Dialogue4Health Web Forum
Making Data Work for the Public's Health: The Current Total
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>> Hello, and welcome to Making Data Work for the Public's Health: The Current Total. My name is Joanna Hathaway, and I will be running today's web forum along with Holly. Closed captioning will be available throughout today's web forum. Regina with Home Team Captions will be providing real time captioning. The closed captioning text will be available in the media viewer. The media viewer can be accessed by clicking on icon that looks like a small circle with the film strip running through it. On PC, top right hand corner of your screen. And on a Mac, located in the bottom right hand corner of your screen. In the media viewer window, you'll see the show/hide header text. Please click on this in order to see more of the live captioning.

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Once the web forum ends today, a survey evaluation will open in a new window. Take a moment to complete the evaluation as we need your feedback to improve.

The record and going presentation slides will be posted on our web site at www.Dialogue4Health.org. We are encouraging you to ask questions throughout today's presentation. Simply quick on the question mark icon. Type your question in and hit send. Please send your question to all panelists. We will be addressing questions both throughout and at the end of the presentation.

We will be using the polling feature to get your feedback during the event. The first poll is on screen now. Please select your answer from the available choices and click the submit button.

I am attending this web forum A, individually, B in a group of 2 to 5 people, C in a group of 6 to 10 people or D.

It is my pleasure to introduce Shell Culp. Shell Culp dropped in on Dialogue4Health with big energy and big ideas and we have been so grateful for both of these things as we put together this California HealthCare Foundation sponsored series. When Shell is not talking data with her here at Dialogue4Health, you can find her talking about data somewhere else. She speaks on performance improvement for government and open data movement across the country. We're so lucky to have her. Shell, please go ahead.

>>Shell Culp: Thank you. Welcome to the Dialogue4Health web forum series. A project of the public health institute or PHI, Dialogue4Health is a community that concedes, builds and shares strategies to improve the public's health. Partners with local, national and global resources. This forum series is sponsored by the California HealthCare Foundation. PH I is dedicated to improving the health, wellbeing and quality of life for people around the world. Learn more about pH I at www.pH I.org.

This series takes a look at increasing focus on improving health and wellness which sectors use data sources range tremendously due to differences in infrastructure, financing, privacy issues and specific issues in particular issue areas. With support from the California HealthCare Foundation, Dialogue4Health is excited to embark on this new web forum series exploring the public sector's relationship with data. In the series, we will explore the landscape of data and public health, investigate exciting work currently being implemented and planning for ways in which improved use of data could advance the public's health.

So this first web forum in the series takes a look at the current total. Where are we in using data for improving health and wellness? And what is important in moving forward? I am your host, Shell Culp from Stewards of Change institute and I'm pleased to introduce our panel.

Dr. Elizabeth Baca is the senior health advisor for the Governor's Office of Planning and Research for California. Damon Davis is the director for Health Data Initiative in the office of the Chief Technology Office at the U.S. Department of Health and Human Services. And Dr. Sandra Hernandez is the president and chief executive officer for the California HealthCare Foundation. For the better part of two decades, Dr. Hernandez served as the CEO of the San Francisco building foundation. At the California HealthCare Foundation, Dr. Hernandez continued change by receiving innovative policy initiatives. And if that wasn't big enough, she's an active clinical physician. We're thrilled to have her welcome us to this important webinar series. Let's jump right in to a welcome from Dr. Hernandez who will help us frame the series.

>>Sandra Hernandez: Thank you, Shell. Really nice to be here and thank you to Dialogue4Health for hosting the webinar.

Judging by the sheer number of attendees that have registered for today's discussion, it's fair to say whether you are working on public health or health disparities, social determinants of health, public advocacy, or working to improve patient care management or population health, readily accessible data coming from varied sources is widely seen as a catalyst for solving pressing health and healthcare problems. The California HealthCare Foundation funded this series of webinars because we know how transformative data can be for program innovation and is a vehicle to accelerate collaborations between public health, population health management organizations. But also more broadly across other sectors.

Today you'll hear some of the exciting working done using public data sources that have implications for built environments and really for thinking about how public agencies themselves begin to innovate and collaborate to solve many of our pressing problems.

Public health has always relied on good community surveillance and population-based data to drive prevention and identify emerging public health issues. The open data movement is taking all sorts of data from many different sources and reaching well beyond epidemiology to allow a new product development to have data be much closer to real time. And making it relevant to consumers and other constituents. In many cases, at key points of decisions and decision making. We have civic minded entrepreneurs like code for America who will be on a subsequent panel. As well as data scientists creating better and more integrated solutions to

population health management and other public health challenges. Code for America, for example, built an analytic tool used in Long Beach that enables agencies and non-profits to identify addresses that call 911 frequently. The application called address IQ enables a coordinated system of response across multiple first responding agencies. Something that have been difficult, if not impossible, to do if data were locked in databases. Information collected are used to create a more unidentified and integrated approach to how it utilized 911 services.

The focus on innovation which is a core feature of open data encourages all of us to become more data savvy and more willing to collaborate with a range of players and problem solvers. Healthcare providers, for example, want to be able to visualize socio economic data in order to design, test and implement downstream interventions for chronic disease care management and to better understand the environmental factors that exacerbate chronic conditions. And that lead to poor outcomes and higher cost. Open data sources allow for easier and more timely evaluations of new programs and new investments.

Similarly, healthcare organizations and delivery systems such as ACOs are increasingly finding that to succeed and pay for performance or other structures, improving care to targeted populations is vital and requires actionable digestible and multi sourced data.

At CHCF, for example, we're looking at how data on C-section rates can be made available to consumers utilizing their zip code data and leaking it to hospital data in their communities allowing them to see and act and make better healthcare choices for themselves.

There are many other examples of how a natural list of regional or local data can enable less costly strategies. In San Francisco, for example, a coalition of over 100 organizations analyzed regional data that identified emergency rooms that hit high admission rates associated with alcohol abuse. The data informed the best placement of a sobering center. The medical respite center return on investment was over $9 million. And importantly, avoided emergency room visits and improved care delivery for chronic inebriates.

Key vital statistics, healthcare organizations have access to an incredible amount of data. They too see many opportunities for using this data to more rapidly improve care for populations. Using data to better understand care delivery, health behaviors, physical and social environment can provide useful knowledge to how to provide more personalized policies and reduce costs, improve care and ultimately make populations and communities healthier.

At CHCF, we believe open data has the potential to generate huge health dividends. Making data available in nonproprietary standards, promote innovations and collaborate new and exciting collaboration. The data management and analysis is a team sport and expertise can come from many partners both inside and outside of government.

It is a fuel for innovation and breaking down silos and CHCF looks forward to this dialogue in California and beyond through this series and other work we will continue to support.

So with that, back to you, Shell.
>>Shell Culp: Thank you for your welcome and terrific framing overview. CHCF the California HealthCare Foundation is a leader in health programs. But also thinks about the factors that affect the effective use of data in health and wellness.

About a year ago, you published a blog post on what's private and what's not which I enjoyed very much and you used an example with an application that would essentially share some data, not necessarily personal data. But some data with a third party.

When we talk about any kind of health or no wrong door in connecting human services with health and healthcare, privacy and confidentiality are addressed there.

What are the progressive minds thinking about to help overcome our society's trepidations around sharing data?
>>Sandra Hernandez: Well, it's a great question, Shell. I think there is privacy concerns that need to be taken into account particularly if the data or the information that's collected or data

sources are so small and so specific that they would lead to information that is inappropriate to share. We talk a lot and think a lot about HIPAA. It was put in place in a time when insurance red lining was common place. And information that might make it difficult to preclude getting access to insurance or insurance rates being exorbitant. All those issues have a contemporary opportunity to rethink under ACA.

I do think all these applications that are wellness or health promotion applications. And we had many great creative applications that are being developed. It's important, of course, for people as they use them and participate in them that they understand what the privacy provisions are and the data sharing provisions are.

I think in general, the notion that even consumers today have. And certainly younger consumers have is that information that's shared and exchanged that can be timely and help them in the decisions is generally a good thing. And there are polls of consumers that say yes, my provider should share data, for example.

So I think it is important to consider them but I think them as obstacles for thinking how to use data sets in creative population solutions is really, I think, seen now as much more of an asset and a tool and a capability. Carefully thinking about the privacy provisions which, of course, public agencies and everybody has responses for physician groups.

We now have great capabilities and great partners through a variety of different sectors that see the power of large data sets that really don't have as much risk of individual health information that might be inappropriate to share. There is much more opportunities for looking how the data sets can be brought together with a lot of different experts to really address and create capabilities for consumers but also address large public health and population health issues.

>>Shell Culp: That sounds great. And hopefully it will be helpful to people for increasing their understanding of what's possible. What can be.

Secondly, if I may keep you for a little longer. The HealthCare Foundation was instrumental in implementing the California health and human services open data portal which will be a year old next month. Since its debut, there has been a lot of activity focused on entrepreneurial uses. You talked about that in the framing message. That would ultimately produce better health. But while technological advances are rightly prized, the problems they seek to address are massive suggesting that the path to scale is through government rather than through the market. Can you talk a little about the HealthCare Foundation's efforts in this regard and how the foundation has been helping local governments make progress using data? Hello?

>> Hi, looks like Dr. Hernandez has dropped off the call. A rough point, I'm sorry. Let's move on then.

Let's move on with Damon Davis, director for the federal Health Data Initiative. Damon Davis is a bit like a father about to deliver his second child. The healthdata.gov site is getting an overhaul. In addition to updated experience, wants to help a community with the more useable platform that's going to allow them to understand how the data can be used. Not just how it was collected. He's got a good grounding in building community from his work on the blue button initiative where he worked with over 400 public, private, and non-profit organizations committed to easy secure access to personal health information. And sum up the use of health information technology to the constituents they serve. Take it away.

>>Damon Davis: Thank you very much, Shell, for that generous introduce. My pleasure to be here with everybody today. Thank you for having me. And thanks for gathering this forum. This is great.

So I'm Damon Davis. The director of the Health Data Initiative at the department of health and human services. I work in what is known as a Chief Technology Officer's office. We are now more commonly known as HHS idea lab. Two things I hope to inspire are one, the wide array of data that are often available for free. For some of the innovations that have been

discussed today. Some of the entrepreneurial endeavors, the clinical interventions and the research. I also want to inspire you with a message about how government is innovating on how it is we deliver our services. So I'm going to jump right into our slides here.

I want to set the stage for what it is we're talking about in healthcare. We are now living in a healthcare system where data really is driving change. What I mean by that is that so many of us are utilizing data for various things. Like our own personal health tracking. We're using data at the point of clinical care where electronic medical records and other kinds of health information systems are being utilized within the hospital, within the clinical care setting for medicine or what have you. And utilizing data for purposes of changing the way we actually pay for healthcare. We want to pay for healthcare based on the quality of the care that's delivered, not just the volume of the care that is provided.

So when you think about HHS and many of our sister agencies in the government, what we've been trying to do is release more and more data so we can change the default setting for our data from closed to open. And what I mean by that is oftentimes, up until recent years, the governments, local, state and federal, have had a variety of activities they've been focused on that are data collection activities. Surveys and research activities. Grants and all kinds of other projects and initiatives that have basically been collecting it data for a specific purpose. What was realized is these data have an alternative value to the greater Eco system of data users. And we need to try to open that data up for broader availability.

It's important to recognize what we're talking about when we speak of the family of organizations represented by the U.S. Department of Health and Human Services.

What you'll see on your screen right now is a portion of that family. It's a federation of different healthcare and social service related entities. Many of which have very large brand recognition and names you'll be fully aware of. There are others that are lesser known but have no lesser importance. For example, our administration on community living is focused on some of our vulnerable populations that are elderly or aged and that are perhaps physically incapable. You will also see agencies on here like our substance abuse and mental health administration. So just pointing out a couple ones that are smaller agencies but have very important data that can be transformative across the healthcare Eco system.

Each one of these agencies has a huge number of organizations underneath them. As you go to an agency like the national institutes of health. You will see in one portion, the national cancer institute has a ton of other organizations underneath it. So the data is broad and varied. And we're still try to go find all of it but doing a decent job on our web site which is healthdata.gov.

This is from across all the different agencies. They are, again, some of the grants and contracts that we administer. Some of the research work we've done. And trying to turn that data over for all kinds of alternative utilization. We are giving birth to our new version of the platform. You will see it is in beta form. We're trying to create better machine read ability for a wide array of our data sets and try to foster broader utilization and awareness that the data are, in fact, available for free for your use.

So what I want to point out now is a couple examples of what data are being liberated and how it is those data are being utilized. So one of our main very large entities centers for Medicare and Medicaid services has a systematic transformation of healthcare. They have a couple programs that I'll run through quickly. The first of which is a data navigator. Helping you find the data that can be utilized for some alternative purpose documenting what that data was collected for. How it's alternatively useable and what kind of fields and things you are going to find in it. Producing things like quality indicators like nursing home compare. And some other data tools that will allow you to more quickly and easily understand and contextualize some of the data for purposes of understanding what quality looks like. They've set up a research data center that allows you to buy a seat at the table and gain access to CMS data for manipulation

inside of a virtual research data center so you can take the findings, not the data, out of that data center and apply them to some alternative form of knowledge.

And then committing to greater data availability by quarterly data releases. It was unpredictable when you would actually be able to obtain updated information for Medicare and Medicaid services. They are taking an approach to say we're going to focus on quarterly data releases so you can more reliably understand when those data are going to be available for your innovation, research or what have you.

A recent example of someone using CMS data came in recently. This organization called Care Voyance has an interesting story. They are allowing individuals to browse physician relationships and financial data, prescriptions and all kinds of different things for comparative purposes. You can conduct a side by side comparison. And that is valuable towards understanding where quality and value lie across the continuum. If you are looking at a panel of providers, you are able to quickly see some of the outliers who are potentially charging a whole lot for their various services that they provide as compared with those who are also in their same specialty and are charging significantly lower.

Another example of utilization of CMS data is DocGraph. The gentleman that set up DocGraph, named Fred Trotter has been instrumental in driving change that has been happening at CMS. He wants to sort of show, again, more of the referral patterns that are happening across healthcare to try to illuminate on a quality level and the cost relationships or what have you.

The food and drug administration is another great example of the government releasing data in newer formats. And open FDA was released a little over a year ago. They've created application programming interfaces or APIs for some of their most requested data. They are releasing that data in structured formats. And those data come in the form of medical device, adverse events, recalls reports for various drugs, and prescription drug and over the counter drug product labels. So you can see how some of those different segments of FDA data can be made available for all kinds of interesting applications across healthcare. But one that I always like to point out is one that is developed by a sister agency at HHS. The national library of medicine has stood up an organization called pillbox. What they are trying to do is demonstrate that you can document the visual image of all kinds of pills across the healthcare Eco system and marry that up with the data from FDA on over the counter drugs. And actually allow that to be a secondary utilization of FDA data within the government. But then pillbox is available for open innovation across all kinds of components of the healthcare Eco system.

So imaging for pills married up through application program interfaces is a huge stride forward in terms of utilization.

Another application of open FDA was this tool that was stood up shortly after the open FDA tool was launched. A quick and easy way for you to invest this API and visually see what kinds of things are happening so you can have a quick wondering of what FDA recalls looks like overtime. Where there are spikes and things along those lines.

I've mentioned before one of our small but very important agencies, the administration for children and families. And ACF is responsible for things like temporary assistance for needy families and providing people access to coverage for their energy bill or what have you. So that you can alleviate this pressure of an individual who might be trying to make a decision between purchasing their medicines versus having to make the decision to keep the lights on at home.

And an organization called Friendly recently reached out to us from Detroit and they were trying to find more information about social services in the Detroit community. So they can link up those in need with the clinical endeavor so they can bridge the gap for those in need. Those in need of social services. And alleviate one of those so the individual, patient or family can focus on the other.

Another interesting outcome of the use of HHS data, not necessarily related to ACF has been the recent release of this surging score card. An organization called Pro Publica on a

research press agency has been organizing themselves to understand better what surgical quality looks like across the continuum. So this score card was released earlier this week or late last week. And you can find information about surgeons across the nation and their surgical outcomes to understand who has the fewest number of complications after their surgeries. Again, understanding what quality looks like across the healthcare continuum.

Now, I want to turn to the HHS idea lab. I want to inspire you quickly with the vision of what we're trying to accomplish in terms of creating and cultivating innovation in a more modern and affective government. The idea lab is really focused on the idea that there can be individuals across the organization who have great ideas but so varied in the different levels of the organization that it's challenging to get their great idea tested and promulgated up through the system. One of many opportunities for people to raise their hand and share their ideas. That one I'd like to focus on quickly is the entrepreneurs in residence program. Basically, we're bringing in external talent to bring on interesting but high risk high reward projects that they will focus on over a finite period of time in order to test out a hypothesis and actually bring a solution to action.

So the one that directly relates to open data is demand-driven open data. Led by David Portnoy. Go to DDoD.us to learn more. Basically it is striving to correct those with the data sets we have those available and give us feedback on what you'd like to see out of the data sets. There's a couple different scenarios for the use cases you might input. So I'm looking for data I'm not finding anywhere on healthdata.gov and we will go and try to find it. There's the scenario of I found the data I'm interested in, I'm just not able to use it in the way I want. I would love for you to update it in the following way. So you can have these use cases and have the crowd source and opinion about your suggested use case. And we can then have some level of prioritization and bring greater value to the delivery of our public data for the cool innovations I've already talked about.

I'll close with something we're also very interesting in which is our prizes and challenges and competitions. Recently in June, we released an open obesity data challenge in conjunction with the health data consortium. What we've try today accomplish is a challenge competition that invites people to use any level of publically-available data for purposes of creating an intervention clinical professionals can utilize to have a discussion and provide directed approaches to combatting obesity. So we're really looking for a diverse set of data to be mashed up in this challenge. You can imagine taking environmental data about air quality mixed with outside exercise opportunities mashed up with whether you are in a food desert or not and the food data about affordable food and farmer's markets in your area and mix that up with some health system data you might have proprietary access to or what have you.

Create some kind of application that allows for a more focused conversation about how it is that an individual can be more impact full on their own health with support of a professional. So the obesity data challenge is live on challenge.gov. You can tweet about it at #obesitydatachallenge. And we're still encouraging those out there to enter. The challenge is going to be exciting. And the winner will have an opportunity to be in the expo coming up in September. Hope I've inspired you to come and try to find some of the data that might be useful for all of your various public health endeavors. And I hope I've inspired you to recognize the idea lab is trying to change the way government is dog the business of government so we can have a more modern and effective set of public servants here and across government. So with that, Shell, over to you. Thank you so much, everybody, for your time.
>>Shell Culp: Thanks, Damon. I'm having a few technical difficulties. Want to make sure you can hear me.
>>Damon Davis: I can.
>>Shell Culp: That's great. I had a couple questions as our listeners are formulating their questions and trying to get those into the que. One was around the idea lab. It was you a thrilling and innovating situation for the government. It's different. Having an entrepreneur in

residence in the government is something that we wouldn't have heard about ten years ago, maybe not even five years ago.

What sorts of -- is there a culture shift underway? And what sorts of advice would you have with data.gov, what advice would you have for the counties and local governments out there in trying to implement some of these things?

>>Damon Davis: Well, I think to answer your culture shift question first, yes, there is one for sure. There's a wide recognition that we cannot continue to do everything the way we've always done it because that's the way we've always done it. And so the culture shift really is in allowing ourselves to be experimental. And I think the state and local governments should take use from as well as share best practices and all of their different experiments themselves with the federal government so we can be more conversational with one another about how we can be innovative. We have a wide array of things happening here with this demand driven open data thing to interventions in trying to find more improved ways for getting organ donation to have an uptick across the nation. Better improvements to IT procurement so we're not stuck in this waterfall approach but able to take angle of life cycles for purposes of better IT deployments across the government there are a lot of cool and interesting things states and local entities can be talking with the federal government about in order to learn and take the cue that you can experiment and really build upon your own idea of an idea lab within your own entity.

I think those things need to have senior leadership buy in that innovation is not going away. But we also need to take the cues from the public as to what kinds of things they'd like to see us work on and not be afraid to tackle some of the more challenging issues on our collective plates.

>>Shell Culp: Thank you. One more question for you, Damon. Lots and lots of effort coming up around the notion of open data. And I suspect many of our audience listeners have experienced open data or codathons on some level. And it's enormous benefits for local governments to have this civic technology and civic engagement kind of tool to build collaborative bridges within the local government and the communities. One recent article proclaimed that data is the new black. I'm thinking that co-creating is the new black. What are some of your favorite examples of good things that have come from health and human services data? Good examples of how people are using your data in a co-creating sense?

>>Damon Davis: Yeah, there's so many, it's really hard to point them out. Some of the examples we've brought up before were things like purple binder, that is a small organization that has grown quite a bit that's basically trying to marry up the availability of social services with the continuum in an automated fashion so a social worker can try to find some of the resources that are available in their localized area and not have to rely on a stack of loose sticky notes to try to find a person they knew at the organization they have a relationship with.

There's all kinds of different activities in trying to figure out disease tracking and management. Very much in the public health sphere, how is it we can track the burden. How is it we can prepare for disaster preparedness? Many of our local cities have been impacted by some form of natural disaster. Only in the face of emergency and adversity we start to realize we've got a real problem in knowing where our resources are, where resources are around us that can be contributory. There's a lot of work to try to understand more fully what it means to be prepared for disasters and emergency responses.

The examples are endless, it seems. And it's really exciting too. And this goes back to the invitation to bring expertise back into the government. By opening the data, we open people's minds. And it really creates an availability and opportunity that wasn't present previously. So all kinds of creative things happen that we couldn't predicted. That's the excitement of opening the data and allowing it to be available. It allows us to seek out some of these folks coming up with creative ideas that may be only implemented at a small scale but have true value at a much larger scale and nationwide.

So there's so much innovation and so many hot spots for it. And so many undiscovered. It's probably one of the more fun things is learning about the data and coming to forms trying to explain what kinds of exciting things happening.

>>Shell Culp: Great examples. Really exciting stuff. And thank you very much for sharing that with us.

>>Damon Davis: My pleasure. Thank you.

>>Shell Culp: I have neglected a poll that we had set up. So let's take some time now to go through the second poll. And let me just read the poll. What is the biggest barrier to using public health data? Lack of funding. Security/privacy issues. Inability to integrate systems. Inability to find the data that you need. E, lack of innovation relevant to the work at hand. F, what do you mean? There are no barriers. Or G, something else. And please tell us what that something else is.

So now we'll go on to our next presenter Dr. Elizabeth Baca. And when I first bet Dr. Baca. She made me laugh out loud by saying how she learned from me. She's about half my age and has a career working on four continents in the areas of clinical care, environmental health policy and sustain ability. She is the senior health advisor in the Governor's Office of Planning and Research for the 8th largest economy in the world and she's passionate about reducing health disparities and working across sectors to foster collaboration. And elevate the connection between health and built environment. I'm pretty sure I'm the one learning things from her. So take it away.

>>Elizabeth Baca: Thanks, Shell. It makes me laugh when I hear you say that. It's an honor to be with everybody today. There is so much innovation going on, it's an exciting time.

It's a national audience, I wanted to give background about the office of planning and research. It's a different entity. It varies by state. We were created in 1970 and serve the governor and his cabinet for long range planning and research issues. We tend to do a lot of state planning, long range planning and particularly a lot of work in climate and now health. And I would say one of the most exciting parts of this job is that I get to do a lot of work with the local government and local agencies. But I was intrigued, Damon, to be a social entrepreneur with you guys. Sounds like a really fun position.

I think as Damon was mentioning, there is a ton of innovation going on at the federal level. And the city, county and state level. But it's one of those things I spend a lot of time thinking about innovation. And it's usually not when we're thinking about data and technology and innovation. Government doesn't tend to be the first thing to pop into our mind. But I would say that's actually really changing. There was a great article in fast company, one of my favorite magazines to read. They do a lot of work on looking at innovation. And this one was actually about what is innovation? It comes down to connect the dots. They featured a commencement speech by Steve jobs. He said you can't connect the dots looking forward. You can only connect them looking backwards. So you have to trust the dots will connect somehow. There was another quote from Sir Richard Branson who said he had a mantra for all of his companies. It was A, B, C, D. Which is always connecting the dots.

The article went on to conclude that the difference between the innovator and the ordinary person was one person saw the dots and another connected them. I thought that was really interesting. It stood out to me. It applies to companies and to products and brands. We are working to make health better. And data can be that vehicle to help us connect the dots. And I'll give you stories about that. But I hope that through this afternoon, it's really to start inspire to think outside of the box. And as Damon mentioned, we're starting to see a lot of that. The problems we're facing are interwoven and complex. So there's this opportunity and this paradigm shift to really start to think differently.

One of the things is when I used to teach medicine, I used to work with pediatric residents. And we spent a lot of time thinking about all of the social economic and environmental factors that impact health. And it really struck me, Damon, as you were talking

about this app. To bring in social services. One of the things that we used to do is the residents would do a survey of all of the resources in the community so when a patient came in who was having problems with housing or a roach infestation, we could actually refer them to the appropriate entity to really help take care of the problems cause it affected health so much. It is amazing to think about we're get to go the place where a lot of that will be seem less and available in more real time.

One of the other things that we used to do -- and it's interesting. When we're in healthcare, it always struck me that when we're seeing a patient, so much of our time is data driven. You are looking at vital signs -- [Audio cut out].

Those data sets were much harder to come by. And in fact, the residents used to -- we would use data sets available so look at health outcomes and health disparities in the region. One of the things that was so interesting was that the residents noted really quickly that sometimes if they had a particular question, the data was challenging to find. And the other thing was it varied amongst counties. They were between San Mateo and Santa Clara county. What we've started to see is a change and definitely looking at individual healthcare statistics and also starting to think towards more of the population health.

And one of the questions was having the healthy people 2020. Hopefully, we'll have that as a discussion point. That would be amazing.

I think one really great example of data and decision making, more of the community level actually, they did ground breaking work. They started doing this work in 1985. So this is Jacksonville, Florida. And they put together this quality of life and progress report. And they really grounded it in a model for community change. And as they put together the vision of how they wanted their community to be, they recognized they really wanted it to be informed by data. And it's really interesting, one of their measures was reducing vehicle miles traveled. And I'll flag that so that we can come back to it in a few minutes. It's really interesting. That was back in 1985. And I know over the last decade, a lot of us have seen these community dash boards to start to think about it at community level. Really, what kinds of data sets we're looking at. Thinking about tuberculosis diseases and voter turnout, heart disease. People who have access to health insurance. Really being able to think about the population level. And taking that out of one entity but expanding to other groups.

Out of curiosity, I wanted to do a poll. I thought it would be interesting to see how many of the folks on our webinar are currently using a public facing tracking system in your city or county? If we can put the poll up. So yes, no or you don't know. If you can answer that, we'll be great.

But I think one of the things is dash boards are fantastic. And it's a great place to start to really have as a rallying point to bring folks together in the community. We've also seen this continued progression of level of sophisticated of analysis.

I think Robert Wood Johnson example is a great way to start thinking more about the geographical scale and more looking at different health related indicators of income and safety. It's continued to progress. It's really the access with open data. Starting to get out to the public realm. And this is an example of really thinking outside of the box. This is from Yelp. For those of you who haven't used it, it's an application. You can use it on your phone or the computer. It's really a way for the community to be engaged and think about how they rate different services whether it's from dry cleaning to restaurants. But what they did and they've expanded this to other cities, they actually have their story is interesting. They have interesting challenges. Health scores are done differently in different places. But essentially, they partnered -- this is from San Francisco. And it basically broadened the health score. So if there were food violations, they took that data and put it in a public way, in the hands for people to make decisions. There's been interesting research that shows when those data are released to the public, they actually can see a decrease in hospitalization from food-borne illness. It's

one of many really interesting examples of taking data and making it out there and easily accessible.

So part of the reason I'm involved in a lot of different data projects. One of the things that will come up through the series is difference between big data and open data and private data. I think that's really -- they are key distinctions. One of the reasons I wanted to get more involved in the open data work particularly with what was going on here in California with health and human services was based on part of the work that we've been doing in our office. So as I mentioned, one of our statutory requirements, we do long range planning. Something we do is put together an advisory document for local cities and counties to do their general plan. The best kind of practices and information available. And in most places, this is called a comprehensive plan. But in California, we call it the general plan. But it's essentially the same thing. There are certain statutory requirements. So how cars move through the area. How housing is cited. Where it's located, et cetera. Given these links to the environment and healthy communities and a lot of momentum happening both at the state level and a lot of innovation also at the local level, we were able to integrate health considerations and some things people could voluntarily think about at the local city and county level.

In order to do this, we had a clean you slate. This hasn't been done in the past. We thought it was very important to do a lot of outreach to the public, to planning departments, to foundations, to community groups. Even meetings with private sector of what healthy communities would look like in the planning process. So we heard a number of things. A lot of emphasis on things such as walkable communities. Making sure places were safe. Having access to healthy food and parks and rec.

In addition to that, we heard from people saying we're really interested in doing this but then how do we know where we're making a difference? What data is out there to start to inform this and attract outcomes? So it was really interesting. And that's where open data started. We got a lot of input from folks on different data sets that are out there. But it was also my own process of starting to look at what we could pull together and a tool that we're building.

So for instance, there are many themes within the document. We're going to be releasing for public draft very soon. But an active living and recreation. The idea is if we're trying to build communities that have more places for people to be active. Again, we'll have to touch base on the data sets that come from obesity challenge. But really starting to think about what type of data, baseline, what it looks like in this area. Came with the co-morbidities.

And then at the same time, because this is a document geared towards the planning profession, what is the land use mix look like and how do those relate? And linking those two example policy options.

We have a whole host of example policy language from plans that has been adopted throughout the state. Similar idea as an example with social connection and safety. So thinking about ideas for data analysis would be, for instance, if we're trying to get folks active and out there, if it's not safe from either I'm worried I'm going to get hit by a car or something serious happen to me, then folks really won't make those decisions. So the idea is what kinds of data and analysis could be brought in. And what kind of policy solutions could be implemented such as specific policies to make that pedestrian bicycle and auto area safer.

And I wanted to share a really great example that I think has been written up quite a bit. This was a local open data example from San Francisco. It basically -- San Francisco is an extremely walkable place. And yet it has -- had a lot of injury. So the department and public health actually looked at their pedestrian victims and they saw there was half of them with motorcycle accidents. Half in San Francisco compared to the national which is around 13%. And there was a great recognition that there was a lot of works that needed to be done. And I think this type of open data example really shows that when you put the data together, it creates this picture. Again, connecting the dots. Thinking about how all of it comes together.

They were able to see that essential low 5% of the high injury corridors street miles were responsible for around half of the severe and fatal injuries.

It's really a powerful way. And one of the other piece was this actually spurred an informed policy change. They were able to put together a strategy and to really make it actionable. And data as common language, it really was able to bring a lot of community groups and others together around this data as well as bring in millions of dollars of funding to think about how to do some of the infrastructure improvements and changes.

So as far as with some of our current work as we've been thinking about data accessibility, this is a screen shot of our tool that is really going to be geared towards. Planners use a ton of data to do a lot of their planning work. There is a lot of data that they are required to look at and so the idea based on the feedback was as we're doing this, what kind of additional data could we make? And I think as its process was moving forward, it was at the same time that a lot of the work was happening for the health and human services open data portal with the department and public health. So it's been fantastic. There are a number of challenges with all these different data projects on the scale and privacy and accessibility and reliability. And so having some of those data sets available, for instance, just for asthma, emergency visits, for example. From the open data portal is a huge resource and great to be able to pull that into our tool and will be really exciting as it continues to move along.

I think, just transitioning back to the example from Jacksonville, thinking about the vision. As we're doing a lot of this, sometimes there can be challenges doing these projects. But a lot of it starts with thinking about where we're at and where we're going and how data can help inform that process. This is a picture from partner at your ban advantage. They do these amazing photos. This is a very common scenario across the U.S. you can see it's not the most walkable place. But with some changes, you can start to integrate that. You can think that might be more injury broken. Being able to link all of those things as you put in some of the adjustments and safety measures and track them can really be quite powerful.

The other thing is that, I think, as we are using this, Shell mentioned I've worked in a lot of countries. Sometimes doing this cross-sector work, which is so important, can be different cultures as well as different languages. And data, I've seen it happen many times, can actually be somewhat of this unifying force to help align issues.

For instance, going back to the example in Jacksonville, they were looking at vehicle miles traveled as a quality of life measure. And it's really interesting. As we think about some of the work that we're doing, specifically around climate change. At the same time that can be increasing walk ability. So seeing those co-benefits allows for wins. And the data can be the thing that pulls a lot of this together between different sectors and think about funding and implementation.

I guess I would end by saying I think it's an exciting time and this requires a ton of cross sector partnership. Data can be that common thing to bring people together. Innovation as we talked about a little already and love to hear that in discussion, it definitely is a culture shift. A lot of the wins that happen at the local level, the city, county, state level can be shared to help move that forward. And also say the small steps can really matter.

The last thing I was going to say is it's interesting. If we look at the poll results, I don't see it in percentages. As far as folks using right now. Looks like 46 out of 357 are. And the rest don't know or are not. So that's interesting. On that, I will say thank you and turn it back over to Shell.

>>Shell Culp: Thanks, Elizabeth. Well, let's see. You have covered a pretty broad spectrum here of how data in other sectors can be thought of in terms of public health.

Your broad view of what impacts health seems to drive from your background. Given your focus on improving collaboration across sectors, who is missing from that conversation when we talk about helping to build the environment? And what's the message they need to get and pass along?

>>Elizabeth Baca: I think a lot of people are starting to come in. Even the development sector really starting to come in and innovative ways thinking about the hospitals doing their health needs assessment and using that for their development processes. I think that's great. I think definitely having more of that and the coders coming in is a lot of what's been going on with the federal government and here in the state is really exciting.

One of the things about data is sometimes the data sometimes is available and sometimes it's not. There's a really unique opportunity to think about additional data sources from all of these new technologies in how we can start to leverage individuals in that to be part of the process.

>>Shell Culp: You mentioned yourself and I mentioned it as well. You've worked on four continents. What were some of the ways other countries were using data right and what can we learn from them?

>>Elizabeth Baca: Yeah, well, there are often challenges with data. It can sometimes be overwhelming. There can be a little challenging to get it up and running. And so I believe that I think it's Dr. Seahorn is his name, is presenting on one of your other -- [Audio cut out].

>>Shell Culp: So if you wouldn't mind sharing with us, what do you see as the most important 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 advanced use of data into the workplace. Or F, something else. And please let us know what that something else is. While we're waiting, there have been a number of questions. Damon has gone through and answered all of them. I do want to share those answers and invite Elizabeth to respond. How can public health professionals at the local, which is county and city level, use healthdata.gov? Like census track data and data at a local level to measure within the counties? So Damon, you have provided a bit of an answer. And if you would just expand on that a little bit for folks who haven't been watching the answers?

>>Damon Davis: Sure. So I'll go first and pass it to Elizabeth. What I said in my answer was that the local census track is one of the more challenging used cases for federal data. Federal data is at such a large national level. It oftentimes is not great for some of the more granular local data grinding. There are opportunities in getting states to have data activities at the state and local level such that you can begin to see some of those more granular data tracks. Don't be discouraged by the fact you can't use federal data for your most granular level of analysis. There are reasons for that. Privacy protections and things along those lines prevent us from putting out the most granular levels of data. And oftentimes, the data is not collected. Because the program is federally funded and not as specific as some of those local census tracks.

>>Elizabeth Baca: Yeah, that's one of the challenges. But I think small steps. So whatever is available starting to use that. Some of it is it's not collected at that scale. But one of the pieces that you mentioned was the virtual research data center. For a lot of this data that might be more granular, being able to have more way of accessing it for reporting system for a specific thing that would allow that to be released. I don't know. What are your thoughts?

>>Damon Davis: Can you restate it would be a reporting system -- say it again?

>>Elizabeth Baca: If you needed the granular data but not more widely available due to privacy concerns, that maybe you can go in. I know some of the places do that.

>>Damon Davis: Yeah, that's right, actually. There were virtual research data centers in this instance I raised was specific to CMS. But our national center for health statistics which is out of CDC also has a research data center. But you are right. The accessibility of the data inside the data enclave in a secure fashion is one opportunity for folks to engage at the most grab U lumbar levels with identifiable data. Again, you are not able to take that data out. What you can take out is your findings and make them applicable. You can do things like set up

algorithms and test out hypothesis and take those refined algorithms out but not the actual calculations of what was found.

>>Shell Culp: I think I would adhere we alluded to it a couple times over the last 40 or so minutes. But one of the more popular uses for the healthdata.gov data at the local level has been maybe less of a data function and more of a civic engagement function by having the local folks, the local citizens and others who are just interested in it engaged with their data as they come through the healthdata.gov portal to help generate civic engagement and sometimes build useful applications that help the local governments learn more or keep their citizens more engaged.

>>Damon Davis: Yeah, that's a good point.

>>Shell Culp: Another question here. Do any of the panelists think there is a role for schools or school-based health centers or school nurses to engage with data sharing in both providing and using health data?

>>Damon Davis: Elizabeth, I'm going to let you start.

>>Elizabeth Baca: Okay. I think yeah, definitely. Is it possible to ask with a little more background what types of data they were thinking about? I mean, I think there is a lot of the school-based health centers have access to a lot of the fitness data. Some of that has definitely been put out there. I think there are other interesting things around social services that could be combined. But yeah, I think there could definitely be a role. Damon, what do you think?

>>Damon Davis: One of the things I answered in the chat was with regard to immunization records. Sounded like the asker was interested in a bi-directional use of data. Many of us are parents. We've been through the challenge of trying to get immunization records from our pediatrician's office. Let alone going home, scanning it, emailing it over. Or if you can, to the camp or the nurse's office at the school. It would be fantastic to have a Moro bust set of activities where the pediatrician or primary care family care provider has given access to the immunization records that I can download and pass on to the nurse's office who was then able to receive them electronically alleviating a significant amount of stress for we as parents, you as school nurses and healthcare practitioners.

There's an ignite program. That is focused on a more personalized immunization experience. There's fascinating thing there's and would be a great opportunity to capitalize on things already happening in immunizations.

>>Shell Culp: I would add there there's one region of California that I think it includes three or four counties looking at sharing data between the Health and Human Services Agencies and the school districts for a purpose similar to the immunization in this case that Damon just mentioned. So we're watching that work closely to see how that goes along. Notably, there is a large amount of collaboration that is being expressed by the organizations that are involved which is, I think, a good indicator of how far we've come with the notion of sharing data between health and human services. So that's good news. We may have more to report on that in the coming months. I think that's a good thing.

There's a question that was unanswered by Damon.

>>Damon Davis: I fell off on the job.

>>Shell Culp: I know. Abuse and misuse of HIPAA which is the health information accountability and portable act. Continues to inhibiting the data such as between hospitals, health systems and public health agencies. What is being done to help educate on that.

>>Damon Davis: There is a lot of misconception what it does and does not allow. I should get started by saying I'm not a lawyer and not an expert in HIPAA but I understand it is -- as to what HIPAA does actually allow as well as implementing those things at the organizational level so you can breakdown the barrier of thinking this is not allowed by HIPAA. It's something that has to be embraced so we cannot have pockets of saying HIPAA doesn't allow that. Lawyers and physicians were taught lock everything down and don't let any data out. We've gotten to a point

where consumers are requiring the data to be free and available for them to utilize. And so we have to rejigger what things has to mean so that we can all be on the same page and allow the data to flow and be affective for care coordination and healthcare innovation.

>>Shell Culp: Elizabeth?

>>Elizabeth Baca: Yeah. Nothing to add. Shell, you've been doing a fair amount of work in the space as well.

>>Shell Culp: Yes, Stewards of Change in several privacy tool kits for organizations like the national league of cities. The administration for children and families. The city of New York, state of New York. And I mention that because there are compounding regulations and perceived rules around sharing of data at the state and local level. The tool kits kind of help you walk through what is required at the federal level and how does my state differ from that so you can get a pretty good view of what's shareable and what's not.

And there's plenty of ways to try and coax sharing from the actual individuals that are involved. This was also sort of behind my question to Dr. Hernandez earlier on. What is our expectation of privacy in the era of social media? And how details do we need to get with that?

So a great question. Some resources out there that can be brought to bear on the legal and confidentiality issues. There are three states I'm aware that have passed data sharing laws recently. Colorado, Ohio and North Carolina. When I say recently, I mean within the last half dozen years or so. I know it's being looked at broadly.

>>Damon Davis: Can I add one more quick thing in just really fast. There's a consortium of organizations out there that are inspiring individuals to try to obtain access to their own personal health data in the vain of when you go in people will tell you no we can't do that. So getmyhealthdata.org is a partnership with a whole bunch of organizations. I won't name any. But there is a right to access memo outlined by the HHS previous OCR office. Office of civil rights that says HHS has said you do have a right to access health records. And you can walk in with that letter in hand signed by the previous chief that says you do have access. It's a powerful tool. Engage with this get my Health Data Initiative. And start to educate people as to what it allows.

>>Shell Culp: Thank you, Damon. Judging from the questions though, most recently, it appears privacy confidentiality and as it relates to data sharing seems to be top of mind for everyone. Which I think all of us would find not surprising. It is often the single highest barrier to sharing of data.

So I'm going to pick out a question that I think is maybe useful. Are there data sharing policies across both agencies to assure access to agency data sets needed by agencies addressing multiple public health priorities? I assume this to be sort of within jurisdictions and possibly outside of jurisdictions. Are you guys aware of data sharing policies between agencies?

>>Damon Davis: At the federal level, we're working on those kinds of things. There are definitely data sharing agreements across our agencies if I'm understanding it correctly. There's a really interesting experiment that someone at CDC and CMS stood up. That was fun to watch. Where CDC recognized that in doing disease surveillance, there's a lot of really interesting and relevant information in CMS claims data. So they teamed up with CMS to start to at least begin to understand how they could share claims data for purposes of disease surveillance in elderly populations. So within HHS, there's a ton of data sharing. And I heard something interesting today from the CTO that says they adopted a first strategy for their data. While that's beneficial to the external participants. What he highlighted is it will allow for easier data sharing with internal data users so folks inside the census can have quicker more easily machine readable access to other census data. Elizabeth, how about you?

>>Elizabeth Baca: I know more at the local level. I don't know at the states or federal level. There have been data agreements. What you bring you are really interesting development and seeing more of those to help make data more accessible across agencies.

>>Damon Davis: Uh-huh.

>>Shell Culp: I am aware there are a couple initiatives going on at the federal level to be able to share more of the social security administration data determination. State level initiatives within its own Health and Human Services Agency is trying to put together an agreement to share human services. With the healthcare agency. And a similar agreement they are modeling their agreements on one that was put together in Virginia to sort of be a global level data sharing agreement across Health and Human Services Agencies.

>>Damon Davis: That's great.

>>Shell Culp: Yeah. Let's see. Maybe time for one more question. Here's one. Here's an interesting one. A little different than the privacy stuff. Glad to see the FDA data availabilities there want to see private sector data more easily available. [Inaudible] pesticide sales, gun sales, real estate sales, et cetera. That sounds like it's right up your alley for comment. What are your thoughts on that?

>>Elizabeth Baca: Let's see. I'm trying to find it. Where is it?

>>Shell Culp: Towards the bottom of the questions.

>>Elizabeth Baca: Private sector. Ah, yes. So yeah, I mean, interesting question. That data, you know, it's one of the things -- some of the data is available around pesticide use. It's not as easily available. Some of the data around -- I haven't looked at gun sales but that's an interesting one to think about in real estate. I want to say part of it is creating the will to start asking some of those questions. I think one of the things is as it starts to become more of a priority, more of the conversation and makes it more salient to ask for the data. It would be something that collectively as people are prioritizing this more that it would be great to have it out there.

>>Shell Culp: Yeah, I would echo that. And offer that I think a lot of the data sets are actually open and available but just start to get at. As the open data, I'm going to say movement, if you will. As the open data movement picks up steam -- and recall, early on in the webinar, the health and services portal in California is just going to be a year old next month. And it's the first really open data portal for the state. I think we'll see more and more of these kinds of data sets available for folks. So stay tuned.

>>Elizabeth Baca: Go ahead.

>>Shell Culp: No, that's it.

>>Elizabeth Baca: I was going to say that just watching that from a distance. A lot of it is what high use data sets people are interested in. As it becomes salient starting to request those data sets with the other pieces being considered but those help it rise to the top as far as prioritizing it to get it out there.

>>Shell Culp: Great. So we have reached the end of our program. And I wanted to make sure that I thanked everybody. Elizabeth and Dr. Hernandez for participating in this first of our series. And making it such a huge success. I think it was great questions. So thank you to the audience.

Also want to thank our behind the scenes people. Holly and Joanna who have the safety net underneath me and always trying to run around and make sure I have something to fall into if I need it. Also want to thank our sponsor which is the California HealthCare Foundation for all of the work that they have been doing in the area of data and helping us unlock this vital resource for improving not only programs and effectiveness of programs but on down to the individual level.

Upcoming web forum for the next one will be Thursday August 13th at 11:30 Pacific time. 2:30 eastern time. We'll talk about making data work for the public's health: Diving into the details. Also sponsored by the California HealthCare Foundation.

And with that, thank you for joining our web forum.