazy, is the tendency to get data and immediately get really excited about putting it on a map. Code for America also has made this mistake at times in the past, believing you can put a thing on the map and it's going to lead to behavior change. Unfortunately, that is often not the case. We have to understand more deeply why somebody is or is not doing things like using their EBT card at the corner store and assuming more information leading to better decision making. So certainly mapping things is an important thing in our toolkit, don't start those. Start with really understanding what sort of tools are going to change behavior.

Another thing we learned that is really important, public health policies fail more often because of poor implementation than poor data. Certainly there are exceptions to this, but we have often seen kind of a big gap between the amount of time and money and energy put into really, really thinking about a problem, really gathering enough data and good data to deeply understand a problem from the amount of money and data driven decisions that take place once you intervene on a public health problem and I'll go back to the address IQ problem to fully disclose whether succeeded or not succeeded, that community really loves the piece of AddressIQ where it's bring data sets together and seeing where people are utilizing services, but not a lot has happened in terms of changing what services are delivered and where and there's lots of reasons for that. Part is resource allocation and part is a lot of internal work process changes to work across departments.

So I think looking towards the future for AddressIQ, we're looking for pilot sites that want to work on that whole arc, if you have more information about one facility versus another, what resources and people do you have in place that could do something with that information?

And that relates to the sort of last thing I would share.

How do we have a clear theory of change what we do with more data or better data. And to sort of look back at my training during medical school we were told again and again, don't order one more lab, don't do one more X-ray unless you have a sense of how additional information would change your decision making. I would encourage us to put efforts in open data and sort of through that same analysis.

And one of my favorite South Park episodes, which I will not play for this audience because it would be inappropriate due to their language, but it is a good representation of this. We hear people getting really excited about getting more data, better data, planning what the next step would be and more data, better data means more health, but think about what that theory of change is in the middle.

So briefly a few changes on the future by some of our current work and what things are hang in the industry. We believe in the future understanding a population will really mean understanding individuals in that population, so certainly understanding the scope and scale of the program will always be really, really important, but things that were already mentioned on this call, like ability to gather data from social media, our ability to have data openly shared and submitted to us by people in our community will help us to dig in and understand subgroups and individual

level what they're going to need in terms of prevention and intervention.

Especially on a digital side.

We believe there's a behavior science that is going to get as good as the bad guys. A funny example, a group of us during medical school we own downloaded add block, which you're familiar with, and you can use ad block to fill in all the different ads of pictures with kittens instead of having the ads or blank spaces. We wrote a little script, instead of kittens we would be reminded to drink water or get up and move a couple minute when studying hours on end, just a lot of opportunity to take tools used to convince us to buy shoes to help us make healthy choices.

And finally as I already mentioned, a real opportunity to do polling in crowd-sourced data for public health and healthcare purposes and research. Also opportunities for a lot of that to be community-driven. You've seen a lot of patient communities coming together across the Internet and sharing data which interestingly seems to make a lot of experts in the industry more concerned about privacy and security, especially rare diseases or when children are involved with their health.

We talked about information for decision making at the public healthcare system level. I think you're seeing a change in the amount of information available at the individual level and a much more sophisticated sense of what people actually want and need to solve real problems. I think it's interesting when you talk to people in particular about data they want or making healthcare decisions, a lot of top examples they give is still not information that we've been able to share with them, so things like, you know, really, really good cost information, more consumer-driven plans and high deductible plans.

Individualized quality data, I think it's fantastic that that's released a lot of quality data and procedures. My father had his gallbladder out and immediately jumped on that website to see his physician and quality information was and was glad to see it was one of the best in the state.

Physician network information and formulary information are really, really important, you know, two data sets that people need when making insurance purchasing decisions and right now we're seeing situations where people have something relatively complex like colon cancer and they find out maybe hospitals and clinics is -- the hospital is on the plan and they only find that out unfortunately when they get a bill, if something is not covered. But the real question is people actually have the ability or the incentive to use the information, not just health plans as -- perhaps I know an example using good RX, I know my prescription will be much less expensive if I went to a pharmacy four blocks away, but it's still really hard to move your prescription from one pharmacy to the other. It takes phone calls and negotiation and your primary care doctor writing that prescription, so we really need to change things about patients making decisions and how people effectively use that information.

So I end this presentation with a reminder there's a couple things I would love to hear from all of you about. We're looking to do more AddressIQ market research and pilot sites, especially if you're going from utilization of data, if anybody is working on usability of SNAP, the food stamp program in your county or states, we're doing work there. And Code for America has our yearly summit coming up. We have thousands of people from local government across the country representing hundreds of different governments and a pretty robust health track this year. If you're interested,

I would be happy to provide the discount.

>> Shell Culp: Thank you, Rebecca. You covered a lot of territory and I was trying desperately to jot down questions. One of the things that struck me was, you know, the idea that the Code for America applications and focus seems to be at a very personal level for people, right? These are things that people can carry around on their phone and they can get more information, like what Ross was talking about, sort of monitor their health or get more information where is an EBT near them or where is a farmer's market and what is at the farmers market and what is the pricing and that sort of thing? And juxtaposing that with the idea that government public health programs exist because the problems are really, really big. Is there a tendency for public health to programs, maybe at the state or county levels across the country to kind of dismiss the work of Code for America as maybe not applicable? And if there is, how does Code for America deal with that?

>> Rebecca Coelius: Yeah, I think -- so a couple things. I think a lot of the practice in public health is looking across a much larger population, and a lot from Code for America are trying to understand the size and scope of the problem for policy reasons, but when it comes to interviewing a lot of problems that public health practice identifies, we find that many are at the personal level. I wouldn't say we have an opinion about an approach, you know, sort of like population levels, general approach being better or worse, more effective or less effective, in the general sense, and a personalized approach, but in all the work we do, we do start at the user level and sort of explore outwards from there, because to us, success in our work is showing that we have a group of people healthier. We have changed the decision making around healthy food. We have helped them enroll in a food stamp program, and I think often we're finding those interventions really do require reaching people where they are and deeply understanding what is going to motivate them and what their barriers are. Certainly having to balance that with the need for our programs and our products to be able to spread to be financially feasible for anybody to support and deliver.

So I would say it's less that public health departments miss Code for America. We've had a lot of wonderful cooperations and we're looking forward to more, but more that I think all of us are grappling with what technology is making possible and once we get past the understanding problems.

>> Shell Culp: I may have a question a little later about what you mentioned around measuring success in terms of human impact, but I see that we're kind of running a little beyond what I had thought we would run, so I'm going to turn now to our next poll.

And thank you very much, Rebecca.

I think we have put this poll up a little earlier, but I was having sound difficulties, so let's do it again.

Poll number 2, do you believe data will change how public health works?

Yes, we are well on our way.

Yes, but the changes won't be as dramatic as people may think.

Maybe, the jury is still out.

D, is it possible? It is possible but unlikely will have the funding and infrastructure to move the needle enough.

E, no, there are too many problems that data won't answer. And...

F, other. Please tell us what other means to you.

Okay.

As we mentioned, Dr. Nirav Shah is not able to be with us due to a family emergency, so next up is Daniel Stein, the co-founder and president of Stewards of Change institute. Daniel has been working in the area of health and human services data, interoperability and holistic views of people processes and systems more than a decade and is this country's foremost authority and leading advocate for these notions. Daniel worked with some of the largest and challenging jurisdictions, including California, New York, Washington D. C, Louisiana, Connecticut and New Jersey for achieving interoperable health and systems and data. Welcome to the Web Forum, Daniel.

>> Daniel Stein: Thank you very much, Shell. And welcome to all the visitors here listening attentively to the program today. I have the great pleasure of being clean-up hitter, so to speak, and I really have enjoyed Rebecca's presentation and discussions around Code for America and having had the opportunity to work with Dave Ross on the data for health under the Robert Johnson foundation, I appreciate him. Even if recorded, he's a transcendent person and great advocate.

So I have an opportunity here to talk a little more about social determinants of health and wellness, and a topic I've grown to learn more about and love as we at Stewards of Change look at how do we enhance information sharing and interoperability, how do systems connect and share the information?

And so it's been a real journey for us and I'm pleased to be able to share some of the thoughts that we have -- we've been focused on lately. This presentation is kind of both at the macro level and at the micro level and I hope you see what we mean as we go through this. As I can simply advance this, that would be great.

Let me see how we're doing here.

Okay, so I would like to start off with some basic definitions. We often use the terms HHS, and because the second H or the first H often referred to as health oftentimes dominate the second H, human services, both in terms of spending as well in terms of population, but we think about the other H relative to one's health and wellness both individually and at the community level, so I propose to the Department of Health and Human Services that we change it to either the Department of Health and Human Services or the department of Human and Health Services. Well, they're still contemplating that.

What I am really surprised by -- and you may be as well.

This is a national view of the size of the programs. They're not exactly in proportionate order, but just to give you a sense of where on a national basis we are, Medicaid today serves as the Affordable Care Act brought in some 7 million new members. 70 million people across the country. When we look roughly at human services, the numbers are exceeding that. We're probably at 100 to 150 million and you get a sense of the various programs here, whether or not there are developmental disabilities or child support or supplement nutrition programs and WIC and these other ones. What is missing from Social Security also treats and provides services to 65 million people. So the numbers are really quite gargantuan. The overlap is quite significant and it's important that we really think about the role of human services and I would deem all of these human services and I would even lump health into the human services, but for discussion purposes, I would like to separate them out just so we get a sense of the

magnitude of it.

The term social determinants of health is probably a concept that if not all of you, many of you have been exposed to or heard about or studied over your career, and it is indeed a concept, as I've learned that's been around for multiple decades originated in the '70s, actually in Canada and has gone through its own particular lifecycles over time, but there's been a growing body of knowledge and now an acknowledgment that the social determinants, the social factors are really dominant in terms of contributing to the overall health and wellness of a community.

So if you look at some of the research, you'll find essentially a variety of percentages that ascribe value to one's overall health and wellness, while they're not exactly the same, the conclusion is very similar, which is healthcare, meaning hospital, health, pharmacy kind of things, actually contribute a minor percentage of one's overall health and wellness. It's the other factors, such as the environment, human biology and life sometime kinds of things that contribute a dominant percentage of the overall wellness and health. The fact that it's now coming back into vogue and recognized is something we're excited about. I think one of the things that has been one of the constricting or inhibiting factors for actually doing something for the social determinants on a scale basis has to do with information technology, and the inability of our systems to be able to share information about many of these programs that we know influence wellness and health -- we know influence wellness and health and what are the important factors. We'll come back in a second, but the key point is that the other stuff that we have a lot of control over or some control over actually has a dominant effect on our overall wellness individually and as a community.

You may have seen this. I became familiar with this 3-4-50 moniker from the good folks in San Diego county who are -- who have been on the long march towards impacting population health by paying close attention to social determinants as they have worked over the last decade to improve everything to being able to wire up through electronic health records, hospitals that change service not only to the communities but to veterans. As part of the World Health Organizations study, there's a concept, as I said, 3-4-50, which is pretty powerful, clearly stated on the slide, but three behaviors, exercise and tobacco use affect four chronic diseases, cancer, diabetes and lung diseases, which counts for 54% of untimely deaths.

So when you look at this, it really is quite impressive and impactful that the kinds of things that are causing people to die early are in effect many things we have the ability to control for.

I think there is minor deviations depending on where you live on this, whether or not you're in good weather, bad weather, those kind of things, but in general these statistics hold true as a general approach.

So as we go from these macro concepts, I want to call attention to some of the micro things, what is it about this that would actually affect individuals?

And how do we get our arms around the issues in how do we think about macro issues? We come at health and wellness from a client-centered perspective, whether or not you're dealing with foster care or persons with physical and intellectual disabilities or behavioral health or families or seniors or veterans, we're talking about people. We're talking about families and people. We always need to keep the person in the center of this while it's important to think about communities and

populations and public health as well, it does come down to individuals and what this all means to me and my family, what is in it for me, as they say.

So one of the things that is a very accessible way to think about social determinants and to think about information sharing and these broad concepts of interoperability and how systems work together, just quickly take a look at a scenario or a persona as we like to call them. I've chosen one that we've developed. This is not a real person, although it probably signifies a cohort of people that is probably rather reflective of their situation. This is a family, the Garcia family. Mrs. Garcia is 40 years old and widowed and we described the situation, the grandmother and mother, lives in a rural community, fixed income on disability due to an accident and she is involved with services whether or not child services, need in transportation and child care and adult services, and the reason is she has a daughter, 20 years old. She's a teen mom and she also is pregnant again with the second child.

She's known for being involved with the child welfare system. She's transient living situation and drug addicted and potentially being sexually exploited. Her needs are extensive, including health, prenatal care, housing, transportation, medical referral for substance abuse and many others.

And if we look at the third person in this relationship is the baby, Angelina, who is two years old, separated from her mom because she's living with her grandmother. At the risk of removal and being adopted in placed in another home and series of potential issues from developmental issues due to chemical exposure. And she also has a lot of needs, most importantly a permanent mom, immunization screening, lead screening, all these things that affect her individual health. If we look from a current system perspective we begin to see the complexity of the types of services. One small family is trying to access, whether health or child protective, essentially childhood, Medicaid, other array of HHS services and the needs are varied. Marisol, or whether it's Angelina or Mrs. Garcia, the needs are complex, and they are cut across the various programs. As a result of that, obviously, it's very difficult to provide those services and some kind of coherent fashion without some case coordination, and that's where data comes into play. It says we look at this idea of how do you organize this complex set of needs for all of these various types of different personas so to speak. We see it's a very complex endeavor. And we talk about this in terms of care coordination through interoperability. These systems need to be able to share information within an appropriate legal framework, but they also need to be able to do it to expedite care. And there needs to be coordination whether or not it's a hub or a variety of other methods to actually share information. The important note here is that there is a need to do that, an urgent need to do that. And I think in some ways this actually explains the complexity.

Over the years we've tried to explain interoperability and the need for operation sharing, technical language and I think it gets lost on people quickly.

Here we see an opportunity to share the complexity of this through a human eyes and human situations. I think that one of the things that this provides for not only individuals but systems that are trying to create solutions is that we have the ability to see the client from whatever perspective you happen to come from, whether or not it's from health or social services or human services or justice, you as a team or the organization or the various organizations can view the individual and see the impact

on them. And that's an important criteria for both creating a new culture and a new way to have doing business and a new way of sharing information. Because regardless of where you sit, you can actually see where and how the person is impacted.

Care coordination. It's all about the data. But the question is, what type to have data are we talking about?

Are we talking about personally identifiable data, research and administrative data, big data? And are we talking about open data?

I think we're talking about all of those kind of data. I think that's the important point. And I think that what we are potentially want to do is also silo-ize our data. A number of years ago we held a national symposium and brought together people who represent the various streams of data and I believe it might have been the first time that they actually sat on a panel talking about their particular needs, but recognizing that each hold one particular part of the equation. Individually they don't have a complete view of the individual or the community and that makes it very difficult.

So the caution here is there's lots of different types of data and that we also need to think about how do we de-silo-ize our data as thinking about addressing both policy and implementation questions.

What I wanted to focus on in just the last few minutes of this presentation is open data.

I'm really excited about open data. We heard a little about it from Rebecca, and we heard a lot about it in our data for health series as we went around in terms of getting access to information.

Obviously it's a relatively new field and the explosion of open data is quite astounding in terms of what is coming into the field. And of course we do need to be careful that it's not sufficient just to have the data but it's what we can do with the data.

For those of you who may be new to the open data world I've just provided a brief definition, so we are at least both on the same page. And open data, as it's commonly referred to, describes data fully available, machine readable, formatted according to national standards to facilitate visibility and reuse. A couple words, machine readable. There's a lot of data, the government collects a tremendous amount of data. It's not formatted in a common way, so it's difficult and expensive to access and use it. Now under open data world, we're finding because of the structures and requirements that it's becoming more available in ways more easily usable by researchers, by policy folks, by entrepreneurs and government workers to be able to use it.

Interestingly California has come from behind, so to speak and has now in fact taking the lead in many ways on open data.

And they have really committed some significant resources both within the Department of Health and human services and more broadly across the state and part funded by the California Healthcare Foundation who has really been pressing in terms of seeing the need for this and investing foundation resources to get this moving.

Uses of open data, as you can see on the slide here, are really quite many. They're useful for individuals, businesses researchers, journalists, developers and

government. One quick example is the measles outbreak in California last year, and in alternative times, it would have been a very difficult problem for both the journalists and the government to understand what was going on, but because that data had been posted to the open data portal in the state, it was immediately accessible. Journalists found within a few days, there were articles in "The New York Times" and The Washington Post, understanding the issue and pointing to the places and the issues where the lack of immunization was actually quite significant. And the hot spotting brought it -- it was easily identifiable and sense then within a short period of time there's been legislation that addressed the ability for people to opt out of that.

I just want to mention a few more things about open data and call your attention to it if you haven't been familiar with it. It's very exciting. We as stewards have had the great pleasure of working with the state and foundation to bring people together across the state. We helped launch the initial portal. I might say under Shell Culp's leadership when at the state and office of system integration, she saw the value of it and we were able to work together to create the first open data Fest leveraging data at the palooza level and we created something in California, two years of conferences and planning a year in 2016 to bring examples from across the state. These are posted at sites if you're interested in the lectures and the presentations and some of the work that's come out of it.

For your information, this is the current California Health and Human Services portal. Maybe a little small to read, but very navigable and very accessible. For instance, you won't be able to read this next slide. You can click on the tiles. This is clicking on the health tile, and what you would do here, these are just an assortment of data, click on the data sets and it puts it into a format that you can download, analyze, graft, do all sorts of stuff. So it really has become a really click-and-play methodology, which makes accessing data externally very useful, and this is prompting the internal uses of data throughout the California healthcare agency to turn the same tools internally to share information broadly across various programs. I think we're still in the infancy of this and it's very exciting to see what the possibilities are.

I think open data has got a lot of uses. It may be over-hyped at the moment, but I think we're just now exploring uses of it. I think what is exciting to me is the opportunity to facilitate community needs assessments in a very rapid order fashion, and because more and more data is available, local communities can get access to what are the trends in their communities almost from an epidemiological perspective and other sorts of trends combining with other data and compare it to other communities. So those kinds of needs are now becoming really much, much easier to address.

So in closing, I just have two more slides I want to share with you. We at stewards think about data. While I said before, it's all about the data -- well, I was lying a little bit. You've got to start with the data. But if you only stop there, you're lost. We believe you need the data to make sense out of it and get information. From the information phase we ideally are being able to create some knowledge by which we can make better decisions because now we have access to better data, and ultimately that materializes in terms of wisdom.

How do we know about our systems? How can we do predictions and understand what the issues are?

And finally we think about how you actually implement this. A series of

changes. It's critically important and we don't have time to go through that today, but the way we think about it is being able to link together the interoperability or the plumbing along with the integration, and with data sharing, and that creates something called interoperability, which is a term we created to think about what do you do after you've got the pieces together, how do you integrate and optimize? And that's where we believe the industry is at right now, we're perched at the ability to use the data with the technology we have available to make change and implement it. Of course, we cannot solve our problems with the same thinking we used. We need to do something different.

With that, thank you very much.

>> Thank you for your insights, Daniel. We have a couple of questions, and let me just encourage people to-though is the time to go ahead and send in your questions so that we can see if we can get them answered.

One of the questions, Daniel, I'm going to combine one of the questions that we do have from the audience with maybe a bit of my own question, and that is that the question from the audience has to do with who is allowed to -- who is allowed to change a shared system? And I think I would compound that question with what are we really talking about here in terms of sharing data? That can get very frightening for people and as I mentioned, after, you know, in my reaction comments to Dave Ross's recorded message, you know, this notion of what is shareable and what is not is still somewhat fuzzy for people. You give us any more clarity around what we're talking about there with shared data?

>> Daniel Stein: Yes, I think there's different approaches to sharing data, of course, and it depends on, of course, what data you're talking about. Of course, administrative or research data or open data is by definition information that can be shared in whatever format. Certainly if it's following the procedures and there are very strict procedures and processes for releasing open data. It's not a free-for-all, the state itself has a manual that is actually accessible on the website that describes what kind to have data is included in that.

I think that the little more difficult question is, of course, either the personally identifiable information which is not accessible unless you have the right rules and access privileges, and then there's something a little in the middle, which may not be personally identifiable but what does present some very potential risky information because of the cell size and whether you'd be able to identify somebody with a particularly unique condition of sorts.

So I think that what we're advocating for, of course, is not just to throw all the cards on the table and access what you want, but it's recognizing that other organizations, other programs, other agencies have keys to the puzzle or pieces to the puzzle. And that we don't have the ability to see the whole frame without being able to exchange information. And by knowing what kind of information is available and under what conditions, we can begin to assemble a larger picture of that information. And if we know that we're doing that in a trusted environment and that there are protections and there are controls, then we begin to break down some of those barriers and create a culture that is very contradictory to where many people have grown up, which is to not share information for a variety of reasons, but to begin to do that. And I think the open data world is actually a way to get people to start looking at data using it, understanding it, and asking it the kind of questions, the kind of poignant questions

that need to be honed and provided when we start to get with more protected information.

I'm not sure if I answered your question thoroughly, but a follow-up would be fine.

>> Shell Culp: I was talking to myself, having neglected to take myself off of mute. Thank you for reminding me. And thinking of questions, we are going to open it up for your questions here in just a second. We're going to go to our next poll and invite your feedback once more.

What do you see as the most important step -- next step in moving public health forward with respect to using data?

A, improved training for data resources that already exist.

B, more access to specialized data resources for particular causes.

C, better integration of data systems already available.

D, a wider understanding of the possibilities to spark innovation in the general field.

E, a wider understanding of the possibilities to bring more advance use of data to the workplace.

F, other.

And please tell us what other means to you.

While we're waiting for some more questions to come in and you're completing your poll, I think I'm going to go back to Rebecca with a question about measuring success in terms of human impact. And this was something that we heard during the last open data Fest from Will, the director of California department of social services, and Will encouraged all of us at the Open Data Fest to think in terms of impact on people. So it's not enough to pursue technology or to pursue some kind of cool new thing if there isn't a positive impact for the people that are served you know, by the program.

And Rebecca, one of the most difficult things that I -- in my experience that government has to do, it seems like it would be a really simple thing, but again in my experience it's been unusually difficult, is choosing a metric, you know, to gauge progress of a program, and I know that Code for America has attracted all sorts of folks to this notion of, you know, civic technologists and not all of them are technologists. Maybe you could comment or talk a little bit about how government could use Code for America to help it develop meaningful metrics.

>> Rebecca Coelius: Sure. I mean, obviously lots of people on this webinar are far more of an expert in the THD level practice and metrics development than I am, or anybody at Code for America, but because of the way we work, which I shared earlier, we're starting with a user need and building out products and programs from that perspective, we very naturally end up developing metrics which are often new for our government partners that are very much based on, you know, specific user need that we're trying to make a dent in. That we can use with SNAP/food stamp, as one example. States and counties are measured by the federal government on two major things.

One, the percentage of people that are eligible for SNAP and enrolled and then, two, the number of people that are enrolled but shouldn't be enrolled because they don't actually qualify. For a lot of different reasons which we could talk about for several hours, the biggest sign -- actually the only signs are associated with the latter metrics of people being inappropriately enrolled in the program, which all of us to work in the world of metrics development that has consequences in terms of behavior

on the ground. So certainly a challenge of ours at Code for America and that work has been helping our local partners think through the metrics that actually matter to their clients and users of services like SNAP, and obviously for the local user it is, I need this service for myself and my family and I was successful in enrolling within it.

And one of the things I thought was interesting in doing that is realizing when you get people to the place of at least equally prioritizing a metric like that versus one there are financial incentives around, it's hard to measure it sometimes and you need much larger bodies to be working with you to collect those numbers. The numbers of the percentage of people that are eligible and enrolled are measured every five years or so, so it's really, really hard to actually track at the local level howl you're making process -- progress against moving that metric. So I would say Code for America comes in with a certain way of looking at the orientation or type of metrics that we should use in that collaboration but we certainly don't have all the answers or all the muscle that we need to often actually collect that data and need to work with others to do it.

>> Shell Culp: It is a collaborate effort, but I think one of the things I noticed that Code for America brings is that fresh perspective. And it may be a small slice of the total complexity of a program that government runs, but, you know, a fresh perspective is always, you know, I think something of benefit when you're trying to solve these giant problems.

Daniel, there's a question, I think, -- Rebecca, feel free to jump in at any time, but this question, I think, might be something that Daniel is -- that your talk discussed a little bit or maybe motivated from your talk. The question is, are there centralized sources of centralization of sharing data and creating open data?

>> Daniel Stein: So I think there are two answers to that. At least I would like to respond in two ways. There are standards around data exchange that are becoming more and more the norm and there was a number of years ago, the federal government overall wellness-actually Congress put through something called the data standards act and that is attempting to get programs across the federal agency to adopt standards that would allow programs and systems to exchange information more accessibly.

>> Shell Culp: That's implemented currently, isn't it?

>> Dave Ross: Yes, in fact, the new regulations that came out for the next generation of child welfare -- state child welfare information systems specifically contemplates the use of that, and I believe -- and that's called the national information exchange model or affectionately referred to as NIEM, but that's coming now to human services and I believe it's through the reauthorization process that's going through Congress, every program that goes through reauthorization is being encouraged or maybe required to adopt language around that so that as we go forward those standards will come into play.

Now, the second part is for open data, my understanding and others here correct me if I'm wrong, is that it kind of depends on the portal that you're using, right?

So there's an organization that was -- that's been probably the largest to date, one of the largest if not the largest implementer of that called Socrata, software and service, and they certainly have a process and standard for being able to upload data and machine-readable and all sorts of details around that, so if you use the

Socrata portal, the data is transformed into a standardized approach which is you can get in Excel or CfA file or whatever ways you want to download it, so it makes it accessible to whatever program you have. But as far as I understand, there's no national standard for open data. It's more on the portal that is being used and they are now the dominant player out there.

>> Shell Culp: Thank you. I think we have time for one more question and I'm going to ask this one for -- of both of you.

One of the dimensions of unlocking public health data reaches into the idea of building a shared value of health, and this is something that Robert Wood Johnson Foundation talked about in its data for health initiative that Dave Ross referenced and Daniel you referenced it as well. How does the Code for America work and the social determinants of health help move that notion of building a shared value of health along? And what are some to have actions that local health departments can take to make progress with that, with building a shared value of health? Rebecca, you want to go first.

>> Rebecca Coelius: Shell, I couldn't actually quite hear you. So we'll let Daniel answer the question and I'll figure out what it was.

>> Shell Culp: Go ahead, Daniel.

>> Daniel Stein: I think building a shared culture of health, a vision of it, is really coming from a definition or better definition of health, inclusive of health and human services or health and social care, which is becoming more and more accessible and, in fact, we're seeing that in a lot of different places now. Most recently in one of the federal letters that just got put out from three major agencies, Medicaid service, food and nutrition services and children services administration for families referred to as the Tri-agency letter, that actually contemplates social determinants. So I think we're seeing a more uniformed, more harmonious voice coming from the federal level and from leaders in the foundation community like Robert Wood Johnson Foundation and academic institutions and other NGOs really taking hold of this concept of we have to have a holistic perspective. And I think that translates -- I think that's beginning to translate into policies and programs in terms of the technology that is being developed to enable sharing information. I think there's still a long way to go. I think that there are plenty of silos out there and I think there's -- I think there are organizations that are so focused on their niche that either they don't see the individual or they don't see the population that they're addressing, and I think that's one of the things we're training in a more robust curriculum about what we're talking about so we can develop a curriculum around that that will be most useful.

>> Shell Culp: Any thoughts, Rebecca?

>> Rebecca Coelius: Sure, I absolutely agree. The one cautionary thing I would offer in all of that is a pattern I've seen emerging is the interpretation of wanting to think of someone's health holistically often leads people to try and sort of duplicate a capacity or activities, and I think healthcare is a great example of that. There's obviously a great need for case workers and social workers in clinical environments to be proactive in their counseling and such but at the same time there is a massive apparatus with the experienced people out there that do these -- the same thing, and I think it's fair to ask how much of our work is adding capacity to those existing organizations and people and collaboration between the two, nurses trying to

make each person in the system, sort of gauge, trying to impact all persons, and I in particular bring that up because I really liked the slides that were shown earlier on Daniel's presentation speaking to the number of people that participate in various human service programs, but we don't spend a lot of money on those programs. The money we spend on healthcare and percentage of GDP, we need to compare that to many other countries that, you know, have much better health outcomes. Of course, there are a variety of reasons.

It's flipped where they spend much more money on human services and social services than they do healthcare.

So completely agree, cautionary note to that.

>> Shell Culp: Great. Thank you. Well, I would -- at the risk of you know, sort of being hasty here, I think we're over time and I want to be respectful of people's time. I would like to thank our presenters, Dave Ross, Daniel Stein, Rebecca Coelius, thank you very much for participating in our third and final Web Forum on this topic of data for health and how health -- how public health can use data to make better decisions. Thank you to our behind the scenes people, Tonya Hammond and Joanna Hathaway and thank you to California Healthcare Foundation. Check back with Public Health Institute for additional Web Forums and thank you for joining our data and public health series.